by Bill Schmalfeldt

Deep Brain Diary

My Life as a Guy with Parkinson’s Disease and Brain Surgery Volunteer

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Visit my website at http://parkinsondiary.com

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DEDICATION

Dedicated to the good doctors and staff at Vanderbilt University Medical Center who performed my deep brain stimulation surgery, programmed the devices and cared for me during and after my time in their hospital. To Dr. Susanne Goldstein and Dr. Stephen Grill at the Parkinson's and Movement Disorder Center of Maryland for their prior and ongoing care. To my friends and colleagues at the National Institutes of Health for their enduring patience, friendship and understanding. And to my beloved wife, partner, best friend and chastiser-in-chief. I love you, Gail!

FOREWORD

In February 2007, I began a daily blog to chronicle my life as a person with Parkinson's disease. I had been diagnosed in 2000, but for the first seven years of this affliction, I just sort of paid lip service to the whole thing. In early PD, the symptoms are hardly disabling, so it was possible to go days – sometimes weeks – without having to think about it.

That all changed in late 2006 and early 2007 when my symptoms began to progress at a more rapid rate. It was in February when I finally made the decision to get back on medication (after being off meds for years) and to look into a clinical trial involving Deep Brain Stimulation surgery for people in the earlier stages of Parkinson's disease.

Most of what you will read is copied directly from that blog. I will supplement some of the entries with "editor's notes" like this one.

The story is not over. In fact, this is not a story that will have a happy ending. That's just not possible until the day comes when a cure is finally found for Parkinson's disease. This is a diary in the strictest sense of the word… a day by day, month by month reporting of the details of my life as a guy with Parkinson's – a guy who took part in a clinical trial to test the safety and tolerability of Deep Brain Stimulation in early stage PD – a guy who volunteered for brain surgery – a guy who experienced mixed results.

I try to keep it light and humorous. There are days when that’s just not possible. As I write this, I am experiencing increasing difficulty with my walking and balance. And I’ve just been notified, after the fact, that having this procedure may have sped up the process of the disease.

Hopefully, this will be an entertaining read. Not maudlin or smarmy. Just a guy writing about his day to day life as a guy with Parkinson’s disease.

But first? Some history.

1. KARMA HAD NOTHING TO DO WITH IT!

(SUMMER 1972)

The table was set for lunch, although they called it “supper.” I never understood that. To me the word “supper” was interchangeable with the word “dinner.” But I didn’t care what they called it. After a long, hot morning of hauling hay bales with my brother Bob and our friend Eric, I was hungry. And whatever what they called it, there sure was a lot of it! Hot fresh baked rolls with honey to slather over them. A huge bowl of boiled potatoes mashed with the peels still on them. Corn on the cob drizzled with melted butter. A pitcher of Kool-Aid that, for some reason, they called “nectar.” And chicken! Heaping mounds of it. Hot, crispy, golden fried. Delicious!

A guy didn’t make much money hauling hay bales on the Bornemann farm. A nickel per bale got divided three ways, and by the time the week was over if you had a few bucks you considered yourself lucky. That wasn’t the point of the job anyway. The real purpose was to build up arm strength before football season. The little bit of money you got was just icing on the cake.

Oh, yeah. I forgot to mention the cake. A thick, two-layer yellow cake with vanilla frosting waited for dessert.

We may have been working for slave wages. But we ate like lords.

“Boys. Get you some chicken meat,” Mrs. Bornemann said with a smile. She was a round, jolly woman with a large head covered in white curls. She loved to watch teenage boys eat. “Put some gravy on them ‘taters,” she commanded, gravy boat in hand, smothering the potatoes on my plate with rich, creamy goodness.

Mr. Bornemann ate in silence. He rarely spoke, and when he did it was usually to yell at us for lollygagging, meaning we weren’t getting the bales from the field to the flatbed behind his trailer nearly fast enough. I believed Mr. Bornemann was deeply disappointed with the youth of the day. We clearly didn’t understand the value of a hard day’s work, accustomed as we were to sitting around on our candy asses watching the color TV and listening to our rock and roll records on our stereos that our daddies bought for us with their hard-earned money. I'm sure he feared for the future of the America he loved, and I have no doubt that he resented having to pay us – let alone feed us.

"Get you some more chicken meat," Mrs. Bornemann said as I gnawed a drumstick to the cartilage. "Best meat's on the breast," she said and I wondered why such a grandmotherly woman had no kids of her own.

That question would be answered by a quick glance at her husband. A grim, thin man with a pointed nose and crooked neck, his eyes were small, set and mean. Sparse white hair covered the crest of his small head like an early winter snow flurry atop a grain silo. His tiny mouth was set in a concrete frown. He didn't look like he had a drop of blood to spare for something so frivolous as making love to a woman when there were CHORES to be done and CROPS to be raised and a HERD to take care of. Dammit.

There was another thing about him, too. He shook. I thought at first it was because of that ramshackle tractor he rode all day up and down, around and between the neat rows of evenly spaced alfalfa bales. But he shook even when the tractor was still and silent. His head and neck twitched and craned as if he were always trying to get a better look at something. His right arm seemed to have a mind of its own, as if it were trying to break free from its disagreeable owner and find a more hospitable, friendlier body with which to cleave. The only way he could drink his coffee was to hold the cup on the table top with both hands, dip his face down to the cup, and slurp.

He caught me watching him.

"Tend to your business!" he barked. I fixed my gaze on the half-eaten chicken breast on my plate.

"Eat some of these 'taters," Mrs. Bornemann said as she dropped a generous dollop of the spuds onto my brother's plate. "And you, Henry, stop barking at the boys."

"I'll bark at who I wanna," he muttered as he dipped his face back to the coffee cup. Bob and Eric regarded me, smiling the way boys smile when someone's in trouble and it's not them.

Mr. Bornemann picked up his napkin and I noticed that when he used his hand, it didn’t shake. He dabbed at his lips and dropped the napkin back onto the table as his hand resumed its back and forth rhythm. He glared at Eric.

“You, boy. You said you can drive a tractor? When you’re done, the three of you get back to where we left off. I’m gonna lay down awhile. No lollygagging.”

But without him there to keep an eye on us, lollygag we did and how! As Eric drove the tractor, I grabbed bales and pitched them onto the flatbed at Bob who stacked them. And we laughed and laughed as we mocked Mr. Bornemann’s voice, his appearance, his attitude, and mostly – his affliction.

“I wonder if he taught his dog to shake,” I said. Bob laughed.

“That chicken we had today, ya think it was ‘Shake ‘n Bake’?” Eric guffawed and almost drove the tractor into a row of bales as he looked back.

“Betcha five bucks it was,” he said. “Wanna shake on it?”

We laughed and laughed and laughed. The job only lasted a couple weeks more, but our fun at the expense of Mr. Bornemann’s neurological condition lasted all summer.

FROM THE MERRIAM-WEBSTER ONLINE DICTIONARY
Main Entry:
kar•ma
Pronunciation:
\kär-mə also kər-
Function:
noun
Etymology:
Sanskrit karma fate, work
Date:
1827

1. *Often capitalized : the force generated by a person's actions held in Hinduism and Buddhism to perpetuate transmigration*

> *and in its ethical consequences to determine the nature of the person's next existence.*

FEBRUARY 7, 2007

Don't be silly. I do not have Parkinson's because I made fun of an old man and his shaking palsy. I got Parkinson's Disease because a bunch of cells in a portion of my brain known as the substantia nigra (Latin for "black stuff") whose only job is to produce a neurotransmitting chemical called dopamine have decided, for whatever reason, to die. We don't know what killed them – as the popular bumper sticker of the late 1990s put it – shit happens. And I suppose it was in the late 1990s when shit started happening to ME! In late 1999, to be specific…

For about a year I had been dropping things with my right hand. This was not just your garden-variety clumsiness, of which I have always been something of a poster child. I would have something in my right hand – a glass, a cassette tape, a butter knife. Then, suddenly, I wouldn't have it. No tingling. No numbness. No warning. The hand would just "let go and let gravity."

By itself, no big deal. Nor, when taken separately, was I particularly concerned about the cramping in my thighs when I climbed stairs, the fact that I was inexplicably exhausted by the end of the day, or the shaking in my right hand when excited or stressed.

The thing that tipped the scales was when I was doing the morning talk show at a radio station in Naples, Florida, when I couldn't for the life of me remember the name of my co-host. We had been together for nearly four months. I called her by her first name at least three dozen times a day. She was my boss, for God's sake. And with the microphone open and a good part of southwest Florida tuned in, I stammered and fumbled and tried for all I was worth to remember just what in the hell her name was.

But I couldn't. So instead I grabbed a tape cartridge with a recorded public service announcement and told the audience we'd be taking a break. I dropped the tape right into the woman's coffee cup – whatever her name was. I picked it up and dropped it again. My hand shook like a leaf in the wind. I struggled to put the tape into the player, and stabbed at the “start” button, missing it.

Nanci (that was her name! Nanci! How in the hell do you forget a name like Nanci?) pushed my trembling hand out of the way and pushed the button. I turned off the mic. She looked at me and her forehead creased the way it did when I had just said something on the air that she knew would be the focus of a meeting with the station manager after the show.

“Would you please call a doctor,” she said. The show was almost over so she offered to slide behind the control board and finish things off for the day. I went to my desk, pulling out my wallet as I walked. Once seated, I withdrew my insurance card and called the 800 number for “medical advice nurse.” The nice lady on the phone asked me to describe my situation. I told her what I had noticed before and what had just happened.

“Are you near a hospital?” she asked.

“Uh, yeah.”

“Go there,” she said. “Right now. I don’t want to alarm you, but what you are describing sounds like you might be in the early stages of a stroke.”

“Oh. Right. Nothing alarming about that,” I said.

“Don’t drive,” she said. “Call an ambulance.”

“Right,” I said. “Thank you.” I hung up and called my wife. She said she’d be right there to pick me up and take me to the ER. I was not going to be hauled out of the radio station on a gurney, down the hallway of the office building, into the elevator, out into the parking lot, a topic of conversation, a focus of entertainment above and beyond the call of my duties as morning radio show host.

I sat at my desk and wondered if I’d notice or recognize any of the subtle signs of approaching and imminent death. Not that I’m a melodramatic sort. But I did have some time to kill.

The first thing they did in the ER was take my blood pressure. It was fine. They did an EKG. It was fine. Off to the CT scanner. The images were normal. I was admitted for observation – which was an odd thing to call it, since to my knowledge no one “observed” me. I lay in my hospital bed feeling fine – somewhat hungry, but otherwise fit. I watched TV, and every couple hours or so, someone would take my blood pressure.

The next morning, a neurologist came to visit me.

"Good news," he said. Those are the best two words a doctor can say. I smiled. "You didn't have a stroke. You don't have a tumor. But I think you do have a little something going on there."

A "little something", eh, I thought. Hell. I can deal with a "little" something.

"Do me a favor," he said. "Get out of bed and walk up and down the hallway for me."

"You're the doctor," I said. I got up, walked to the door, turned around and came back.

"One more time," he said. I complied.

"Why aren't you swinging your right arm?" he asked. I looked at my arm as I walked. It just kind of hung there. My left arm was moving back and forth, doing the work for both arms apparently.

"Damned if I know," I said. The doctor patted the edge of the bed. I walked over – this time forcing my right arm to do its damn job – and sat.

He told me to open and close my right hand fast as I could. Then the left. Then tap my right index finger and thumb. Then the left. Then he told me to put my right palm on my thigh and turn it over, like flipping a burger, over and over, fast as I could. I did. Then he told me to do the same thing, but this time while opening and closing my left hand as fast as I could.

That's when we came to a screeching halt. I couldn't do it. Not smoothly, anyway. I could do one or the other. But doing both required massive concentration.

"OK, here's the problem," he said. "Like I said, you didn't have a stroke, you don't have a tumor. So, you don't have anything that's going to kill you. But I think you might have Parkinson's disease."

"That's nice," I said. I knew a little bit about Parkinson's disease. Months earlier, actor Michael J. Fox had gone public with his own diagnosis. I admired him for doing so and marveled that one so young would have an old guy's disease.

"I'm going to suggest you see a special kind of neurologist," he said. "A movement disorder specialist. There's a great one in Miami, Dr. William Koller. If you'd like, I can set up an appointment."

I thanked him and explained that my insurance company required that I jump through their hoops before doing anything so drastic as seeing a specialist. I asked him to write down the doctor's name and I would try to work the system with the ultimate end of seeing this Dr. Koller he spoke so highly of.

My insurance company said I had to first see my family doctor. There was a problem with that. I didn't have a family doctor. My insurance didn't go into effect until three months after employment, which was just a month ago, and I hadn't needed a doctor until then.

But bureaucracy must be honored, so after being discharged from the hospital I scanned the insurance company's preferred provider list and picked out a family practitioner. I called for an appointment.

"And what is this appointment for," the appointment clerk asked.

"So I can see a neurologist," I explained.

"The doctor isn't a neurologist," she said patiently.

"I know that," I said. "But I need him to give me a referral to see a neurologist."

"How do you know you need to see a neurologist if you haven't even seen a family practitioner yet," she asked, that sweet "I'm talking to an idiot" tone in her voice.

I explained my situation and she set the appointment for a couple days later.

The doctor sat and listened as I described the events of the past several days. Then he shook his head. "I don't think it's Parkinson's," he said. "You're too young for that."

"You would think so," I said. "But look at Michael J. Fox…"

"Who's he?" the doctor asked.

"Alex P. Keaton on 'Family Ties'. 'Back to the Future'…"

"Oh yeah," he said, the light of recognition finally burning. "That guy. But that has to be a rare case. Did seeing that on the news make you think you had PD too?"

“I thought I was having a stroke,” I told him. “The neurologist at the hospital said he thought I had PD.”

“Nah, you’re too young,” he said. But he agreed – at my insistence – to refer me to a neurologist.

A couple weeks later, the neurologist told me I was too young to have PD. He tested my reflexes, noticed some twitching in my calves and some hyper reflexes in my Achilles tendons.

“I don’t think it’s Parkinson’s,” he said in a thick accent – maybe Middle Eastern, I’m not sure. “But you might want to prepare yourself for the possibility that you may have Lou Gehrig’s disease.”

Oh! Fine! A fatal disease! MUCH better than Parkinson’s, I thought. I told him I wanted a second opinion. We set up an appointment with one of his colleagues.

The next doctor told me I did not have ALS. We did all the testing I had done in the hospital room. Then he shut the door and sat down, leaning toward me with the air of a conspirator.

“What do you think it is?” he asked me.

“My money’s still on Parkinson’s Disease,” I said.

“That’s probably a good bet. But you know what? I’m an HMO doctor. And I’m going to be very honest with you. And if you repeat this to anyone, I will swear I never said it. OK?”

I assured him I was cool with it.

“I’m going to diagnose you with extrapyramidal syndrome. It’s a catch-all phrase for a variety of conditions, including Parkinson’s. If I pull the trigger on the PD diagnosis, it goes on my record. It’s an expensive diagnosis. And it’s the sort of thing the HMO looks at when they do the books at the end of the year. I don’t want it on my record. What I will do, is refer you to the Parkinson’s disease Foundation clinic in Miami. We’ll let them pull the trigger. Any problem with that?”

Nope. Other than the corporate cowardice, I had no problem with that at all.

On January 30, 2000 I saw Dr. William Koller – the same doctor the neurologist at the ER in Naples wanted to send me to 90 days earlier. We did all the tests again. And he made the diagnosis.

“How do you feel about that?” he asked me.

"Beats Lou Gehrig's Disease," I said.

He smiled and patted me on the shoulder. "Remember, Bill… it's not a death sentence. It's a life sentence."

So. My disease had a name.

But it wasn't until early 2007 until I really began to take it seriously.

At first, I took a medication called Mirapex. It's a so-called "dopamine agonist" which means it activates the dopamine receptors in the brain. So you're not actually getting MORE dopamine, just more mileage out of the dopamine your brain already produces. It has some side effects. For one, it can make a person fall asleep without warning. And let me say that there are few things more unsettling that being woken up by the blaring car horns behind you because you've nodded off at a stop light. And then there's the problem with hallucinations. Not the scary kind where you're confronted by demons, monsters or your ex-wife's mother wearing a thong bikini, but small, innocent little hallucinations, seen for an instant out of the corner of the mind's eye. In my case, I was sitting at the computer when I noticed a movement off to my right. I turned just in time to see the back half of my cat dashing behind a cabinet. There was only one problem – I didn't HAVE a cat. (My wife thought this was hilarious and dubbed the ghost cat "Spooky.")

By the end of 2000 I started taking Sinemet CR – a controlled release mixture of levodopa (which the body converts into dopamine) and carbidopa (which keeps the body from metabolizing the levodopa in your stomach, allowing more of it to reach your brain, which is the only way it can do you any good). The improvement was instantaneous. I felt wonderful! But it's a double-edged sword. Sinemet can cause some pretty noticeable side effects – like the twisting, jerky motions known as dyskinesia. For instance, when you see Michael J. Fox on TV and he's twisting and writhing and can't sit still… that's dyskinesia! It's caused by the levodopa. No one knows why. But after years of levodopa use that sweet spot between "control of symptoms" and dyskinesia gets smaller and smaller and sometimes disappears altogether. By early 2003 I was beginning to show signs of it – mostly in my right pinky. I'd be sitting there, comfortable, watching TV, and my pinky would twist and dance as if it wanted to separate from my hand… tear itself right off from the edge of my palm and crawl like an inchworm across the floor, out the door, onto the street, where it would no doubt be crushed by a passing truck.

In early 2003, after discussing it with my neurologist, I stopped drug therapy completely. My symptoms weren't so severe that I wanted to expose myself to the increased onset of dyskinesia.

By 2005 I was working for the federal government and the HMO I elected for health coverage insisted that I stop seeing the movement disorder specialist I had been seeing to that point and start seeing an "in-house" neurologist.

The insurance company's neurologist told me he didn't think I had Parkinson's because I was much too young. He thought it was carpal tunnel syndrome.

When testing for carpal tunnel came back negative, he decided I had cervical spinal stenosis – a narrowing of the canal the spinal cord goes through in the neck.

I had an MRI and CT of the cervical spine, and yes, the spinal canal was narrower than it should be, but not so narrow as to cause the symptoms I was having.

So then he decided it must be some other condition I can't even remember the name of and it doesn't matter because I fired him during health insurance "open season" in 2006 and started seeing my previous movement disorder specialist. By this time I was walking very slowly, my whole body was stiff, and my balance was getting worse.

I had an appointment with her on February 1, 2007 and I related my frustration with the situation and the doctor I had been seeing the previous year. After doing the neurological tests she said, "With all due respect to your former neurologist, you DO seem to have Parkinson's disease -- and a fairly classical case of it."

Yaaaay! I'm CLASSICAL!

She gave me samples of Stalevo 100 – this is a relatively new medication – a mixture of levodopa and carbidopa, and something called entacapone, which enhances the benefit of the levodopa. After the appointment I took one in the car.

Within 30 minutes...

I was standing up straight!

I was walking with a normal stride!

I actually had ARM SWING on my right side as I walked!

I made a vow to heaven above that if I ever have another child -- I will name it STALEVO!!!

So... now what?

(Well, "now what" became my entry into a clinical trial at the Vanderbilt University Medical Center in Nashville. You'll read more about that in the next chapter.)

MARCH 7, 2007

Remember that scene in the Wizard of Oz where Dorothy and the Scarecrow come upon the rusted-up Tin Man? Remember how happy he looked when Dorothy lubricated his joints with the nearby oil can?

I had one of "those moments" this morning.

See, I take my last Stalevo pill of the day at around 8 p.m. Then I go to bed. I get up at around 4am, or whenever Raven and Shiloh decide the yard needs to be moistened. So, at that point, it's been eight hours since the last pill.

This morning was particularly difficult. I struggled to get to my feet from sitting on the edge of the bed. I staggered to the door to get my robe as both dogs nudged my exposed backside with their cold, wet noses because I wasn't moving fast enough. (Raven's a border collie. Shiloh's a German shepherd. Their purpose in life? To "herd" things. I was being "herded" to the door.)

I was walking like Frankenstein -- stiff legged, short steps. I had to put my hands out to keep from toppling over as I made my way down the hallway to the front door. As I bent over to put the leash on Raven (she gets to go out first -- she's the "senior dog"), I "kept going" and bumped my head on the doorknob. It hurt. Raven didn't care. She's seen it before.

The dogs did "their thing" with their usual early morning efficiency. (Both eyed our neighbor's trash cans in the driveway with suspicion -- my dogs think Osama lives next door. Actually, they're very nice people who would never attack America. My dogs think EVERYONE outside the immediate family is Al Qaeda.) I brought them back into the house and herded THEM this time -- back to the bedroom. They hopped up onto the bed and I slowly bent over to kiss my wife goodbye for the day. I put my hands onto the mattress to keep from falling onto her, which is not something I'm generally allowed to do at 4 a.m. on a weekday morning. She frowns on being fallen upon. Who wouldn't?

I stiff-legged my way back to the kitchen to prepare the morning coffee. When that was done, I grabbed "my morning three" -- that being a Prilosec, a Lopressor (for blood pressure) and a Stalevo. I downed them, and then adjourned to the porcelain convenience.

After doing in there what the dogs had done in the yard (but with much less superfluous sniffing), I repaired to my office to do my morning Internet browsing. I generally check to see if the world is still "out there" before I go through the effort of getting ready for work. No sense going to work if the world isn't still "out there," right?

At about 4:25, I felt it. I've rather gotten used to it... but this morning I could really feel it. My arms started to feel looser. My right hand slowly relaxed from its death grip on the mouse. I could feel the Stalevo kicking in.

It felt wonderful.

Now it's a bit after 8 a.m. I still feel somewhat stiff-legged, but that might have something to do with my daily half-hour on the "dreadmill" yesterday. I think I'll give myself the day off from exercise, see how I feel this afternoon.

I've said it before, I'll say it again.

If I were to ever have another child -- I would name it "Stalevo."

MARCH 8, 2007

In my podcast the other day I made a passing reference to stupid things well-meaning people say when they learn you have Parkinson's disease. My favorite is, "but you LOOK fine!" (I always reply -- mentally -- "Yes. I AM fine. I'm LYING to you about having

PD! Joke’s on YOU, dimwit! Ha ha ha!") Then there are the folks who think you may be faking it because you can move better today than you did yesterday.

This lack of understanding came into glaring focus when Michael J. Fox did a political ad for a Democratic candidate for Senate in Missouri. Conservative critics (like the idiot Rush Limbaugh) attacked him -- first for faking the dyskinesia, then for being a shill for embryonic stem cell research. When Fox explained that the dyskinesia was caused by "too much levodopa" -- he obviously meant that the "sweet spot" where the right amount of medication leaves him relatively smooth and fluid was getting smaller and smaller. Limbaugh and others took it to mean he "took an overdose" just to appear dyskinetic in the political ad.

Some people seem to prefer to be stupid.

Then there's the wearing off -- when you walk into the movie theater looking just fine, and by the time the movie's done you need help getting out of the chair.

How do we educate people about this without seeming whiny about it? And what do YOU say when someone tells you, "Oh, I get twitches all the time! Are you sure it's Parkinson's?"

Sigh…

MARCH 9, 2007

Not such a good day yesterday.

After doing a half hour on the "dreadmill" yesterday afternoon (another 2 lbs. gone -- congratulate me!), I was completely WIPED for the rest of the day. My 3 p.m. pill (the 3rd of 4 I take each day) may as well have been rubbed on my forehead instead of swallowed for all the good it did. I spent the evening wobbly, shaky, unsteady, and taking small, staggering steps.

I guess that's what they mean by "off."

I'm supposing this was due to the workout. But I need to exercise. What to do?

I think I'll modify the routine ... do it three times a week instead of five. The weight will come off slower. But what the hell?

MARCH 15, 2007

I really, really, REALLY don't feel like writing anything today.

So, I suppose I really should. Right?

Pardon my French -- but I am just SO damn TIRED today. I had a crappy night sleep Monday night -- just couldn't get a good "snooze" going. Then last night I slept deep and long and had one strange dream after another... including one in which I was watching an episode of “The Sopranos” that kept switching back and forth between some kind of fictional story line and the real life of star James Gandolfini. Just strange.

I have no energy, no motivation, no desire to GET motivated. My meds are "on" but only at about 2/3-strength it would seem. I feel slow mentally and physically.

Yesterday I almost started crying when my wife made a perfectly innocent joke.

Maybe I'm exercising too much now. I did my half-hour on the "dreadmill" yesterday and was a zombie for the rest of the day. I've cut back to 3 times a week. Not exercising today.

I’m staying on the diet although I pigged out on chicken patty sandwiches last night. Gonna have a Slim Fast, mango slices and Propel for lunch. I want to go down to the cafeteria and get several cupcakes and rub them all over my face.

Not a good day, not a good day, not a good day at all.

MARCH 16, 2007

OK. I feel better today. Thanks!

Odd to feel better on such a miserable, cold and rainy day and to have felt so lousy on a warm, sunny one. Oh well. I guess we don't get to choose.

Yesterday was tough. Maybe the toughest yet, and I know I have a long way to go before things get really bad for me. Makes me wonder how I'm gonna handle it when it gets REALLY bad.

I think I'll just adopt the Scarlett O'Hara approach for now -- I'm not going to think about it right now.

Maybe the diet has something to do with it. I've been cutting back on carbs -- now I see that I'm not SUPPOSED to cut back on carbs. I'm supposed to cut back on PROTEIN because it interferes with dopamine receptors in the brain. OK. As long as I cut back on something, I guess.

I actually gained a half pound this week -- starving myself, working out on the dreadmill. And I'm actually heavier. In heaven, God laughs. I want a donut worse than I've ever wanted a pastry before in my life!

To quote my favorite philosopher, Homer J. Simpson…

“Oh, cruel fate! Why do you MOCK me?”

2. VOLUNTEERING FOR BRAIN SURGERY

(Or, "Hitting the Old Clinical Trail!")

(In this section, I tell the story of how I came to be involved in a clinical trial, looking at the safety and tolerability of Deep Brain Stimulation in the early stages of Parkinson's disease at Vanderbilt University Medical Center in Nashville, Tenn. Once again, all the entries were blogged on the indicated date.)

FEBRUARY 7, 2007

I'm no longer working in regular radio. I am a medical podcaster at the National Institutes of Health in Bethesda, Maryland, living in the greater Washington/Baltimore area. My job -- radio news reports, including the bi-weekly podcast.

In my research on a story about clinical trials (medical studies in which folks volunteer to become test subjects) I noticed that a major university is conducting a study on people like me! Early stage PD patients who have had a positive response to medications. Age 50 to 65. Willing to undergo brain surgery.

Yup! That's ME!

The study -- to see whether deep brain stimulation has a neuroprotective effect on early stage PD, meaning it might slow or stop the progression of PD.

I ran the idea past my neurologist -- she said she thought the study was worthwhile. So I e-mailed for more info.

The upshot -- on February 16th I will drive to Nashville and meet with the doctors, et al. Then on the 19th, if I still want to do this, I will sign the consents and enter the screening process.

First they have to see if I'm a nut case. (Who ELSE would volunteer for brain surgery, someone SANE???) Then they have to take me off the meds for a week and poke, prod, and test me -- on video. Then they flip a coin and I either get the surgery -- implantation of electrodes deep into my noodle -- or go to the control group, where I just keep taking the meds.

This could get interesting.

FEBRUARY 16, 2007

I made it to Nashville.

Eleven hours in a car is a long time.

It sucks when the FM part of your car radio doesn't work.

All the sports talk radio shows spent the day yesterday talking about former NBA player Tim Hardaway and why he hates gays.

Trees look very pretty in the sunlight with a coating of ice on them. The same cannot be said for highways. Thank God the roads were clean and dry.

I got here at about 5 p.m. Nashville time, which was about an hour after I was due to take my third Stalevo of the day. I staggered into the hotel lobby, happy that I had taken the time a few days ago to complete the "express check-in" thing on the hotel's website. It turned out to be a futile gesture as there was a tourist couple in front of me experiencing some sort of problem that took the sole clerk at the desk some 15 minutes to sort out. But once it was MY turn, check-in was a breeze!

Got to my room. Took a Stalevo. Got a bag of burgers. Watched a movie on Showtime. Fell asleep at 8:30.

Today, feeling more or less fresh, but with a sleep hangover. Meds don't seem to be working quite as well today. I've got a work laptop with me, so I'm connected to the office, checking e-mails, uploading sound files as I would ordinarily do on a Friday. Ain't technology GRAND?

At 1 p.m. local, I will meet with Dr. P. David Charles, neurologist, lead researcher on this study. At 2 p.m. I’ll meet with Dr. Peter Konrad, the neurosurgeon who will become intimately acquainted with my brain if I enter the study and am selected for surgery. At 3 p.m. I will meet Dr. Stuart Finder, the medical ethicist, who will -- I suppose -- ensure to the satisfaction of all that I know what the risks are.

On Saturday I will meet with my book agent. Nice fella. Happens to have an office in Nashville. This will be our first face-to-face.

On Sunday I will swim in the hotel pool and otherwise vegetate.

Then on Monday, I go back to Vanderbilt University Medical Center to sign the consents -- providing I don't chicken out first. That's what the 72 hour waiting period is all about, I suppose. It might sound good on Friday, but by Monday I might decide that I need this surgery like I need a hole in the head.

Two holes.

Then, on Tuesday, I will go home.

LATER THAT DAY

Such nice people, these doctors.

Seriously!

Met first with a very pleasant young lady named Chandler Gill. She's the coordinator for the clinical trial. We discussed the protocol, why I want to take part, all the stuff you would expect would be discussed.

Then I met Dr. Charles. Nice guy. Youngish. Has identical twin sons. VERY optimistic about the research. He really did a great job explaining the theory behind the possibility of neuroprotection from DBS. And although it's just a theory -- it makes great sense!

Then I met Dr. Konrad -- who basically wrote the book on this procedure. He gave me a copy of the book. And he laid out the whole procedure, start to finish. Very steady hands. I like that. Clean fingernails, too!

Then I met Dr. Finder -- and it was his job to ensure that I was fully informed and was making a wise decision based on my needs and expectations.

Very nice afternoon. We'll get back together on Monday and I'll sign the consents. Unless I chicken out. Which I won't.

Probably.

FEBRUARY 19, 2007

Oh my God!

What have I DONE?

I SIGNED "THE CONSENT FORM!"

No! NO!!! NOOOOOOOO!!!!!!!

Heh! That was written for the benefit of the medical ethicist, Dr. Finder.   The man was relentless! And that's just what you would want from someone whose job it is to make absolutely certain that YOU are absolutely certain that you are making a decision like this for the right reasons.

I'm sure.

Absolutely.

I’ll explain.

A large part of my job as production manager of the National Institutes of Health Radio News Service is writing radio news stories and public service announcements about the importance of clinical research.

As a person suffering from a condition where research holds so much hope for a cure, I felt it would be hypocritical of me to not take an opportunity to participate in clinical research if presented with a chance to do so.

Also, think about the concept they're trying to prove with this particular clinical study into the safety and tolerability of deep brain stimulation in early Parkinson's disease. This pilot trial is designed specifically to collect the preliminary safety and tolerability data necessary to conduct a future phase III clinical trial to investigate the hypothesis that deep brain stimulation of the subthalamic nucleus in subjects with early Parkinson’s will slow the progression of the disease.

If there's a CHANCE that this procedure could slow the progression of PD, then I want a piece of the action! I am clearly in early Stage II (in the Four Stage Hoehn & Yahr Ratings Scale). I have a long way to go before being profoundly handicapped by this disease. What a wonderful thing it would be if this procedure slowed -- or even HALTED the progression! And how wonderful it will feel to have been on the cutting edge of this thing if it turns out that deep brain stimulation someday becomes the treatment of choice for patients -- earlier rather than later in the course of the disease.

There are risks. For one, I could have a stroke and die. Right there on the table. Boom. Gone. Or I could be profoundly crippled as a result. Or there could be an infection of the electrode leads or the implanted neurostimulators which would be placed in my chest. And there's a bunch of other stuff that could go wrong. And it might not work! But it probably will. The odds are in my favor. And it beats doing nothing. And for me, at least, that tips the balance.

Back home tomorrow. Back down here sometime in March for a couple days. Then April 10-18, I'm here for the 8-day drool-fest... I mean, 8 days without medication.

But the first step has been taken.

FEBRUARY 27, 2007

Been home about a week now. I don't think I'll be driving to and from Nashville any more. I was wiped when I got to there on the 15th, even more so when I got home on the 20th.

Depending on whether or not I'm randomized for the surgery, I may have to make the trip several more times this spring.

I'll fly, thank you.

At present, I'm waiting for Chandler to contact me with the dates for the first step in the screening -- the CT/MRI, neuro and psych screening. Thank goodness they've changed the protocol to allow out-of-towners like me to bunk down in the Clinical Research Center when we're in town for these sorts of things.

After that, it's two weeks of keeping hourly symptom diaries. Then the 8-day inspection, tentatively set for April 10-18.

Actually, I'm doing well. The three Stalevo 100s per day weren't getting the job done, so my neurologist suggested taking four a day. That seems to be working quite nicely.

Did the NIH bi-weekly podcast on Friday. Talked at length about the clinical trial and why such things are important.

So... I wait. I should hear something soon I would suppose.

One thing I've decided. I'm too friggin' fat. Gail and I have both started a calorie-cutback, and as of tomorrow I will be a member of the fitness center here at work. If I can get 30-minutes each workday on the exercise cycles down there, it couldn't hurt. Right?

Tipped my scales at home yesterday at a robust and Rubenesque 320.5 lbs. If I could get down to 250, I'd be thrilled.

A couple pounds a week? Why not?

MARCH 27, 2007

Nice place they got here at the Vanderbilt University Medical Center Clinical Research Center!

I arrived about an hour before I was expected on Sunday, but the staff was ready. They took me back to my room and got my vital signs. My BP was through the roof for some reason -- I expect that part of the reason was that I had been off the Stalevo since Saturday morning. After a bit of relaxing and a couple eight-ounce cans of Sprite, I was able to register a relatively decent BP.

Slept like an innocent man on Sunday night. It's a tiny bed, but when you consider how much sleeping space I actually get at home with Gail on one side of the bed and Raven absorbing as much space as a border collie possibly can... I probably actually have MORE room here.

Yesterday morning, about a half hour before our appointment time, Dr. Charles came in and gave me the standard neurological exam. He left to get Chandler, the coordinator, and when they came back they gave me the Unified Parkinson's Disease Rating Scale -- henceforth to be known as the UPDRS. I suppose I was marginally impaired after being off the meds for more than 48 hours at that point. Dr. Charles told me to take 1-1/2 of my Stalevo 100s and they'd come back in an hour.

I LIKE 1-1/2 STALEVOS!!! In about 30 minutes I was fully "on" and loving life again. Dr. Charles and Ms. Chandler returned and I breezed through the UPDRS like a person without PD. And that's one of the inclusion factors of the study... you have to have a positive reaction to your PD medications. Dr. Charles said my reaction was one of the most striking they've seen in this study.

After allowing me to interview them for the NIH podcast, they went on their way and I took a stroll down towards the location of my afternoon screening test to just get out of the room for awhile. After I located the place -- the Vanderbilt Psychiatry Clinic -- I ducked into a convenience store, got some sodas and chips and came back to the room all hot and sweaty.

At 3, I was back at the Psych Clinic for my neuropsychological screening with Dr. Tramontana and his assistant, who put me through the rugged paces of a cognition test. Then I visited with the doctor, he asked a few basic questions about my history with PD, my state of mind and emotion, and that was that.

Back to the room for dinner, relaxed, watched "24" and went to bed. Slept like a lord once again.

Now I'm killing time. Dr. Konrad, the neurosurgeon, is slated to drop by at 4:30 for a podcast interview and to look over the MRI's I brought down with me. Chandler just dropped by to give me a form for Dr. Konrad to sign. I just finagled a laptop from the nice folks at the nurse's station so I could enter all this fascinating information.

Tomorrow... back home after a psychiatric screening with Dr. Salomon. Then I'm back here on April 10-18.

MARCH 29, 2007

Why is there no such thing as a straight-line flight from somewhere to somewhere?

I got home last night at about 10:15 p.m. Plane A flew from Nashville to Memphis -- which was EXACTLY the opposite direction from home. But for some reason, I had to fly THERE before I could fly to Baltimore. When I go back to Vanderbilt in April, I fly from Baltimore to Charlotte, NC, THEN to Nashville. When I come home, it will be via Chicago.

Also, as long as I'm complaining, why are airplane seats made with children in mind? There's just not enough room for a plus-sized individual like me. I had to hold my right arm over my chest to give the poor lady sitting next to me all the room she paid for with her ticket. By the time we landed, my poor ass was in agony!

Then there were the two idiot women sitting right behind me. I think it was a skank mom and her skank daughter. They both had the look of "skank" about them -- the mom was nearly as old as I am, but dressed in a t-shirt and short bike pants with various piercings in her eyebrows, nose and lips. She looked like a fishing lure. She and her daughter were playing cards and SLAMMING the fold-down table as they laid down their hands, rattling my already uncomfortable seat. Must be nice to be so absolutely thoughtless as to believe you are the only two people on the friggin' airplane.

I already have plane tickets for the eight-day droolfest in April. I may choose to drive to and from after that.

I hate flying!

HOWEVER -- the overall experience at Vandy was a positive one. The staff at the Clinical Research Center was polite and professional and accommodating and pleasant beyond the call of duty. The room was small but efficient and comfortable with a little fridge for cold sodas and snacks. The bed was surprisingly comfortable. A better selection on the TV might have been an improvement, but they had all the network channels (Billy's GOT to see his "24" every Monday!) as well as CNN and ESPN -- and, oddly enough, one channel that has a blue screen with white letters proclaiming "THIS IS SCREEN 2."

(So, what the hell happened to Screen 1?)

The food, by and large, plentiful and non-offensive. My only problem lies with the "Lump O' Egg" one receives with breakfast... a scoop of scrambled eggs that has something of a slight "rubber" taste -- I think it gets that flavor from the container in which it's microwaved.

A Tasty Vanderbilt Breakfast!

I mentioned my visit with Dr. Charles and Ms. Gill -- on Tuesday I met for an extended and lively chat with Dr. Konrad, the neurosurgeon who will have my brain in his hands should I be randomized for the surgery. My conversations with Drs. Charles and Konrad and Ms. Gill will be included on my NIH Research Radio podcasts at a later date, as well as on my personal "What's Shakin'" podcast.

On Wednesday I met with Dr. Salomon, a psychiatrist, whose job it was to make sure I wasn't a crazy or a depressed person who was hoping to be killed by the surgery. After a spirited chat, he declared me "normal" -- which was about the nicest thing anyone would say to me all day. I should have gotten it in writing.

At any rate, I'm looking forward to the eight-day droolfest -- to "Get It Over With" more than any other reason. Eight days off the Stalevo will suck in many various ways. On the final day, the flip of the coin and we learn if I am to be randomized to the surgical group or the control group.

But it's nice to know I'll be cared for by such great folks in a comfortable facility. That makes the small headaches -- like the rubber eggs -- much easier to take.

(Ah! Droolfest! Eight days spent in the General Clinical Research Center in the oldest part of the Vanderbilt University Medical Center. No PD meds! Every day, they measure your blood pressure repeatedly, put you through your paces to test your PD symptoms, and lots and lots and lots of laying around watching TV. Lord, how I miss it!

In this first Droolfest, in addition to all the testing, one had to sweat out the final day in which he would be randomized to either the surgical group or the control group which would just stay on meds and be used to measure the surgical patients against. Thirty people

in the trial. Fifteen would get the surgery, fifteen would not.)

APRIL 10, 2007

It's Day 0: of the 8-Day Drool Fest -- the first of the several visits to the Vanderbilt University Medical Center for eight days off the meds. Let us keep track of each day's events, say wot?

7:16 AM

Woke up, as usual, shortly before 4 a.m. Time for a pill. Hit the hay quite early last night -- a bit after 8. Was gonna stay up to watch "24" but I was falling asleep on the recliner. Stalevo doesn't seem to have all that much impact on the "fatigue" part of PD. Added to this, the stress of my hillbilly neighbor's dog getting loose again and attacking MY chained-up dogs in MY yard. The cops are now involved. Anyhoo -- we'll head to the airport in a bit more than an hour. Gonna be a lot of sitting around today -- nearly a 4-hour layover in Charlotte. Why is there no "non-stop" between Baltimore and Nashville? Are they not both relatively major cities? Oh well.

12:40 PM

So far, so good. Made it to Charlotte. Oddly enough, for the first flight in MANY times, I actually had no one sitting next to me, so there was a little room to stretch out. Now I'm sitting here in the main concourse, sipping a Sam Adams, watching the folks walk by. We're about 2 hours and 20 minutes from load-up time. I'm not at all hungry, but I may go grab sumthin' anyway, cuz who the heck knows when I'm gonna get any grub tonight. Neat thing about this airport -- there's a row of rocking chairs... like the kind you'd see in front of a Cracker Barrel Restaurant, for folks to sit on and relax. Very nice touch. The flight was kinda bumpy at both ends... bumpy takeoff, bumpy landing, but smooth as silk in between.

7:10 PM (CDT)

Ok... I'm in Nashville. Using the Treo to make this entry. More tomorrow when the laptop's hooked up.

APRIL 11, 2007

8:58 AM

Hey! The computer's working! The IT guy had to come in and add the wireless network to my network connections, but that's done and once again I'm in touch with the world. Crapped out at around 9 last night, woke up at 4 to take a pill, then slept in until about 6:45. Took a shower and laid around waiting for brekky, which showed up at 8. Sausage links, "Lump 'o Egg", French toast, cereal, orange segments, a tiny blueberry muffin, apple juice. No coffee. Then my nurse of the day, Christa, came in and took my blood pressure. 16 times. I'm not kidding. It's part of the protocol. First sitting, then standing. Then 2 minutes later while standing. Then once each 30 seconds for 6 minutes. My poor arm was purple. And we'll do this every morning. Chandler, the study coordinator, is supposed to come in sometime this morning for the 8-hour symptom diary, after which I go OFF the meds at 4 p.m. Then the fun begins.

12:54 PM

Another dandy lunch. BBQ Pork, turkey veggie soup, pineapple chunks, baked beans. Before that, Chandler came by and we went through the entire UPDRS, except for the physical exam part... Dr. Charles is supposed to be coming by this afternoon to do that part, and get it on tape. This provides the researchers with an objective measurement of how I'm doing, and how fast I can do it. With Chandler timing me, I opened and closed each hand as fast as I could, tapped finger to thumb on each hand, and tapped each heel on the floor for 30 seconds each. Chandler produced this contraption – a long, metal thingamabob with a pair of what looked like old fashioned Royal typewriter keys about a foot apart, each connected to a counter. My job… press each key, back and forth, fast as I could, with the index finger of each hand for 30 seconds. Then we stepped out into the hallway and she measured off a set distance. I sat in a chair, and at her command stood up, walked the distance, turned around, walked back and sat down. And not once did I get a cookie, a piece of candy, or any other form of "reward" for performing these stunts.

3:09 PM

OK, so now I'm a video star. Went through the videotaped portion of the UPDRS... I'll be videotaped again on the final day. But this is supposed to show me at my most "on". With Chandler running the video camera and me sitting in a chair, Dr. Charles directed me first to open and close my right hand as fast as I could. Then the left. Then the finger tapping. Then I was told to extend my right arm with my hand positioned as if I had just picked an apple from a tree, then to invert that hand back and forth, as if I were trying to shake dew from the apple. First the right hand, then the left. Then I was directed to tap my right heel on the floor as fast as I could. Then the left. I was told to cross my arms over my chest and rise to my feet. Dr. Charles had me walk back and forth in front of the camera a couple times. Then he told me to stand still. He came up behind me, put a couple fingers on my shoulders and delivered a backwards tug to see how many steps (if any) it would take me to keep from falling. It took none. I was Steady Eddie personified! And thus ended the video session. My 8-hour symptom diary will wrap up at 4, so even though I would ordinarily take a pill right about now, there's no real reason to do so. May as well "get it on" -- as they say. I enjoyed "feeling good"... now it's time to see the other side again.

6:44 PM

More than 9 hours since my last pill. Already starting to feel the decline. Muscles starting to tighten. Feeling a little headachy. Let the good times roll.

APRIL 12, 2007

9:10 AM

It sucks to wake up early here. I crawled out of the sack at about 5:45 because my body still thinks we're on Eastern Time. Breakfast doesn't come around until 8 am. So there's two-plus hours with little to do. And the TV reception was crappy... it's cable/Dish TV or something like that, but it was all snowy and impossible to watch. I got cleaned up, then watched last Monday's episode of "24" online. By the time that was done, the TV situation had been remedied. At 8, brekky showed up, and it wasn't bad! No "Lump 'o Egg" today... it was a cheese omelet, and it wasn't bad. A couple bacon strips, a tiny cheese Danish, cornflakes, orange juice and coffee. At 8:30, my day nurse Christa (she's also the manager of the GCRC) came in. She's a delightful German lady of 60-some years. We did the 16-times blood pressure thing... I'm running a bit on the high side... maybe the stress of not having my Stalevo? Then Chandler called. Dr. Charles won't make it until 1 p.m. today. Which is fine. It's a lovely day and I may head out for a stroll here in a bit. I'm feeling somewhat hindered, but not as bad as I probably will feel before I can take my next Stalevo on the 18th.

2:37 PM

I had just typed a whole bunch of stuff here, but before I saved it, the heel of my right hand touched "something" on the body of this laptop, and it decided to go back to the previous page. So I lost everything I wrote. With this laptop, for some reason, if any part of your hand is touching anything other than the keyboard when you write, it acts goofy. Anyway, Dr. Charles came by at 1:30 and we did today's UPDRS thing – basically, a reprise of the bit we had videotaped yesterday. Today my score was 4. Yesterday I was a 2. Still minimal, but progressing. Then he asked me to rate my independence, based on the Schwab and England Activities of Daily Living Scale. 100% means I can do all chores without slowness, difficulty or impairment; that is to say – normal. 90% indicates I can do all chores but with some degree of slowness, difficulty or impairment, beginning to be aware of difficulty. I decided I was at a good 90%, since I was noticing some stiffness and slowness, but not too bad at the moment. I decided to take a stroll to a little market about six blocks from here. Got some cookies and little Irish Crème candies. A guy needs yummy things when he's away from home. On the way back, my upper back tightened and my legs throbbed. My brain seems to be saying, "No Stalevo, no leisurely strolls." To hell with my brain. There are little restaurants I intend to check out. Cheeseburger Charley is at the top of the list. Maybe tomorrow. We'll see.

8:22 PM

I was really wiped out from the walk. Amazing what a difference a little pill can make. Dr. Charles says it will take about 3 days to wash the Stalevo from my body... so the next couple days should be interesting. The good doctor prescribed an Ambien for sleeping, so I'm expecting a good night's sleep and a better tomorrow.

APRIL 13, 2007

9:51 AM

Slept through the night like a little angel. Ambien. Good stuff. Not feeling particularly hindered this morning... more "slow" than "tight". The typing is starting to slow down and get a bit difficult. But nowhere near "bad" just yet.

There was some sort of power outage early this morning. Got woke up when it came back on and the BP monitor near my bed started going "bee-DOOP! bee-DOOP!" over and over again. It's done something bad to the TV here in the room, too. I have the volume turned up all the way on the bedside remote, and you have to be lying in bed by the speaker to hear it. When you press the "volume" button on the TV... it changes the channel. But at least, you can still tell when you're watching "Screen 2." (I still wonder what happened to "Screen 1".)

Did the 16-times BP thing again.... and it's still trending kinda high. So I called and left a message with Dr. Geller's (home physician) staff asking if I should double up on my daily Lopressor script. Chandler just dropped by with some personality tests I'm supposed to fill out before seeing the neuropsych guy on Monday. And we're waiting on our daily neurology test from Dr. Charles. Such a busy, busy boy I am.

1:49 PM

Did it again! Had an entry typed and a part of my hand touched some other part of this useless laptop and it "went back to the previous page". And when I came back to THIS page, my entry was gone!!! DAMMITT!!! Anyhow, Dr. Charles and Chandler came by before lunch and we did the UPDRS thing (I swear, ossifer, I only had a coupla liddle beers!). My right hand and arm are more rigid than they were yesterday, and so is my left hand. But I still place myself at 90% because in order to be classified at 80%, I would have to take “twice as long” to do some things, and we ain’t there just yet.

Chandler will do the UPRDS thing tomorrow since Dr. Charles will be gone for the day. Lunch was a workable turkey breast sandwich, a cookie, a salad, some sort of soup or another, and a fruit cup. Heard back from my family doc, and now I will be taking 2 BP pills a day. Despite yesterday's discomfort, I was planning on taking a stroll, but it looks like rain is in the offing, so instead I'll eat cookies and watch TV. Yeah, it SOUNDS good...

APRIL 14, 2007

8:25 AM

Mmmm. "Lump o' Egg." I will miss my daily "Lump o' Egg" when I'm done here. Does that mean I'm suffering from "Stockholm Syndrome"? Watched “Law and Order” last night. The story was about a college student with PD who killed another student while attempting to assassinate an Ann Coulter type for speaking out against embryonic stem cell research. They showed the dude in court in full-blown dyskinesia, and the prosecutor said, "Hey, he had no trouble sitting still in my office." The dude's lawyer said, "That was him on medication, this is him off meds." Bullshit. That's just the same sort of crap Limbaugh was spreading. One does not get dyskinetic from NOT taking meds. It's a small thing, I suppose, but it spreads the kind of disinformation that we had to overcome last fall with Limbaugh spreading the lies he was spreading. Grrrr.... Anyway, just had my daily 16-times blood pressure test done. Much better numbers today now that I'm taking two Lopressors a day. Now to await Chandler's visit at around 10 or so, then I'll pound out this 567-question "personality test" I'm supposed to have done for Monday. No rest for the wobbly.

3:08 PM

A crappy, miserable, doleful day here at the GCRC at Vanderbilt University Medical Center in Nashville, TN.

I'm currently on the 3rd floor. Broke out of the joint for a little while earlier today after Chandler came by to put me through the UPDRS -- or, field sobriety test if you will. There was a break in the rain, so I wandered up to Cheeseburger Charley's and found the place to be aptly named. Then I staggered to the CVS store and got some chocolate milk and orange sherbet for later. Hopefully the sherbet won't be a fluid sludge when I get around to eating it -- this fridge isn't the coldest in history. Pounded through the 567 questions on this Minnesota Multiphasic Personality Inventory test I'm supposed to have done before my Monday visit with Dr. Tramontana -- the neuropsychiatrist. Cool true-false questions, such as, "Sometimes I'm so strongly attracted by the personal articles of others, such as shoes, gloves, etc., that I want to handle or steal them, even though I have no use for them." For the record, the answer to THAT one was "false." Other than that, just killing time, listening to music, grateful that I'm halfway through this event, looking forward to randomization and taking that next wonderful, blessed, lamented STALEVO!

APRIL 15, 2007

8:57 AM

How odd. "Lump o' Egg" took the morning off. Cheese omelet instead. I feel somehow... empty. It's another dreary, rainy day in Nashville... doesn't look like I'll be getting outside any time today. Even with the Ambien, I had trouble getting to sleep last night... just couldn't shut my mind off. Got up at about 7-ish. Gonna be rough getting back into the routine when I get home later this week. MAN, am I looking forward to getting home. Everyone here is perfectly lovely, especially Christa -- the manager of the place. We always have a nice chat about this, that and the other when we do the 16-times blood pressure thing in the morning. Dr. Charles is supposed to come in to do my "field sobriety test" later today, but that's gonna depend on air travel. He went to Silver Spring, Maryland yesterday and is due back this evening. The weather has the entire east coast balled up. So, we shall see. Took almost a half hour to get showered this morning. The right hand is delinquent, and I'm slow and stiff. And I'm still more than 72 hours away from my next Stalevo. Bitch, bitch, bitch.

8:12 PM

I seem to be the patient that time forgot tonight. My dinner tray is still sitting here, 3 hours after the fact. And usually someone has popped in to take vitals or at least see if I'm still breathing... well...

how's THAT for timing! As soon as I wrote that, my night nurse came to get my tray. She also told me that Dr. Charles probably wouldn't be in until after 9 pm. That's fine. I'll still be here. Looking forward to tomorrow, just because there will be something to DO! First the visit with Dr. Tramontana, then out to dinner with my entertainment lawyer. Three more days. Three more days. Three more days.

APRIL 16, 2007

7:31 AM

It's still a half-hour until brekky. I'm pretty sure "Lump o' Egg" will be back on the menu today. You can't go more than a day with no "Lump o' Egg." No doubt, there are abstracts in medical journals to that effect. I found an occasion for a little impromptu humor this morning. I had just gotten out of the shower and was shaving, when my nurse for the day -- a jolly little lady named Eunice -- came in to check on me. She said that if I needed anything, I should be sure to press the call button, as she would be pretty scarce today ... they have a patient who is getting her blood drawn every 15 minutes. I opened my eyes in faux shock. "A new needle every 15 minutes? Sweet Jesus! Is that a punishment? Did she press the call button once too often? I swear! I won't bother you! I promise! I'll be good! I'll be good!" She laughed nervously and retreated from my room. I wonder if this little exchange will make it into my chart? I have an appointment for cognitive testing this afternoon. (PD can affect -- and WILL affect if it goes on long enough -- a person's cognitive abilities.) If they greet me with one of them long-sleeved leather jackets with buckles, I'll know it DID get entered in the chart. Dr. Charles finally dropped by at about 9 last night, looking tired and unshaven. He had just flown in from Baltimore, and he's heading back up there today. Ah, the wild life of the research scientist! As for me, my right hand is so tight and stiff, it actually causes mild pain when I try to make a fist. I'm stiff and rigid and MORE than ready for a pill, thank you.

10:21 AM

I topped off the morning by dumping a full 16-oz. cup of coffee with creamer and sugar all over the floor. The nice dude from housekeeping didn't even make fun of me. Dr. Charles has come and gone for the day, and now I'm waiting for the cognitive testing -- which promises to be grueling and frustrating.

12:57 PM

The world keeps turning. Horrible day at Virginia Tech... 30 dead in shootings. The story is still breaking. Back on topic, my cognitive testing for today has been cancelled. It's been reset for tomorrow at 4. Oh well. Dinner is still on for tonight.

7:51 PM

Felt great getting out of here for awhile. Had dinner at the Longhorn with my entertainment attorney. Had the 20 oz. Porterhouse and a man sized portion of mashed taters. Lifted my spirits nicely. And since I'm not taking Stalevo, didn't have to worry about the protein messing up the levodopa uptake. Now to relax and watch "24." Just one more full day, then a half day, then the coin flip, then I can take a pill and go home. Yaaay, home!

APRIL 17, 2007

9:17 AM

So far today, I've survived "Lump o' Egg" and the Blood Pressure Torture. Now the rest of the day is mine until about 3:30, when I will begin my shamble to the psych hospital for the cognitive testing. Hope they don't mind that one of the forms has coffee spots on it from the great Coffee Spill of yesterday. Numbers were still kinda high -- but not bad -- with the Arm Purpling Blood Pressure Procedure from Hell. I personally think a big part of it is that I'm not on the Stalevo and my whole body is in a state of perpetual clench. Whatever. Hopefully at or around this time tomorrow, we do the final testing, I get randomized, and I can take a Stalevo and rejoin the human race, walking erect and speaking clearly again.

6:27 PM

Went to have the cognitive testing. There was a young boy in the lobby, looked like he had Down syndrome. He walked up to me, smiling, and touched my beard. "Santa," he said, giggling. I smiled and said, "No, I'm not Santa... but I am one of his helpers." The testing was exquisite torture. And frankly, I'm too tired right now to really detail it like it deserves to be detailed. Got back to the room, had dinner, called Gail. Tomorrow... the final UPDRS, the flip of the coin, and STALEVO!!!

APRIL 18, 2007
7:12 AM

At last, we reach the end of the Droolfest. Sometime after brekky, Chandler will put me through the paces of the full UPDRS. Then, I guess around 11 or so, Dr. Charles will take care of the Part III of the UPDRS. Then the "opening of the envelope" and we'll find out what's what. This has been a very interesting experience. For one, I didn't know I was as impaired as I am. I must have certainly deteriorated in the months since I went back on the Stalevo... perception is everything, and I might have a different perspective on it now, but I can't imagine that I lived my life every day feeling as bad as I do now. It actually hurts to open and close my right hand. My walk is more of a stagger -- not as bad as it WILL get if the PD progresses -- but it certainly is different from the way I walk when I'm medicated. Sitting here typing this, my arms are aching, my upper back is aching, my neck aches, and even my thighs are aching. As soon as we do that last UPDRS, I will be able to take a Stalevo... so I suppose that by the time I get to the airport I will be pretty much "ON" again. If I'm assigned to the control group, that's fine. Over the next six months, it will be interesting to see if I develop dyskinesia and then again to see how far gone I am when they take me off the meds for the NEXT 8-day Droolfest. If I were a betting man, I'd bet that I will be in the control group. And that's just fine. Other than the possibility of getting this surgery, the whole point of this for me is "putting my money where my mouth is." Now, at least, I'll have the satisfaction of having taken part -- and continuing to take part -- in an important clinical research study. And that will give me a voice of authority as I do my reports for the NIH Radio News Service. I'll TRY to do one more entry from here at the GCRC before I leave... otherwise, I'll hope for a WiFi access at the airport. Once again, the folks here at the GCRC have been great. I was kept as comfortable as person can be --

in a hospital. And everyone was delightful. Now... brekky, the Arm Purpling Blood Pressure Procedure, then I wait for Chandler.

11:06 AM

We're almost there. Chandler just came by and we did the whole UPDRS -- save for Part III, which we'll do on tape with Dr. Charles performing the honors. I seem to have slowed down by about half on the right, by about a third on the left. This has certainly been instructive as far as knowing how far along I am in the progression of this disease. BTW -- for those who might be reading this while considering taking part in this very study, if you qualify and don't at least look into participating... I have to ask you... WHY NOT? Here's my official take on it... even if you are not chosen for the surgery, it is a VERY worthwhile experience -- for yourself to know where you stand in the progression of your OWN disease, and in the interest of science finding newer and better treatments for PD. I have been a bit -- shall we say, "colorful" in my descriptive language regarding the bill of fare (which, as far as hospital food goes, is not really all that bad), and the Arm Purpling Blood Pressure Procedure -- which isn't exactly as much fun as eating CANDY, but nor is it particularly unpleasant -- but that's just the ranting of a creative writer.

6:07 PM

The last entry in CDT... and the last of the 8-Day Droolfest. *Huzzah and hooray!* I was randomized to the surgical group! After carrying out Part III of the UPDRS, Dr. Charles opened the little grey envelope, and it contained the initials DBS. So, sometime in June or July I will have Deep Brain Stimulation. I was 100% prepared to be told that I was going to the control group. But now I can start preparing myself -- mentally, physically and spiritually -- for what will, no doubt, be the greatest adventure of the latter portion of my life! I took a Stalevo at about 1:10 p.m., and by the time I got to the Nashville Airport I was almost fully "ON." It feels GREAT!!! As I type this, I'm sitting near my gate at O'Hare Airport in Chicago. My flight from here to Baltimore has been delayed about 45 minutes, so it gives me this opportunity to end today's entry on a high note. Back to work tomorrow.

APRIL 25, 2007

June 13, 2007

That's when I'll have bilateral deep brain stimulation of my subthalamic nuclei. Got the word yesterday from Chandler down at Vanderbilt.

On June 4, pre-op testing.

June 5, insertion of the bone markers.

June 13, DBS surgery.

June 25, implantation of the IPG devices.

OK -- now we have a date. And it's sooner than I thought it would be. Excellent. Better make those airline reservations.

APRIL 27, 2007

Anyway, it's still over a month away, but plans are being planned. I'll travel solo for the bone marker implantation on June 5th. Gail will go with me for the lead implants on June 13th. Then I'll go by myself for the IPG placements on the 25th. I can't believe that all this will be over and done with by the end of June, save for the programming.

Also, I now know of an airline that has direct service from Baltimore to Nashville, cutting way back on the time and stress of air travel. From now on, call me a Southwest Airlines Frequent Flyer.

Speaking of stress, Gail was letting the pooches out for a yard-moistening and was just out the door with Raven when our black border collie began barking in full alert-mode.

Hillbilly neighbor's dog. Off his leash. Wanting to play.

Raven was having none of it and Gail struggled to get her into the house.

I went out to the yard and saw the dog dash out into the street. I called him (not knowing his name, "C'mere Boy!" had to suffice). He eventually walked over to me and it was obvious he's just a big pup, and all he really wanted to do with Raven was romp with her. But Raven, a true product of these post 9/11 times, considers everyone she doesn't know on a first name basis to be potential Al Qaeda.

There was a small length of leash hanging from this guy's collar, so I walked him back to his house. He was jumping and smiling and licking my hand, obviously glad to be paid attention to.

His owner wasn't home. They had a big dog cage on their porch, and it was open. Obviously, "Houdini" here had figured out the latch. So I tied him securely to the porch and went home.

My next door neighbor saw me and said that I was being "more neighborly that I had a right to be" by taking this wandering pooch back home. I told him that it wasn't the dog's fault, and that people who can't control their dogs shouldn't be allowed to HAVE one.

"For one thing," I said, "you gotta be SMARTER than the dog."

When the same dogs escape their owners time and time again, you know who's winning THAT battle.

MAY 7, 2007

Four weeks from today I will have my pre-op workup done at Vanderbilt University Medical Center. The next day, I'll visit the radiology clinic where I'll be put under general anesthesia. Four temporary bone markers will be inserted into my skull and I'll remain under for a CT and MRI scan. The surgeons will use these pictures to plot their course of attack in the deep brain stimulation surgery I'll have eight days later on June 13. Then, it's back to the hospital on June 25th for the installation of the IPG devices which will control the stimulation the STN region of my brain will receive. And really, all I can do in the intervening days and weeks is wait -- and prepare.

I need a hat. God, in his infinite wisdom, has decided that my scalp should be visible to friends, family, acquaintances, total strangers, and even satellite imagery. I've been bald since my mid 20s. And for everything I've heard about this surgical process being relatively painless, there will be some scarring. Pictures I've seen of folks taken shortly after their DBS surgery experiences indicate head bones that look to varying degrees as if they'd come out on the short end of a battle with a meat grinder.

I exaggerate, of course... but consider the insult my shiny bald pate must endure all in the merry month of June.

First, the installation of the bone markers. Look at the pictures from the Vanderbilt University Medical Center pamphlet on the procedure that I've posted on my home page -- www.billywisdom.com. Now, thank goodness, those big "thumb tack" looking things are removed right after they get their CT and MRI pictures (a fact that my smiling, she thinks she's so funny WIFE lamented, saying that if those post were left in place she could envision a delightful macramé project that would be the talk of the DC-area craft community. Sorry, hon... the posts come out)... but the stainless steel anchors will remain embedded in the skull so the surgeons will have a place to attach the individually made platform they use at Vandy -- replacing the superstructure-like stereotactic frame that gets bolted to the surgical bed, rendering the patient immobile -- captive.

When I return home on June 6, it will be with four little puncture wounds in my noggin -- one in front, one towards the back, one on each side, each closed with a staple. That in and of itself would make for some uncomfortable moments on the airplane ride home as fellow passengers gawk and wonder who I had angered, and why that person had used a b-b gun to perforate my scalp. Then, after the June 13th lead implants, depending on which technique the surgeon uses, the top of my big, bald head will look like it's either been bitten by a small shark with two semi-circular scars -- or it will look like it's been used as a landing pad for small alien spacecraft with two parallel 4-inch scars. Either way, they'll be a stapled or stitched ugly mess and if I thought my fellow air passengers would be wondering about the four simple puncture wounds from the week before, I imagine they'll think I'm an escaped mental patient from the double-lobotomy ward of a psychiatric facility.

So I need a hat.

I have lots of hats, all of varying degree of cleanliness. Some new... like the Vanderbilt University cap I recently purchased to show my pride in the alma mater... although I've never taken a single college class at Vandy, I will have my skull opened and my brain probed there... so I get to take SOME small amount of pride in my attendance, do I not? Some hats are older -- like the weather and sweat stained

"ON BROADWAY" hat I still own from my days as the original program director of the show tunes channel at XM Satellite Radio.

None of these hats will do. I need a hat that will cover the wounds, keep them clean, and most of all -- NOT TOUCH the wounds or allow the bodily fluids that will no doubt seep from them over the first few days to clot in the cloth, making removal of the hat uncomfortable and perhaps even dangerous.

So... my wife and I went to a place at a nearby mall that sells surgical scrubs. We bought a "scrub hat." I was hoping for something like you see doctors wearing in the OR. What I got was something that my stepson TJ said makes me look like "The Grand Mufti" -- whatever the hell THAT is. I think it makes me look like an older, paler, fatter version of hall of fame NFL running back Jim Brown. But it fits the parameters. It will cover the scalp without TOUCHING the scalp and therefore STICKING to the scalp.

Oh, sure... passengers will gawk. But at least they won't be sickened. And with my wife's help, my freshly insulted scalp and I will be able to make our way on and off the airplane, into the car, and home... where no doubt my two dogs will have to be restrained from jumping onto my lap so they can get a closer sniff at the source of that strange, new aroma of recent surgery.

Thank goodness when I have the IPG devices installed under each collarbone on June 25th... that gets covered with a shirt. Although one has to wonder what fresh hell awaits the first time I strap on the shoulder belt when I next attempt to drive the car.

But that's something to worry about another time.

MAY 9, 2007

Well. That’s a relief.

One of my biggest problems is that I’m just too damn curious for my own good. Once it is clear that something is going to “happen to me” I want to read everything I can find on the subject. I want to know what kind of scars I’m going to have on the top of my head – the semi-circular ones or the racing stripes. I want to know what the bone anchors look like. (Hex nuts! They look like little hex nuts! And I get four of them. In my skull! But only temporarily – they get removed when I have the implant surgery.)

For the last couple days, I've been wondering about the IPG devices that will be installed on June 25. I know there are basically two models made by Medtronics. One is the "Soletra" which controls one set of electrodes. The other is the "Kinetra" which controls two sets. I've seen diagrams of both in place. With the Soletra model, you get one under each collarbone. With the Kinetra, you get one, with wires leading up one side of the neck that attach to both leads as they poke from their little plug caps in the skull.

Now, a normal person would probably not even think about this. A normal person would wake up after the surgery to implant the device and say, "Oh! Only one owie!" And then he'd know he got the Kinetra.

But I need to know. I can't even tell you why, other than the fact that I just need to know.

So yesterday I sent an e-mail to Chandler. She's a lovely young lady with, it would seem, the patience of a saint. As I've mentioned, she is the clinical trials coordinator for the Neurology Department at the Vanderbilt University Medical Center – and not just for this clinical trial, but for all their clinical trials. I expect her job resembles juggling cats – trying to keep as many of them in the air as possible without getting scratched. I imagine by now when she sees an e-mail from my address, she smiles and wonders what manner of ridiculous question awaits her attention. Including the e-mail I sent on February 2 asking for more information about the clinical trial, I have sent 19 e-mails from my work computer. I have no idea how many I've sent from my home computer. I've asked about travel plans, availability of the doctors (and herself) for podcast interviews, time frames for the various procedures, acquisition of previous CT and MRI films, queries about when I'm supposed to stop the medication before a visit, and whether or not they can provide a rollaway bed for my wife when I'm there for the implant and IPG surgeries. Each e-mail has been answered promptly, courteously, and cheerfully. She's a delightful young lady. She'll be attending medical school in the future, and I betcha she'll be a dandy neurologist some day.

This most recent e-mail asked whether I'd be getting the Kinetra or the Soletra.

(And while we're on the subject, why do these devices sound more like car models than electrical stimulation generators? I can picture DC-area professionals stuck in heavy Beltway rush hour traffic behind the wheels of their new 2008 Soletra with power steering, dual air bags, heating and cooling cup holders and state of the art anti-lock braking systems. The Kinetra would be an SUV with a DVD player in the back seat to keep the kids quiet and off your nerves. If I were naming electrical stimulation generators, I'd probably come up with something that glorifies the FUNCTION of the device – the TREMOR TAZER or the STIFFNESS STUNNER. Or, the new, 2008 model BRAIN BUZZER!!! Now THAT's MARKETING!!!)

Where was I? Oh yeah.

Anyway, true to form, Chandler responded promptly and cheerfully and informed me that as of June 25 I'd be walking around with the Soletra. Two devices. One for each set of electrodes. One under each collarbone.

OK. Two scars instead of one. No problem. Besides, I have this thing about symmetry. If I only had one, I'd no doubt feel off balance. My body's feng shui would be out of whack. And that's not good.

Symmetry. Two scars on the top of the head. Four puncture marks from the bone markers. Two scars, one behind each ear, for connecting the wires from the IPG devices to the electrode leads. Two scars, under each collarbone. Ten scars. Nice round number.

I don't think I'll need a costume to scare the neighborhood kiddies when they come trick-or-treating this year!

MAY 10, 2007

3 p.m. yesterday.

I'm heading out the door. I'm one of those early arrivers, early departers. I get to work at about 6:30 a.m. and I leave at about 3 p.m. For one thing, traffic between here and home isn't nearly as bad in the early mornings and early afternoons. For another thing, there's always room in the parking garage when I get here. If you wait until a more reasonable hour – say, 8 a.m. – you'll be lucky to find a spot in the parking garage. And it's a long walk to the other parking lots on the campus. So I blow this pop stand every day around 3-ish.

I'm standing at the elevator when a colleague walks up behind me. This is someone I see from time to time, we are on a first name basis but have never really been what one would call conversational acquaintances. Still, when you're waiting for an elevator, ya gotta say something.

"Makin' a break for it?" I asked.

"Yeah, getting out of here early today," he replied.

"This is about the time I usually leave," I said.

He nodded and the scintillating conversation was temporarily halted by the "ding" announcing the arrival of the elevator. We both stepped through the door. I pressed the button for B-3 (government logic dictates that the ground floor leading to the parking garage should be labeled the third basement level). The door "schusshed" shut.

My colleague noticed I was wearing my "Vanderbilt" ball cap.

"Wearing a Vandy cap, huh?"

"Yeah," I said. "Since that's where I'm having all this stuff done, I feel a certain sense of commonality with the institution."

(See, everyone in our unit pretty much knows what's going on with me. For one thing, I've been reporting about the clinical trial in the NIH biweekly podcast. For another, when we have our monthly "all hands" meetings, during "share and care" time – as I call it – I've related to the group that I've entered the clinical trial. So my colleague instantly knew what I meant by "all this stuff".)

"So, they're gonna do it?" he asked.

"Yep," I said. "They're gonna pluck my head like a melon and see if it's ripe." (Folks who know me are used to my sense of gallows humor regarding such things.)

He squinched his face a bit. "Do you really think you're going to get any benefit from this?"

I looked at him for just a second before responding. It struck me as a profoundly stupid question.

"Uh, well… yeah. I mean, otherwise why would I be volunteering for brain surgery?"

"Mmm-hmmm," he said, turning to watch the red LED numbers count down the floors. There was silence. I felt more needed to be said.

"Besides," I said, "I make a living telling people about the benefits of clinical research. What kind of hypocrite would I be if I didn't take an opportunity to put my money where my mouth is?"

He looked at me, smiled and shook his head.

"You're a braver man than I am," he said as the doors opened on the B-3 level. We both stepped through.

"It's not a decision YOU have to MAKE," I thought but didn't say. "You're not confronting a steady decline in your motor function, the onset of dyskinesia that will have folks staring at you as you flop and twist like a fish out of water, and the certain onset of cognitive difficulties as you get older," I continued to think. "You don't lie awake at night with images of Pope John Paul II in his final days in your head – this brilliant man, stooped, trembling, hardly able to speak, his face a Parkinsonian mask. So no, I am NOT a braver man than you are. I know what WILL happen to me if I don't do this. There's a chance this might NOT happen to me if I DO take this chance. Idiot."

These words stayed safely locked between my brain and mouth. Instead, I smiled.

"Well, it's not like I'm being completely altruistic here," I said. "I do expect that this procedure will perhaps slow down the progression of the disease. At least, I should be able to get by with less medication. And if it turns out that this clinical trial leads to earlier and better treatment for folks in the early stages of PD, that's icing on the cake."

He shook his head and looked down at the floor.

"Still, you're a braver man than I am." His expression clearly indicated that he was saying the word "braver" while thinking the word "goofier". He strode towards the sliding glass door leading to the little courtyard outside the building. All of a sudden, I decided I didn't want to walk with this guy all the way to the parking garage.

“Well, have a good one,” I said, as I ducked into the men’s room.

(Up until now, the concept of volunteering for brain surgery was just that – a concept. Now it was time to put my money where my mouth was. It was time for the first of the three surgical procedures that constitute Deep Brain Stimulation at Vanderbilt.)

JUNE 7, 2007

One down, two to go.

My head hurts.

I look like the Peter Boyle character in “Young Frankenstein” – but not nearly so dapper or charming.

It hurts to raise my eyebrows.

The bone markers are in – the anchors that Dr. Konrad will use to attach the stereotactic platform he'll use to guide the probes and electrodes during my brain surgery June 13. And despite the bitching you might detect in the above paragraphs, the whole thing went quite smoothly… once I got through the security gate at BWI airport, anyway.

"That bag's too big," the TSA agent snapped. I looked at the small, rolling suitcase by my side. Borrowed from my stepson – this suitcase was purchased for the sole purpose of serving as carry-on luggage. I opened my mouth to inform the agent of that fact when he pointed at the plastic bag holding my toothpaste, deodorant, etc. that I removed from the bag so that the TSA could see my liquid toiletries and satisfy themselves that I was not going to concoct a toothpaste and deodorant bomb onboard the aircraft.

"It's supposed to be a QUART bag," he hissed. (I swear… he HISSED!) "That's a GALLON bag."

"I'll be damned," I said, contemplating whether or not they'd have to clear the terminal because of this breach of security. I mean, you could clearly see the toothpaste, the deodorant, the little bottle of liquid soap, the tiny bottle of mouthwash – all purchased to comply with the idiotic new security requirements designed to prevent Osama bin Laden and his legion of evildoers from blowing airplanes out of the sky with commercially-available toiletries.

"I thought the purpose was to make the items visible to the inspector," I said. "I didn't know the size of the bag was the issue."

Earning every cent of his $8 per hour salary, the TSA agent pointed at a sign. "It says right there… a quart-sized clear plastic bag. That bag is a gallon-sized bag."

I braced myself, anticipating at any moment to find myself being pushed down to the floor, my face pressed into the carpet as this diligent guardian of the airport rifled through my bag to see what other dangerous things I might be carrying in as of yet unseen clear plastic bags of unauthorized volume.

"Is there any way around this, or do you have to confiscate the bag?" I asked. The agent considered for a moment.

"Well, if that's the only size bag you have," he said, apparently deciding that my gallon-sized plastic freezer bag of toiletries was not a clear and present danger to America and its freedom. He gave me a dismissive wave and I was allowed to proceed to the x-ray conveyor belt. I pulled off my shoes, took off my hat, stripped off my belt, emptied my pockets, and placed everything into the grey plastic bin along with the freshly-pardoned plastic bag. With my suitcase and the bin on the conveyor, I showed another TSA agent my boarding pass and walked through the metal detector. No beeps. Good.

Moments later I sat in a nearby chair, put my shoes and belt back on, put the plastic bag of stuff back into the suitcase, refilled my pockets, and made my way to the gate.

Southwest Airlines has an interesting way of boarding passengers. No assigned seats. When you get your boarding pass, you are assigned a letter – A, B or C. At each Southwest gate, there are three gates marked accordingly, A, B and C. When I got to my gate, there were a few people standing in the "A" row. Most were seated in nearby chairs. I found an empty chair near the head of the "A" row – I had an "A" boarding pass, after all – and sat down.

"Do you have an 'A' boarding pass," a fellow passenger asked. I told him I did.

"The line begins back there," he said, pointing to a group of people sitting about 10 yards away. There were a bunch of empty seats in this area. But apparently this gent had appointed himself "row captain". So I shrugged and made my way towards the back of the row.

As it turned out, folks sat pretty much wherever they wanted to sit as we awaited boarding. "A's" sat with "B's" and even the otherwise untouchable "C's" were allowed to mingle among their betters without being ostracized. But once the gate personnel started loading the pre-boarding passengers… the elderly in wheelchairs, folks with tiny kids… it was every man for himself as we queued into our respective lines.

I got lucky. When I got on the plane there was a front, aisle seat. Being a fat man, I like the aisle. I can lean into the aisle and give my center-seat mate a little more breathing room. I am a humanitarian and make no bones about it.

The flight to Nashville took about 90 minutes and was without event – except for some rocky turbulence as we dropped through thunderstorms on our descent into the Music City. I was first off the plane. A short cab ride later, I was once again at the entrance to Medical Center North at Vanderbilt University Medical Center.

The door was locked.

I pondered this for a moment, recalling that my first visit to the General Clinical Research Center at Vandy also started on a Sunday, and the door was open then. I walked to the side door along 21st Street. Also locked.

Thank goodness for technology. I pulled out my trusty Treo, did a web search and found the phone number for the desk at the GCRC. A few moments a later a young nurse named Ben opened the door and let me in. I asked why the door was locked.

“It’s Sunday,” he said.

Ben took me to my room where I stashed my gear, turned on the TV, made myself comfortable and waited for dinner which arrived with its usual punctuality. You can almost set your watch by the meal times at the GCRC… breakfast at 8, lunch at 12, dinner at 5.

Monday morning, I noticed something different about breakfast. “Lump o’ Egg” no longer had that “rubbery” taste. In fact, it was in a different kind of container. I felt a brief, unreasonable sensation of pride believing that my blogging on the subject might have led to this improvement in the bill of fare. They’re my delusions, and I cling to them fiercely.

The only official item on the agenda for Monday was the pre-op anesthesia evaluation. It was a relatively standard affair – for obvious reasons, they want to make sure the patient is likely to survive the application of anesthesia. This involves an EKG, answering questions about one’s medical history, a chest x-ray and blood tests. The very nice nurse practitioner who interviewed me cleared me for the procedure, but asked that I provide her with a copy of a cardiac stress test I had in 2006 (or was it 2005) before the final procedure on June 25. This struck me as rather odd… I would be having surgery in less than 24 hours, and if I were likely to be killed by the anesthesia on the 25th, I was just as likely to die from it sooner rather than later. But I agreed to find the report and send it

At 6:45 Tuesday morning I made my way to the radiology clinic at the main hospital. After filling out more forms, I was ushered back to the preparation/recovery room. After getting into a gown and lying down on the gurney, a gent from the MRI department ran a tape measure over my mid section.

"He's right on the border line," he told one of the techs. "60 inches… that's right at the limit." This meant that I would likely not fit into the MRI tube without being stuffed into it like cream cheese into a cannoli.

"We'd have to squeeze your arms into your chest, and that would restrict your breathing… and we won't do that," the tech said.

"Well, I hope I haven't come all the way down here for nothing," I whined, wondering if this was the end of my participation in the clinical trial. I could visualize my patient file, with the word "Closed" stamped on it in bold red letters with the notation "Too Fat!" written below the stamp.

"No, Dr. Konrad says he has some old MRIs of you he can use," the tech said.

"We'll get the CT and go from there."

Bernard, the tech who checked me into the radiology department, came back and started an IV in my right hand. "This is my least favorite part of surgery," I said.

"We'd worry if it was your favorite part," he said without a smile.

Then came the procession of professionals to my little gurney. Associates of Dr. Konrad ("We've been told what a HOOT you are," one said.), members of the anesthesia department, and the folks who would drill the bone markers in my skull all dropped by to say howdy.

Then they rolled my gurney into the CT lab. I slid from the gurney onto the CT table and the professionals gathered about me. Everyone was so busy. I almost felt guilty just laying there doing nothing. The two anesthesia ladies discussed which of them would stand on my left and which would stand on my right, and I got the feeling that the younger of the two was a trainee. For a fleeting moment it occurred to me that all I had to say was "I'd like to stop now" and then everything would come to a screeching halt, I could get up off the table and go home. I decided against it.

The more senior of the anesthesia ladies told me she was just about to inject something into my IV. "This burns sometimes," she said… and it did, but just a little. Her junior put an oxygen mask over my nose and mouth.

"You're going to feel very sleepy in a second," the senior one said.

I concentrated. I focused. I wanted to actually FEEL myself drift off to anesthesia-land. I've never been able to catch the feeling before.

Nor would I this time.

A moment later I was back in the recovery room.

"Are they done?" I asked.

"Yup," Bernard said.

"What time is it?"

"About 8:30," Bernard said. The whole thing took less than an hour. I raised a hand to my forehead and gently explored the region. I was expecting a puncture mark in the middle-upper part of my forehead, since the Vanderbilt handbook on the subject indicated that the bone markers are installed in a diamond-like pattern – one in front, one in back, one on each side of the head.

I had two bumps on my forehead and two in the back… not a diamond… a rectangle.

"Don't touch those," Bernard said. "Your fingers are dirty."

"I washed them this morning," I said with a pout.

I asked for – and got -- three cups of coffee, and they monitored my blood pressure for the next hour before turning me loose. I felt fine! In addition to the general anesthesia, they used local anesthetic to numb the top of my head. For the first time in my life – despite taunts to the contrary over the span of my entire existence – for the moment I actually was a "numbskull."

After a wheelchair ride back to the GCRC, I called Gail and told her I had survived the procedure. She seemed glad to hear this. I took pictures of myself with the Treo and e-mailed them to her. “Oh, my!” she said as she saw the first one.

I was beautiful. But I wasn’t done yet.

My nurse-of-the-day came into the room and said radiology called. They were sending someone to take me back down for an MRI.

“I thought I was too fat,” I said.

“They’re going to try it anyway,” she said with a shrug.

Moments later, two young ladies arrived with a gurney. “Where’s your hospital gown?” one asked, no doubt puzzled by the fact that I was wearing a black t-shirt, green shorts and sneakers.

“Don’t have one,” I said. “And this is silly. I can walk down there.”

“No, this is procedure,” she said.

“Fine,” I said as I hopped onto the rolling bed. I pulled the sheet up over my face and said, “Let’s go.”

“You’re gonna scare everyone,” my driver said, pulling the sheet down. “Stop that.”

We went back the way we came… through the tunnel separating the main hospital from the Medical Center North. There in the MRI lab was the guy from earlier – the one with the tape measure.

“I thought I was too fat,” I said.

“So did I,” he said, “but we’re gonna try anyway.”

He rolled the gurney into the MRI room and I got on the table. He asked me to lay down with the back of my head in the coil they use to get better pictures of the brain. My head didn’t fit. It’s a large head. What can I say?

I sat up so they could change the coil, and noticed something trickling into my right ear.

“How did I get water on me?” I wondered as I wiped my ear. My right hand came back with my index and middle fingers soaked in blood.

“Fellas, I seem to be bleeding here,” I said as calmly as a guy with a bleeding head can say.” Turns out I bumped one of my new scars on the skull coil. As it was still numb from anesthesia, I didn’t feel it.

They put a gauze and tape over the incision and tried another coil. This one was even smaller… it was like trying to put 10 pounds of cheddar into a box meant for five pounds. They decided to go with a larger coil. This one fit tightly, like a football helmet, but it did the trick.

“All right,” the tech said, “we’re going to strap your arms to your side and slide you into the tube and see if we can get you in there. Pull your arms in as tight as you can.”

I did as directed and they slid me into the tube. My arms and elbows pressed into my rib cage, but they were able to get my head where they needed it. After nearly a half hour they pulled me out of the tube, injected me with a contrast agent, and stuffed me back inside. Another 12 minutes and they were done. I was treated to another gurney ride back to my room, and never was I so glad to see a hospital lunch as I was when they brought it in to me.

After lunch, I relaxed and waited for the local anesthetic in my head to begin wearing off. It did. And that’s when I noticed how much the entire scalp is involved in something as routine as the movement of an eyebrow. Each motion of expression was met with pain. It wasn’t so much a “headache” as it was a feeling of getting the crap beaten out of you by someone with brass knuckles. My eyes felt swollen. My sinuses ached. Tylenol took the edge off. But there was no way to lie comfortably. I was able to sleep that night, but woke up frequently – every time I moved my head.

By the next morning it felt a little better. By the time I got on the plane to come home, it was even better. I had the same seat on the flight home as I did on the flight to Nashville – but now I was paranoid about passengers swinging their carry-on luggage and smacking me on the head with it. When Gail met me at the airport, I was paranoid about banging my head on the car door as I sat down. It’s amazing how much you think about and care about a previously ignored body part when it aches and throbs with each and every movement.

My sense of humor, however, was not affected. Gail and I stopped at a grocery store on the way home and I noticed an elderly woman pushing a cart towards her car. “Howzabout I take off my hat and stagger towards that lady – Frankenstein-like – and demand that she give me my brain back?" I asked. Gail shook her head.

"Yes, that's a good idea. Why don't you do that? I'll wait here."

She knows me too well.

It felt good to be home. Oddly, neither Shiloh nor Raven seemed interested enough to jump into my lap and sniff what I feared might be the enticing scent of fresh blood on my bean. Gail had purchased one of those foam wedge pillows, and that made it somewhat easier to sleep through the night.

And now, the day after, as I sit here at my desk wearing a "Thompson Cigar Company" hat to protect my co-workers from having to look at my scarred and stapled skull – unless they ask first – the pain isn't much more than a dull ache.

A week from right now will be the morning after the actual electrode implantation. With two 4-inch incisions and two dime-sized holes in my skull, I imagine that will feel a bit tender as well.

But that's another battle for another day. This one's behind me. Like I said…

One down…

Two to go.

(On June 13, 2007, I had the second procedure done… the actual implantation of the probes into my subthalamic nucleus. I was home the next day. But it took me four days to finally sit down and write about the experience.)

JUNE 12-18, 2007

I have no idea why this is so hard to write about. More than once over the past few days I've found myself typing words on the blank screen, only to delete them, start over again, delete those words as well, and then just give up. It's like there's something stopping me from telling the story. I have no idea what that might be, but it's hard to get started. I'm thinking perhaps it's just a case of there being so much to write about that I just don't know where to start.

So, I guess what I'll do is just start writing and keep writing until the story is told. If I don't like it, I can change it later. Just put your head down and push. Here goes.

We parked the car in the airport's hourly parking lot – the one with the $20 daily maximum. I figured that when the plane got back on Thursday, the last thing I would want to do would be to stand around waiting for a bus to take me back to the long-term parking lot on the perimeter of the airport property. If I survived the surgery, that is…

If I survived the surgery…

Now that the deed is done, I suppose it would be all right to admit that the idea of not surviving the surgery did pop up more than just from time to time. Dying during deep brain stimulation surgery is not unheard of. It's rare, but it happens – most usually a result of a ruptured blood vessel in the brain. So the possibility is there. It's a card in the deck that you hope doesn't get turned up while you're playing. It's like the "Bankrupt" space on "Wheel of Fortune". You spin the wheel and hope against hope that you don't hit that "Bankrupt" spot and lose everything you've gained up to that point. Odds are it won't happen.

But it can. And it does. And you don't get another spin when it happens during this surgery. Instead of Pat Sajak saying, "Oh, too bad, Bill," I suspect that the last thing you would hear would be the neurosurgeon saying something like, "Oh, shit!" and then the techs would rush about in a controlled panic as everything fades to black forever.

See? These are the things a creative mind thinks about but doesn't like to write about BEFORE a procedure like this because it would be bad juju. But the possibility is there, in the shadows. The odds are in your favor, and hugely so. But that "Bankrupt" space is on the wheel. And one can never say for sure…

Not that I want YOU to worry about it if you're considering this surgery… but you will. And you will most likely do what I did… and that's go ahead with it anyway.

(Seems to me that this is the sort of thing Dr. Finder – the Vanderbilt University ethicist – wanted me to really, really think about before I signed the consent forms back in February. I thought I did give these concerns their proper consideration. Hah!)

But now that part of it is over. As I write this, I'm five-days post op. And what I really, really want to do right now is write about what happened – which I was starting to do. (Is lack of focus a side effect of DBS surgery? I'll have to check that…)

Anyway, we parked the car in the hourly lot and made our way into the airport. I toted the suitcase, and Gail trailed me like a Mama Duck following her Drake as we went inside. We checked the bag, made our way through security, and found a place to sit down for a beer.

I ordered up a Sam Adams. "Ah! Goin' to Massachusetts, are ya?" a voice to my left said.

"Beg pardon?"

"Goin' to Massachusetts?" he asked again? The stranger was wearing a cowboy hat and a shirt that was reminiscent of military fatigues. But the accent was Bostonian.

"Metaphorically speaking, I suppose," I said as the bartender handed me a tall frosty mug of the most famous non-bean Boston export. I turned away, towards Gail, hoping he would get the hint that I was not looking for a conversation partner. No such luck.

"So, you live up there or just visitin'?" he asked. He missed my metaphor.

"No, I'm from here," I said. "I was just making a little joke because you asked if I was going to Boston because I ordered a Sam Adams." I turned away again. It didn't stop him.

So, for the length of time it took me to drink a big, frosty mug of Sam Adams – which I really wanted to linger over and enjoy – the stranger to my left went on and on about the fact that he was from Boston, that he now lived in Phoenix, that he once served in the Army for six years, that he drove tanks, that his father drove tanks, that the tanks these kids have today are like luxury hotel rooms compared to the tanks he had to drive, and so on and so forth. As he would make a particularly interesting or humorous point, he would accentuate it by slapping me on the shoulder, the back, or my forearm. He did that about six times.

I pounded down my beer and looked at Gail. “Well, hon, we’d better head for the gate…”

“What time’s yer plane leavin’?” he asked.

“Any minute now,” I said. I told him to have a great trip and even shook his hand. As we walked away, I told Gail that if he had slapped me on the back one more time I might have knocked him off his barstool.

In fact, there was still an hour before boarding time. But folks with “A” boarding passes were already lining up in the Southwest Airlines boarding queues. I took a spot in line and invited Gail to sit and wait for the line to start moving. She decided to stand with me for a while, but as it became apparent that our plane was going to be late arriving, she sat and waited while I held our place.

We boarded, and the flight itself was pleasant and uneventful. We had good luck with baggage claim – our suitcase was one of the first offloaded – and we made our way to the taxi stand.

The taxi itself was a clean, well-maintained SUV driven by a polite young man of Middle Eastern origin. He got us to the Vanderbilt Medical Center North entrance without delay.

We were greeted by the friendly, welcoming folks in the GCRC who said that this time I would be in a special room – with wall decorations. And true it was! There was a wall painting – tropical fish, swimming in a tranquil ocean setting. Very peaceful. Nurse Ben checked me in, and Gail and I went out to get a bite to eat.

Later, Nurse Ben showed up with a rollaway bed for Gail. We watched TV until about 10 p.m. and then decided to turn in for the night.

I spent a lot of time looking at the ceiling. I was glad Gail was there with me. But at 3 a.m. on the morning before brain surgery, in a dark room, you can only be alone with your thoughts.

I checked the time frequently. Nurse Patrice said she would make sure we were up by 5 a.m. so we could check into Admissions by 6. I was ready.

After a quick shower – Gail folded up the bed, her sheets, blankets and pillows so the nursing staff wouldn't have to do it – we were ready to go. I was discharged from the GCRC and we walked the short distance to the main lobby at the Vanderbilt University Medical Center. The Admissions office was full, with only a few seats available. Gail decided to wait with the suitcase out in the main waiting area. I checked in and took a seat. As each patient was admitted, he or she would leave with a group of four or five friends or relatives. Then another would arrive with five or six relatives in tow, and they would all sit in the admissions office waiting area. When it was my turn, I gave the admissions person all my information. She punched up a wristband and a blue card with my info in raised letters and told me to take a seat in the main waiting area.

In a few minutes, a gent called my name and that of another patient. Gail and I followed into the elevator up to the pre-surgical area. Now that things were rolling, I was no longer nervous. I was just ready to get this show on the road.

Gail was asked to sit in the waiting room while I was taken to a gurney in the pre-op area. The nurse told me to strip down to my birthday suit, put on the green hospital gown, and have a seat on the gurney. I did as told and waited for the nurse, who was a cheerful, chipper middle-aged lady whose name I cannot remember. She started an IV on my left hand, and since she used a numbing agent before inserting the IV catheter, it didn't hurt much. I was visited by surgical residents who explained the procedure, anesthesia doctors who explained that I would get some sedative in the first and third phase of the operation, I signed various consents. Then it was time to be catheterized.

See, this is a long procedure. A patient cannot get up to go to the bathroom. So a tube into the bladder is a necessity. My cheerful, chipper middle-aged nurse would not be the one performing this duty. That particular chore fell to a young man named Donta.

Let me set this up properly. Donta is a very nice, very pleasant young man. He has the build and look of a middle linebacker in the NFL. He looked as if he could lift me off the bed with one hand, insert the catheter with the other, and slam me back down to the gurney – all without breaking a sweat.

Donta walked into my area with the sterile catheter kit and shook his head sadly. “You’ve done lots of these, right?” I asked. He nodded. He opened the package, poured out the antiseptic solution he’d use to wipe down the tip of my urethra, and applied lube to the tip of the catheter.

“Take a deep breath,” he said.

Now, to be fair, I didn’t scream. I didn’t yell. If you had been standing outside my cubicle you would have heard sounds like “Oooof, Nnnnngh, Unnnnnh,” but no screaming. Donta showed no mercy. He got that thing where it needed to go in short order, and got the front of his scrubs doused in urine as a reward.

“Struck gold on the first try,” he said. I sheepishly explained that I wanted there to be a little urine in my bladder so he’d know he had hit a bull’s-eye. He smiled, then went to change his scrubs.

As the clock sneaked up on 7:30, the pre-op room got busier. Then, like the biblical Hebrews fleeing the pharaoh’s Egypt, patients on gurneys were wheeled out of the staging area and into their various OR’s.

As I was rolled into mine, I announced that the star of the show had arrived. The various residents and techs assured me that I was the star of this particular show, and they set about getting me ready for my performance.

I had brought my iPod along with 132 songs on a playlist I called “DBS Ditties.” This included an eclectic mix of jazz, classical music, tunes from the 30s, and lounge music. The fact that I brought the iPod was communicated to Dr. Konrad, who hadn’t arrived yet. I was told that the good neurosurgeon was at the moment digging through his office for his iPod player. We would have MUSIC this cheerful morning!

Dr. Konrad arrived and brandished the iPod player, he took my iPod, plugged it in, and I told him to go to the “DBS Ditties” playlist. This generated a bit of a chuckle among the crew, and the concert began with Mozart’s “Concerto for Piano and Orchestra, No. 24 in C Minor, KV 491, Allegro.” It set a dramatic tone as the crew scrubbed my head, set up the plastic sheeting, and generally made ready to dig in for their morning's work.

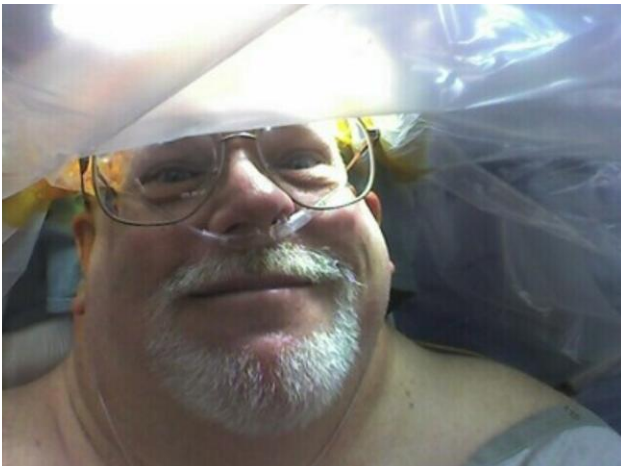
I kept up the banter, talking about things I don't recall at present. It was important for the success of the surgery that I be placed in as comfortable a position as possible. And they were able to do this quite simply. Imagine being in a large lounge chair aside a swimming pool for hours. My neck was fully supported, they put pillows under my knees, foam pads under my heels, and foam rests under the entire length of each arm. Then Dr. Konrad said it was time to numb up my skull. I had been expecting to be sedated for this portion, but wasn't feeling the effects yet. "This is going to feel like giant hornet's stinging," Dr. K said. And he wasn't far off. After a few very painful injections, I began to feel the sedation… don't know what caused the delay. But it didn't seem to hurt quite as badly after the sedation started running in.

I didn't feel it at all when they pulled out the staples over the bone markers, nor did I feel it when they cut two four inch lateral incisions into the top of my head. I was good and groggy when they drilled holes into my skull. Dr. K made a point of explaining that the driver on the drill was set to cut off instantly when there was no further resistance from skull – thereby avoiding the damage that could have been done to the covering of my brain. And darned if it didn't cut off the instant it was supposed to. I felt the vibration through my entire skull, and smelled the kind of "burned bone" smell one might recall from drilling at a dentist's.

I felt myself being roused from my groggy reverie, and asked if this was being done intentionally. I was assured that this was the case, because they needed me awake and alert for the next phase. I felt somewhat nauseous from the sedative and my entire body had broken into something of a light sweat. Everyone was so busy fastening the frame to my bone markers, installing the probe drivers, and getting everything else ready to go, I didn't want to bother them with such a petty complaint. Eventually, someone noticed I was glistening and asked if I was warm. They covered me with one of those air-cooled blankets and it was like heaven.

As I lay there, fully awake and listening, they began inserting the probes. First, the “listening” probes. Now keep in mind that for the last eight days, they had a good map to go by – my CT and MRI scans. And based on previous experience and using data from other patients they had a pretty good idea of where their “target” would lie. The subthalamic nucleus isn’t highlighted on the scans. And every brain is slightly different. But you go with the averages, and you have a general idea of where this tiny, football-shaped piece of brain will be found. So, since my right side is the most profoundly affected, they advanced the “listening” probe into my left brain.

(And here, I will mention that once they had my head opened, one of the doctors called down to the waiting room and left a message for my wife, saying that they had dug two holes in my head and found brain in both of them. Knowing my sense of humor, they felt my wife would appreciate the joke. She did. She also appreciated Dr. K sending her a photo of me on the table, taken with his Treo cell phone. I showed him how to shoot it to my phone number. He also took a photo of what was going on there on the other side of the plastic sheeting. He sent that to Gail, too. I wondered how much she would appreciate that.)



Dr. Konrad took this photo on his Treo during surgery.

As the probe advanced, we could hear what sounded like an AM radio that wasn't set on a station, picking up faint static. As the probe approached the target, the static started to pick up in intensity, like there was a thunderstorm in the distance. They attempted a few different approaches, and each time in the area of the STN, there were the crackly sounds of misfiring neurons… and they were able to increase the intensity even further by manipulating my right shoulder, elbow, wrist, and foot, demonstrating that these were movement neurons that were misfiring. Dr. K remarked how easy it had been to find the area.

"And to think, not a year ago, I was seeing a neurologist who stated that I did not have Parkinson's," I said.

"We'll send him a copy of the paper we're writing," Dr. K joked.

This is how it looked on the other side of the sheet.

It was necessary for me to be quiet during this portion of the operation. If I spoke, there was a problem with bone conduction artifact… meaning that the test probe would pick up the sound of my voice as it was heard in the depths of my skull. But being quiet came with some challenges.

For one, my neurologist, Dr. Charles arrived around this time and took part in the limb manipulation efforts. He stood at the foot of the OR gurney and waved. "Hi, Bill! David Charles here."

"Hi, Dr. Cha…"

I could hear my words coming out of the speakers, distorted but recognizable. "So, this is how my brain hears sound," I thought. I smiled and waved.

Other times, if something was said that I wanted to agree with, I found myself nodding my head. Not a good idea when you have probes in your brain. I adopted a "thumbs up" signal to indicate my agreement with something being said.

Now that they had secured the target area, it was time for the stimulation test.

This was, in a word, freaky. I had no idea what to expect, save for some possible pulling, numbness, tingling and the like. But they needed to find that "sweet spot" between "no effect" and "side effect" and this was the only way to do it.

(Now, keep in mind that what follows isn't exact, that for the sake of narrative I am playing fast and loose with the numbers being called out, but that this is generally how it went.)

They started with the left brain and advanced the probe to an area close to the target they had identified. Dr. Charles held my right arm and began to manipulate it. "One. No efficacy," he said, meaning that set at 1, the stimulation had no effect. He called for it to be raised to 1.5.

"There it is," he said. And he continued manipulation. He asked me to open and close my fist, and to rotate my hand. Even though I had been off the medication since the previous Sunday, my hand was loose and free.

"You can really feel it," he said about the stimulation. "The cogwheeling (that ratcheting stiffness in a limb that comes with Parkinson's) just melts away. Raise it to 2."

He asked me how I felt, and I replied "fine."

"OK, 2.5 then."

I felt something… even now, it's still almost impossible to describe the feeling. It was something like nausea, but not quite. But "nausea" was the only word I could think of for it. Dr. Charles told me to take a few deep breaths and we'd try one more.

"Up to 3," he said. "How's this? Any different."

"It's… It's… It's…"

"Yes?"

"…hard … to … talk…"

And besides, I noticed I couldn't move my eyes. He held a fist up for me to look at, and I was able to follow it on one direction, but not the other.

"Turn it off," he said. And as if a magnet that had been holding my eyes and tongue had been turned off, I was able to at least try to explain what had happened. But words still failed me, and I was more than just a little freaked out by the experience.

But now that I knew this was likely to happen with each successive testing of the electrodes, I was ready for it and felt I could make a good effort to define and describe what was going on with me.

Bit by bit, the electrode in my left brain made its way towards, into, and through the target area in my STN. We found that with therapeutic stimulation, the symptoms on my right side were eliminated. With too much stimulation, I had varying degrees of dysarthria (difficulty in speech) and eye-freeze. The speech difficulty ranged from speaking in a slow, slurred voice, to being completely unable to think of the proper word, or even to think of a word to say.

Testing my right brain followed a similar course. The only difference was when they reached the high end of stimulation on the last few passes, my mouth pulled to the left with a half-grimace as I tried to speak, and my gaze was averted in that direction as well. But the instant the stimulation was turned off, I would return to normal.

Dr. Charles seemed a bit frustrated that I wasn't able to be a bit more specific with what I was feeling and experiencing, but Dr. Konrad seemed more than satisfied with the electrode placements and they agreed to lock them in place and close me up.

By this time, the cooling blanket had left me feeling cold. A heated blanket placed over my chest and shoulders warmed me up nicely as Dr. K and his team began the process of locking everything down, securing the electrodes, and closing the wounds. They put me back into sedation and I listened as the doctors chatted amongst themselves as they applied the absorbable sutures and covered the incisions with derma bond liquid sutures – like Crazy Glue, but more expensive. They created pockets in the skin under my scalp for the wire leads from the electrodes that will be attached to the IPG devices when they are implanted on July 3rd – that date was changed from June 25th due to Dr. K being called out of the country to take part in some other seminar or something… I'm still kinda foggy on the details.

At about 1:30 – six hours after they started, they rolled me into the post-op recovery room, and Dr. K went down to the waiting room to tell Gail the operation was over and I had done well.

In the recovery room, I was assigned to Nurse Tom. A great guy, with a soft, southern drawl, he was easy to like. I asked for water and he brought me ice chips. Never in the history of the world had ice chips been so delicious. Our next step was for me to be taken to radiology for a CT scan, which we did about an hour after I rolled into the recovery room. They let my wife come up to see me briefly, and told her that the CT would determine whether or not I went to a regular room or neuro-ICU. "If there's no bleeding, he'll get a regular room," the doctor said. Shortly before 3 we headed down to radiology.

There was a Tennessee Highway Patrolman in the elevator when we got on. "Afternoon, Officer," I said. He wished me a good afternoon as well.

"I understand I have the right to remain silent, everything I say can and will be used against me in a court of law…" I said. I was recovering from surgery, but my sense of humor was intact.

“Don’t ask him any questions, Officer,” Nurse Tom said. “He’s already had his brain picked today.”

I gave Tom a high five for the zinger.

Still woozy, I crawled onto the CT table. I could still feel the catheter, a very annoying sensation. But they were quick about the CT and I was in and out of there in just a few minutes. We rolled back to the recovery room and waited.

And waited.

And waited.

And waited.

A couple hours later, Dr. K’s intern came by and asked how I was doing. “You tell ME,” I said. “I’ve had my CT taken.” He went to a nearby computer monitor screen and took a look. He came back smiling.”

“We do good work here,” he said. “No bleeding, just some air, but you expect that in this surgery.” He assured me that it was just a matter of waiting for a room to open up and I’d be on my way to a regular room on 6 North.

While we waited, Donta came back and pulled out the catheter. I won’t say it was like he was trying to start a lawnmower, but it sure felt that way. “It’s gonna burn when you pee at first,” he said. I asked for a urinal. He was correct.

Nurse Tom was my constant companion for the next few hours. We chatted about everything under the sun. In the meantime, he kept me hydrated with Sprite, brought me a tub of Jello, and when it was clear I would keep the Jello down – a sandwich.

And we waited, and waited and waited for a room.

Around 6 p.m., Tom rolled me into a larger room with chairs and TVs and said he would bring my wife up to sit with me. Poor Gail had been waiting since being told that the CT scan would determine whether I spent the night in ICU or a regular room. No one had told her the CT was OK. So she was relieved when she showed up to sit with me.

When we were alone, she offered me a Milky Way candy bar. She bought me a candy bar, thinking I might want it. I love her with all my heart.

At 6:30 Nurse Tom went to dinner. Shortly after, the charge nurse for the post-op recovery room told me that they found a room for me, but that we'd have to wait for Tom to get back. When Tom got back, he said we'd have to wait until after shift change, but by 7:30 or so, we'd be in our room. And we were.

For the first time, I got a look at my gruesome surgical scars. I look like I was bitten on the head by a shark. My face was swollen, my head hurt. Gail took pictures to preserve the moment.

There was no rollaway bed for Gail in this room. But they were able to get a pull-out chair for her to sleep on, which she did with varying degrees of success. I know, because I was awake most of the night. For one thing, I was nauseous from the Lortab pill I had taken for pain. The ache wasn't so severe that I wanted morphine, but I had hoped the Lortab would cut it back a little. All it did was make me sick. And I felt constipated. And my head was crackling like a bowl of Rice Krispies.

Seriously. As I lay there, trying to sleep, my head kept up a steady "snap, crackle, pop" as the air that got into my skull was reabsorbed. If I opened my mouth, you could actually hear it. All night long. Snap. Crackle. Pop!

I had no appetite at all the next morning. I was able to eat some of my breakfast, but the eggs, bacon, etc., went uneaten. They were very nice to sneak some brekky in for Gail. Same thing for lunch… just a bite here and there. Dr. K popped in to check me out and said I was free to go home. My nurse for the morning arranged for me to be transported to the Admitting Office in time to catch a cab to the airport. Gail and I spent the better part of the morning dozing and watching TV.

It wasn't quite as nice of a cab that took us to the airport. A chatty young Arab in a run-down, rattletrap cab drove like a madman and hummed Arabic songs to himself when he wasn't grilling me on my medical condition. But we got to the airport alive, and I was able to secure a pre-boarding pass to make sure we got on the plane ahead of everyone else.

I've been home now for four days. In that time, my appetite has returned, my bowels have started working again, my head is still swollen, and I'm sleeping very well. I'm glad I was warned about this, but now my eyes are swollen almost shut because of the downward migration of all the fluid that accumulated under my scalp during and after the surgery. I look like I've done 12 rounds with Mike Tyson – bite marks and all.

Gail has been taking wonderful care of me. She is my healing angel.

TJ has been great, too! Yesterday was Father's Day. He smoked up a bunch of brisket and ribs. I got a pewter Homer Simpson statue to take to work with me. Life is good. I got an e-mail from my daughter Kendra, and Peter called from St. Louis – we talked for nearly a half hour.

Just one more surgery to go. Dr. K. says this one's a two-hour, in-and-out breeze – compared to what I've just gone through.

He's been right so far.

JUNE 20, 2007

God, has it only been a week?

Or… has it been a week already?

Either one of those would describe how I feel at the moment. Or both. Take your pick.

It would be a lie to say that I feel bad at the moment. In fact, it would be a lie to say I feel much of anything. I'm just kinda flat at the moment, like root beer that's been left to sit for too long.

I've made the airline reservations for the trip on the 3rd and 9th. Turns out I had to swap out the reservations for Gail and myself on the 24th… since we're not going. But it's all good – the new reservations for the 2nd thru the 4th actually saved me $94, which at this instant, carrier pigeons with arthritic wings are carrying in lead-lined wallets from the SWA headquarters in wherever the hell their headquarters are towards my bank in Maryland.

To be fair, I just checked the bank balance again. I swapped out the flight on Monday, asked SWA to put the $94 into my account – and here it is Wednesday – TWO DAYS LATER (I can hear those words in my mind as if they were being spoken by my grandmother, who watched each and every penny as if it were a little copper-covered grandchild) and the money is still not in my account. "It's HIGHWAY ROBBERY!" (Another of Granny's favorite sayings when the price of pork chops went up a penny or two a pound.)

Maybe they're waiting to see if I'm actually going to try to fly on the 24th… which I can't, because they cancelled the reservation when I made the new one. Or else they're just screwing me.

I will be going back down on the 9th to get the units programmed. This will be a day trip – down and back, same day. No need to… ooops. Hang on a sec.

That was the phone. It was Ida from Doctor Konrad's office. My appointment's been changed yet again. It's still on the 3rd… just not as early in the morning. Now it will be at 11 a.m. on the 3rd, instead of 10 a.m. which means I don't have to get to admitting until 9 a.m., which means a longer period NPO during that special time of day when I really, really DO want a cup of coffee.

Oh well…

Like I was saying…

No need to linger about and take up a room at the GCRC when I go down for the programming.

Shit. I should have asked Ida about the "No Driving" rule. She wouldn't have known, but she might have checked with someone.

See, I have “No Driving” restrictions. I’ve been taking the train to and from work last couple days.

Work. Cute name for it. Not busy at all. Folks coming by to gawk, to tell me how “good” I look. And I suppose that considering that I had brain surgery a week ago today, I do look pretty good. The swelling around the eyes is going down – not gone yet, but going.

The Derma Bond on my head scars is starting to flake off. Feels like rubber cement. The staples over my little frame holes will be coming out soon. Gonna do it myself… ordered a stainless steel surgical staple remover over Amazon. I’ll do the front two (4 staples total) then show TJ how to do the back two (another 4). No sense paying someone else to do that which I am perfectly capable of doing myself. And TJ’s been ITCHING to do something to my head… back when I had the bone markers put in, he volunteered to take them out for me using tools from his garage at work. When I said I was going to buy a surgical staple remover, he said a friend of his at work has a staple remover, so I should save my money. It’s a staple remover, a regular one. Such a good son to his doddering old dad.

Anyhoo… I’m just a little flat. The writing is coming along nicely (and if you don’t think so, who the hell asked you?) but the speech is still a little rough and stilted. I’m not quick with a comeback like I was pre-op. In a few different conversations today, I found myself struggling to keep up the banter. Oh, I’m sure that I still seem like Noel Coward to some of the folks around here, but to my own mind I sound more like Barney Rubble. The timing just isn’t there. No snap. No zing.

But I feel good. I feel strong, considering. I am tired and fatigue easily. But I knew what to expect. And I know it gets better with time.

Just don’t anyone ask me to do any “stand up” in the meantime…

JUNE 29, 2007

The head scars are coming along nicely. Most of the “Derma Bond” has flaked off. Nah, that’s not accurate. After each shower, the edges of the “Derma Bond” on each scar would sort of pull away from the skin, like dried rubber cement. Although the post-op instructions said, “Do not peel the Derma Bond” – I dare you NOT to. It’s like peeling skin from a sunburn. There’s this little edge there, taunting you from the mirror.

“Come on, fat boy,” it says. “Just give us a little tug. One little tug. That’s all. We’ll come loose REAL easy! And that’s a PROMISE!” So, with the dexterity of a surgeon, I would grasp a small portion of the edge where it was most noticeable and give it a slight tug. And then a little harder tug. Finally enough would come loose to make it worth my while – satisfying, like the aforementioned sunburn peel and not nearly so painful.

I think the people who write things like “Do not peel the Derma Bond” are the same people who advise against scratching mosquito bites.

The scars look much better for my efforts. For one thing, when the doc applied the Derma Bond, in some places he did so over leaking blood. So the stuff dried over the blood, creating instant clots. Ghastly looking things. Now, my head scars are all shiny and clean. No infection (one of the biggest dangers mentioned in the “things that could kill you about DBS” portion of the handbook). The absorbable sutures are still in there, but that’s because they haven’t absorbed yet. Let’s face it… we’re not talking about deep, rich turf here. We’re talking about thin skin stretched over bone.

I still have the staples in the bone anchor holes. They will come out tonight. I’m doing it myself.

I was a hospital corpsman in the Navy for a number of years. And that number would be 5-1/2. I have both put in and taken out surgical skin staples. There’s no trick to it. The only thing you need is a surgical staple remover, which I ordered 8 days ago over Amazon.com – which means they will be here tonight.

Supposedly.

I placed the order and the clippers were immediately shipped from the company that sells them to a Fed Ex warehouse in Keasbey, NJ. That’s about 187 miles from my front door in Elkridge, MD. Then, for some reason (I suspect President Bush had something to do with it… no reason, I just tend to blame him for everything) the remover was shipped to the Fed Ex location in North Salt Lake, UT. That's more than 2,000 miles from Elkridge. I know this, because I got the tracking number and checked. "How odd," I thought, "that in the process of delivering this surgical staple remover they would ship it from New Jersey – which is NEAR to Maryland – all the way to Utah – which is FAR from Maryland.

Several e-mails to Fed Ex later, I now can happily say the surgical staple remover and I are in the same state. A nice customer service person at Fed Ex said he (or she, I forget which) would get to the bottom of the problem and fix it… if such problem could be fixed.

I'm guessing the staple remover was just stuck to something else. Perhaps, even stapled. At any rate, it's on its way to me and should be here tonight.

Supposedly.

We'll have those staples – all eight of them – out of there by the time I go to bed tonight. Then my head will be clean and metal-free for the trip to Nashville on Monday.

(On July 2, Gail and I went back to Nashville for the third part of the surgical procedure. They implanted the neurotransmitters on July 3, and we came home on July 4.)

JULY 6, 2007

I was in the shower when I heard a knock at the door.

"I'M IN THE SHOWER," I hollered. My wife was going about the business of getting dressed and folding up the little cot the GCRC staff had given her for the night.

"They want you over there right now," the nurse said through the door. It was not quite 7:30 a.m.

"I was told I wasn't supposed to even check into the Admissions Office until 9," I replied through the shower door.

"That's what we were told, too," the nurse said. "But they just called. Someone cancelled and they're ready for you now."

"All righty, then," I said. It was good news. I was originally supposed to have this third and final phase of DBS surgery on June 25th. Then it was rescheduled for July 3rd at 10 a.m., meaning I was due in Admissions at 8 a.m. Then it was rescheduled for an hour later. Now, here it was, just about 7:30 a.m. and I was dripping wet in the shower and they were waiting for me in the operating room.

It would be wrong to say I had been "dreading" this operation. All along I had been told that this was the "piece of cake" portion of DBS surgery. Just two hours, in and out. Two cuts into the side of the noggin to locate the ends of the electrode leads left coiled like little wings on the side of my head since June 13. Two cuts into the area below my collarbone to make little pockets for the little Medtronics "Soletra" neurogenerators that would provide the electrical stimulation to the subthalamic nucleus. They run the wires up along the side of the neck from the neurogenerators, connect them to the leads, stitch everything up, badda bing, badda boom! Done! No more surgery!

So I was certainly not dreading this surgery. Perhaps I should have been. Of the three procedures I've gone through thus far, this was the most painful.

We arrived at the GCRC at Vanderbilt University Medical Center the night before after flying in yet again on Southwest – henceforth to be known as "Squealing Baby Airlines." (If anyone is reading this and wants to make a little money, come up with a line of "Thank You for Sharing Your Delightful Screaming Child with the Rest of Us" greeting cards that you can hand out to parents on these kind of flights.) This time, they were clear on the fact that Gail was going to stay with me and they were ready for her with the fold-out cot. The room was smaller than the one from my previous visit, and Gail didn't think there'd be room for the bed, so she at first said she'd be happy to sleep in the little recliner in the room. "I just don't want to put anyone out," she said. But as night came, she was happy to have the bed.

I slept moderately well, but – as one might imagine – I was somewhat apprehensive. In and out, two hours, piece of cake aside… it was surgery, and it required general anesthesia. I had that feeling one has at the beginning of what one knows will be a long, trying day – I'll be glad when this is all behind me.

So now this news that they were ready for me hours earlier than expected came as excellent tidings. All the sooner, all the better to get this whole thing over with once and for all.

This time Gail didn't have to drag the suitcase along with her since we were going to be returning to the GCRC following surgery. We headed out through the front door at Medical Center North and made our way to the Main Hospital Lobby. After going through the Admitting Office, Gail and I sat in the lobby waiting for someone to come take us to the pre-op room.

Eventually a lady called my name and that of five other folks. (I can always tell when someone is about to call my name in a medical office. The nurse – or whoever – will look at the piece of paper with my name on it and say, "William…." and then her expression will become one of confusion as she grapples with my utter unpronounceable last name. "Schmalfeldt," I will generally interject. On the rare occasion that the person gets it right, I will be profuse in my congratulations. It's not a hard name to pronounce – think of a small hat made out of felt. Then say it as if you had a German accent, and you will have a "schmal felt hat". Leave off the "hat" and you have pronounced my last name correctly. Thank you.) We crowded onto an elevator and made our way to the pre-op room. A smiling young lady named Bonnie showed me which bed was mine, and told me to strip down to my birthday suit, put on the hospital gown, and wait on the bed.

Then came the traditional parade of experts – a representative from Medtronics was first. They apparently like to meet the people who will be walking around with their devices implanted. Then the anesthesiologist who told me much more than I needed to know about what he would be doing with me before, during and after putting me to sleep. Maybe I'm wrong, but if I'm not going to be awake for it, or if you're going to give me a medication that will cause me to not remember you did it, then I don't really need to know about it in advance. But that's just me.

Whenever I have surgery, I always seem to present the anesthesiologist with a bit of worry. For one thing, I have a huge neck. That sometimes makes for difficult intubation. Then there's my overall size. Although I've never had a heart problem (knock on wood!) my bulk makes anesthesiologists wonder if they're going to be able to give me enough "nite nite gas" to put me to sleep – without killing me. So far so good.

After we got the IV started, the anesthesiologist told me he was giving me a little "calmative". It made me nice and calm. I may have even been singing when we rolled to the OR. They got me to climb onto the operating table, and I was very happy and very calm and very relaxed when the anesthesiologist said he was going to give me MORE medicine and I don't remember much of anything that happened in the next two hours.

In fact, the next thing I can clearly recall is wondering why in the hell my neck hurt as badly as it did. Was I hard to intubate? Did they have to twist my neck into unusual contortions? Did someone put me into a headlock while I was out? What the hell did these people DO to me???

I opened my eyes and realized I was back in the post-op recovery room. My nurse, in a gentle and reassuring way, told me the operation was over with and I was fine. I asked if they could lift the back of the gurney so I could sit up a bit, and she complied. I took mental stock of my condition. I noticed my two new wounds on my chest and I gently felt the sides of my head for the two new incisions that were there. But I was still wondering about my neck. Eventually it dawned on me that they had to run the wire from the neurostimulators up through the lateral sides of my neck to where they were connected to the electrode leads… and that since there was no natural passage for these wires to traverse, they had to make one. And that would likely cause a bit of trauma. It all started to make sense as I sat there, blinking, taking deep breaths, trying to wake up.

After about an hour they brought Gail in to see me. She walked up to my gurney and gave me a look that reminded me of the way Jackie Kennedy looked at JFK in Frame #317 of the famous Zapruder film. She waited outside the curtains as I got dressed and sat on the wheelchair they brought to roll me back to the GCRC. When I was done, Gail gave me the same look. "There's a huge blood clot on the back of your head," she said. I felt, and sure enough there was a large area of dried and matted blood and hair. "There's a huge blood clot on the back of his head," she told my nurse. Between the two of them they got the blood cleaned off and I was soon on my way back to my room at the GCRC.

The surrealism continued on the following day. I woke up early and trudged out into the hallway to find a cup of coffee.

"Where are you heading," the overnight nurse asked.

"Going to the patient kitchen to get a cup of coffee," I said.

"There isn't any," she said. And it dawned on me. It was the 4th of July. I was the only patient in the joint. The kitchen staff was NOT going to come in and make coffee for just one patient. The nurse said she'd try to find some instant coffee. I told her that would not be necessary.

They brought a heated-up breakfast at 8 a.m. At 9 a.m. we were in a cab heading for the airport. We checked our bag and got into the security line. Gail went through the metal detectors. I got to the head of the line and showed my temporary Medtronics ID card to the TSA agent. (I'll get my permanent one in a couple weeks.) It notifies the agent, "The bearer of this card has an implanted medical device prescribed by his or her doctor." The squat, swarthy TSA agent asked what kind of device.

"Deep brain stimulation," I said.

"What?"

"Like a pacemaker… for the brain," I said.

"If it's safe for you to go through the metal detector, go right ahead," he said.

"I don't think it is," I said. "I just had it put in yesterday." See, the metal detector can turn the neurostimulator on. It can turn it off. It can mess with the stimulation parameters.

Realizing that this meant he'd have to get off his chair for a moment, the agent rolled his eyes and told me to put all my stuff in a bin and run it through the x-ray machine. Then he escorted me through a gate and directed me to take a seat. He pointed to a small row of chairs, in front of each was a small mat with the white outline of two footprints upon it. That way, I would know where to put my feet for the upcoming search. How convenient.

The agent WAS very thorough and after he was done, I realized he knew as much about my physical anatomy as my wife does. As he approached the newly implanted neurostimulators in my chest area, I asked him to be gentle. He was. Thank you.

The flight home was a surreal mixture of comedy and drama as a hyperkinetic flight attendant insisted on playing “Are You Smarter Than a 5th Grader” with the passengers for small door prizes, and various people got sick. One young man staggered to the front of the plane. The flight attendant gave him a large plastic bag and directed him to the lavoratory. Then she had the teenager sit down on the aisle seat, right across from me. I began to wonder how quickly my new wounds would take to infection should this kid puke all over me, but thankfully it didn’t happen.

Eighty or so minutes in the air, and we were on the ground in Baltimore. Then home.

Then we had to bail for a tornado warning. We had been home all of 15 minutes when the Weather Channel said there was a tornado heading directly for our trailer park. We piled the dogs into the car and took a drive to an open spot where we could watch the weather and dive into a ditch for cover should the need arise.

It didn’t. A rather scary wall cloud rolled past as the dogs heaved and whined in the back seat. Raven, especially, is an auto coward. She drools and weeps and rolls her eyes in terror thinking that each trip in the car means she’s going to be spayed again. Shiloh seemed to be upset by Raven’s mental anguish, but otherwise took the emergency in stride.

Thirty minutes later we were back in the trailer. Now it was Shiloh’s turn to be afraid as the local idiots with their fireworks were out in the driving rain making noise. The thunder competed with the firecrackers and for awhile it seemed as if God and my hillbilly neighbors were having a contest to see who could be loudest and most destructive.

I stayed home from work on the 5th. But I was back at my desk on the 6th, regaling friends with much the same details I've just shared here.

Back to Nashville for programming on Monday. Then, hopefully, I'm done for awhile.

(Programming of the neurotransmitters is a process. It can't be done in one visit, it takes several. As a result, I took several day trips to Nashville in July and August, down and back on a plane in the same day. Wearying!)

JULY 10, 2007

I overslept this morning. Got home from Nashville at around 8:15, went to bed shortly after 9, got up at 4:45 a.m. I'm usually up by 4. It's an occupational hazard. Now that I'm taking the train every day, I gotta be at the train station by 5:51 in order to get to work at or near 7 a.m. No time for coffee this morning, and that probably has more to do with my sense of ennui than does the fact that my Deep Brain Stimulation is turned on, programmed and functioning.

The flight to Nashville was uneventful, except for the young father and his two darling, precocious little treasures who sat in the seats in front of me. I'm guessing they were around 2 and 4 respectively and neither child has yet developed an "inside voice." They weren't crying or fussy. But they SQUEALED the entire flight.

"Oooooh, Daddy! Lookit this PICTURE, Daddy! Lookit the PICTURE of the KITTEN, Daddy! Lookit! Lookit! Awwwwww! Lookit the KITTEN, Daddy!"

Daddy was reading a magazine and only nodded the most perfunctory acknowledgement to his daughters and the picture of the kitten.

Grabbed a cab at the airport with a garrulous country boy driver named "Steve" and we chatted like chums all the way to Vanderbilt's Medical Center North. I made my way to the 3rd floor neurology department, checked in, took a seat, and waited.

I resolved that I would try to be a better, more communicative patient during this session than I was during the initial brain surgery. For instance, as I think back, when I told Dr. Charles that I was feeling, “nausea, but that’s not the right word for it” during the test stimulation, I felt like I wasn’t really communicating the effect the stimulation was having.

Chandler called my name and led me back to an examining room, where Dr. Charles was waiting. I brought along my Access Review Model 7438 Therapy Controller (It looks like a garage door opener, and it will be my faithful friend and constant companion for my remaining days) and hopped onto the table at Dr. Charles behest.

“Remember when I said during the test stimulation that one of the side effects was nausea, but that wasn’t really the word for it,” I said without waiting to be asked. “I’ve been thinking about it, and in retrospect I think the best way to describe that feeling would be just a general feeling that something ‘wasn’t quite right.’”

Dr. Charles frowned and looked at Chandler.

“Scratch that paper we were writing on DBS and Nausea,” he said grimly. Then he smiled.

Dr. Charles produced a controller that made my little garage door opener look puny by comparison. He explained the programming process and said that his gadget would be able to tell him if the leads were situated correctly, and if there were any problems with the hardware. They were, and there weren’t.

Each lead has four electrodes. It’s necessary to test each of the electrodes for efficacy and side effects. That’s what we did. First with the left brain, since my right side is the one most affected by PD symptoms. The first electrode was able to reduce my symptoms somewhat. Then the side effects kicked in with a buzzing feeling in my right hand and foot, and double vision as my right eye went off its axis. The second electrode eliminated my PD symptoms completely and the worst side effects consisted of a buzzing in my fingers, foot and lips and tongue. Electrode three didn’t score as well, neither did electrode four.

He put the control magnet on my right-sided neurostimulator and repeated the procedure. The side effects weren’t as pronounced, and it seemed as if the second electrode was the “money” electrode on that side as well.

When we were finished, Dr. Charles said the session was a great success. He turned on both neurostimulators and put them at a low setting, directing me to continue taking my Stalevo as before. I’ll go back in two months for another programming session to get the voltage kicked up a little and that is when we’ll start drawing back on my PD medications.

Dr. Charles had a flight out of Nashville International as well that afternoon and offered me a lift to the airport, which I gladly accepted. We talked of many things, including his idea for a web forum of some sort for those of us in this study to use to stay in touch with each other, to touch base on therapies, and to share the latest news on the study. I said I’d be glad to spearhead such a thing.

On the subject of “other people in the trial,” Dr. Charles shared an experience that happened during a recent surgery with another of the DBS-randomized participants. Actually, it’s something that didn’t happen, but might have had not “better sense” ruled the day. One of the patients – he didn’t say who, since we all (technically) don’t know each other as we maintain our anonymity – mentioned to him during a subsequent programming session that he had entertained the idea of playing a bit of a joke on the good doctor during his DBS surgery – specifically during the electrode programming session.

“He said, ‘I was gonna pretend to be paralyzed on one side,’” Dr. Charles said.

“Well THAT would have been a good idea,” I said. “Very clever! Very funny! And frankly, I entertained the same idea once… for about a half-second. Then I thought that you guys might have a syringe full of ‘something’ that you would immediately inject into the IV line that might save my life if I were REALLY having a stroke, but might otherwise kill me if I were not. And knowing that my self-satisfied chuckling might be the last sound I ever heard, I decided against playing that particular joke on you.”

“What is it with you guys?” Dr. Charles said, shaking his head. “You’re laying there, on the table, your skulls open, having brain surgery, and you’re thinking of jokes to play.”

"Gotta do something," I said with a shrug.

He dropped me off at the door leading to the Southwest Airlines portion of the terminal, I thanked him for the ride and went in.

The flight home was uneventful, save for a young girl traveling by herself, taking her first plane trip to see her grandmother in Albany. She kept up a steady litany of questions to her seat mate and harried flight attendants.

"How can you tell if a plane is going to crash?"

"Does lightning strike airplanes?"

"Is there a ramp at the end of the runway?"

I was grateful when the flight attendant said we could use approved portable electronic devices. My iPod drowned out the nervous child for the remainder of the flight. So did a double scotch on the rocks.

I was celebrating. I made it through the DBS procedure and was sailing down the downhill slope. No more procedures until September.

Life is very, very good.

(It was time to get on with the healing. And if I was a bit on the irritable side for these few weeks, my apologies to anyone I may have been rude to. But I did notice for awhile there that things that ordinarily didn't bother me were, all of a sudden – irritating as hell!)

AUGUST 7, 2007

I'm feeling pretty good. Having a bit of minor discomfort from time to time in the area of my scalp… feels like worms are crawling under the skin between the two incisions sometimes. And there's still some minor pain in the neurostimulators… more on the right than the left. Sometimes it feels like the wire between the head and chest on the right is a bit too tight, like there just isn't enough slack there. But it's nothing horrible. The incisions behind each ear are still a bit tender to the touch.

And it’s no big deal, but it seems like I have two dents on the top of my head.

Since the healing of the surgical scars from my DBS surgery on June 13, I've noticed that there's a bit of a dent towards the front of the scar on the right side of my scalp, and another one just posterior of the burr hole cap that fills the hole the doctor drilled in my skull. It's nothing terribly serious... they look like what you might expect from a large hailstone hitting the hood of your car. My son the auto mechanic has offered to get his hands on a dent-puller at work to fix these dents, but somehow I don't think that is a good idea. Nor do I like his suggestion of filling in the dents with spackle and then sanding them down. But his heart is in the right place.

Now that the old bean is healing up, I will actually walk around in the presence of people without covering my disfigurement with a hat. When everything was still all scabby, I felt the least I could do was keep 'em covered. But now, and especially in these warm, muggy DC-area summer days, I enjoy the feel of air conditioning blowing on my still somewhat-sensitive scalp.

And nobody asks why I'm sitting in the "handicapped" seat on the subway.

On that note, there's this one guy who I think of as a "handicapped bully." I see him from time to time on the MARC train from Union Station to BWI that I ride every afternoon.

The handicapped seats on the MARC train are well-marked, but not reserved. That is to say, if a handicapped person comes on the train, and you are sitting there, you are supposed to rise and allow the handicapped person to sit there. I generally get on the train early enough and can therefore sit wherever I choose.

But every few days or so, this one guy shows up about 10 minutes before the train departs and will walk up to someone sitting in the handicapped seat, point to the sign, and say he wants to sit there. And I have no problem with that. But then, this same guy -- this same, I can't tell WHAT his handicap is guy -- will save the seat with a box or a briefcase, and then STEP OUT ONTO THE TRAIN PLATFORM, STAND THERE IN THE MUGGY AUGUST HEAT, WITH THE HUMIDITY MAKING IT FEEL LIKE 105-degrees, with the SWEAT DRIPPING DOWN HIS FACE... this HANDICAPPED GUY will STAND there and SMOKE until they tell him to get onto the train so they can leave! And maybe this is just me, but if this guy is able to STAND on the PLATFORM and CHAIN SMOKE in the hot, muggy, miserable DC summer afternoon, he can bloody well take whatever other available seats there are on the train and not bother other people to move so he can park his not-all-that-handicapped ass there.

Stuff like that makes me mad. And I think it leads to bad karma.

Add to the mix the fact that I am bored out of my skull at work. It’s summer, this is the government, and nobody seems to be in the mood to do anything. The run of press releases has been slow, so there’s not a whole lot to write about for the radio news service or podcasts. We did shoot an interesting video podcast the other day with Dr. Joe Pancrazio at the NINDS… it was on the subject of DBS, focusing on my surgery. It was interesting to see – to actually HOLD – an example of the electrode leads that currently reside as a pair in my dented, scarred noggin. It was also interesting to get a look at some of the prototypes of the new technology currently being tested for future DBS… although that is some time away. I imagine at some point, decades from now, we will look at DBS the way it is currently performed and marvel at how barbaric and clumsy it was. But for now, it’s state of the art.

Not that it makes my itchy scalp feel any better knowing that…

AUGUST 8, 2007

We’re going to hell in a hand basket. As a country, I mean. And I’m talking about our infrastructure.

Bear with me. This has nothing to do with Parkinson’s or my DBS surgery. I just feel a long-overdue and righteous rant coming on.

The bridge collapse in Minneapolis, for instance… I’m frankly shocked that we don’t hear about stuff like that happening every day. Just look at the condition of our infrastructure. What ISN’T on the verge of breaking down?

Let's start with our train system. Here in Maryland, we have the MARC trains that run from Baltimore to DC. I'm not sure what MARC stands for – it may stand for "Maryland Amateur Railroad Club." In DC proper, you have the METRO – a combination subway/above-ground rail system. Not a week goes by where SOMETHING doesn't break on either the MARC or the METRO… or both.

My commute is ridiculous. There is no direct transportation between little Elkridge – on the south side of the Baltimore Beltway – and Bethesda – on the northwest side of the DC Beltway. Back when I drove to and from work, it was a 35-mile trip. Of course, it could take as much as two hours to GO those 35 miles during rush hour, but that's because we're driving on a freeway system that was outmoded and outdated in 1970 – and because people in the DC area drive like idiots.

It's true! Do a little research on the subject and you will see for yourself that DC-area drivers are certifiable morons. They talk on their cell phones when they drive, because they're all so VERY IMPORTANT that they can't wait until they get HOME or to WORK to make their important, important phone calls. And they're in a HURRY! They can't WAIT that extra six seconds it would take to switch lanes while giving YOU a margin of safety because they are so VERY, VERY IMPORTANT that they MUST get where they're going RIGHT NOW! And it's while they're talking on their cell phones and darting from lane to lane in crowded traffic that they CRASH their very expensive SUVs and BREAK their very expensive bones, and the resulting road block TIES UP THE FRIGGIN' BELTWAY for HOURS and HOURS and HOURS…

(Deep breath… OK, I'm better…)

So, for a couple reasons, I stopped driving to work after my DBS surgery. OK, three reasons. I don't expect there will ever be problems with my DBS system… but if there are, I don't want to have them while I'm driving on the Beltway. I don't even want to talk on my cell phone while I'm driving. Therefore, should my DBS system, oh, I don't know, short circuit and set fire to my brain – which I know CAN'T happen, and I only mention the possibility as a ludicrous and hilarious example of the sort of thing I worry about – I would rather put out the fire while seated comfortably on a train… not behind the wheel of my car.

The second reason is my car. It's old. It's 1996 Neon. It has served us well. And the last thing I want to do to it in its silver years is get it smashed up by some empty headed yuppie government worker who didn't notice I was in the lane he wanted to get into because he was talking on his cell phone and was in a hurry to get to his very, very important job.

Third reason. My car, again. No air conditioning. It has been hot here in the DC area this summer. And muggy. And when you're sitting on the Beltway in STOPPED TRAFFIC (calm down… deep breath… we'll get through this) because some PINHEAD (easy!) in an SUV has wiped out ANOTHER pinhead in HIS SUV and now three lanes of the freeway are blocked… well, it gets pretty hot and uncomfortable. Trains are air conditioned… when the air conditioning works. Which it doesn't always.

(Arrrrrrrgh!!!!!)

So… I generally get out of bed at 3:20, get cleaned up, get Gail out of the sack at 4:20, have her drive me to the BWI MARC station near the airport, catch the 4:59 train to DC, get to Union Station in downtown DC by 5:40, take the escalator down to the METRO station, hop onto the subway, and ride it back OUT of DC to the Medical Center METRO station to arrive at my office at about 6:20. Why so early? Because if I wait until later, I won't get a seat on the train. I will have to pay $48 per week to STAND on the MARC train all the way down to DC, and then I will have to leave my office later and STAND on the METRO all the way back to Union Station, so I can catch a later MARC train and STAND all the way back up to Elkridge.

Screw that.

So…the other day I was on my way home from work, riding down the longest escalator in the world into the belly of the Medical Center METRO station, and I'm greeted by the smell of burning brakes. There is a train on the tracks in the direction of Union Station. It is a BROKEN train. This means no other trains can get around it.

So we all sit and wait in the subpar air conditioning of the METRO station, smelling burned brakes, as the METRO workers fiddle and fiddle and fiddle and fiddle with the train to get it moving. Which they eventually accomplish. And the train rolls south with no one on it, and we all stand there on the platform waiting the next one.

I'll say this for METRO… when they have problems, they generally get them fixed or neutralized pretty quickly.

MARC? Can they sue me if I suggest that perhaps that railroad company is run by chimps? And not even BRIGHT chimps. Just regular, run-of-the-mill, non-circus quality chimps.

Yesterday, for example.

We're on the 4:15 train from Union Station to BWI. It's running smoothly… we left on time and the train is getting close to the BWI station. I know Gail is waiting for me, in the ungodly heat, in an un-air conditioned car.

We've passed Odenton, the last stop before BWI. A few minutes go by, and folks have begun milling towards the exit hoping to be the first to their cars in the parking lot so they can get on their cell phones and make fast and dangerous lane changes before everyone ELSE on the train gets there. We are about two minutes away when…

The train slows down. And slows. And slows. And then stops. And sits. And sits. And… sits.

At length, a conductor speaks to us over the intercom. Seems there's a train ahead of us. The train is broken. They're trying to fix it. More later.

We sit. And sit. And… sit. Fifteen minutes go by. The conductor speaks again.

They can't get the broken train started. So, AMTRAK (which shares the line) is sending a locomotive to push the broken train and they have no idea when this will happen and they will come back on the intercom to let us know when they know more.

Twenty-five minutes have elapsed. And now the train starts moving. The conductor comes back on the intercom. Since the broken down train is just short of the BALTIMORE PENN STATION stop, we’re just gonna go ahead and roll this old train of ours up to the BWI station and let folks off.

WE SAT THERE FOR 25 MINUTES WITH NOTHING BETWEEN US AND BWI STATION EXCEPT HOT, MUGGY AIR! There was no reason, explained or otherwise, why our train could not have arrived on time at BWI. No explanation, no apologies. Nothing.

Gail was parked in the “Kiss and Ride” area, basting in her own perspiration. She had no cell phone, so I had no way of contacting her about the delay. So, we hurried home with the aim of relaxing in our air conditioned living room.

Then… at 5:50 p.m., the power went out.

BGE, our gas and electric supplier, raised our rates 70 percent in June. Yes, they did. Seven-Zero percent. And did they use the money to make sure our lights and a/c would stay on during a hot summer evening? Apparently not.

Our trailer got hotter and hotter as we baked in the late afternoon and early evening sun. It was 98 degrees outside with a heat index of 110. The dogs laid by the air conditioning vents on the floor, panting, wondering (no doubt) why we had shut off their cool air since, in their universe, we are absolutely responsible for EVERYTHING that happens… including thunder and fireworks. Raven barked at every sound she heard outside (because she’s alert to danger and the ever-present terrorist menace) and Shiloh whined.

At 7:50 p.m., the power came back on. The air conditioner whirred to life, our ceiling fan began to spin, and the room was soon beginning to cool down.

Ten minutes later, just as we were beginning to get comfortable again, the power went off. It stayed off until 9:20 p.m. Gail and I were both soaked in sweat. The dogs looked like they were nearly ready to pass out. But the cool air began to circulate and soon we were comfortable enough to go to bed.

Today, we’re doing the commute differently. Instead of having Gail drop me off at the BWI station (with its “you gotta pay to park” garages), I drive to the nearby Dorsey station on MARC’s Camden Line. The trains on the Camden Line share the tracks with CSX freight trains. The tracks are, in fact, owned by CSX, and their motto is “to hell with your passengers, MARC… the freight’s gotta go through!” But the Dorsey station has a parking lot, and it’s free. So, I caught the 5:29 train this morning, which got me to Union Station by 6:10, meaning I could get on the METRO at 6:20 and make it to the Medical Center station by 7 a.m. Tonight I will leave the office at 3:30, get to the METRO 10 minutes later, arrive at Union Station by 4:15 and catch the MARC Camden Line train at 4:39, which is supposed to have me to Dorsey Station by 5:22 p.m.

But it’s going to be another hot day, so that means there will be heat restrictions on the Camden Line, meaning we can’t go any faster than 40 miles an hour, and that will delay my arrival at Dorsey by about 15-20 minutes, so I can get home at around 6 or so in time to see whether or not BGE has spent our 70 percent rate increase to improve their electric grid to withstand the demand brought on by the heat wave.

My money’s on the heat wave.

Now, lest anyone raise an eyebrow and suggest that “crankiness” is a possible adverse effect of deep brain stimulation, just hold that thought. In other words, shut up. This rant is a long-overdue, perfectly acceptable reaction to crumbling infrastructure and a long and frustrating commute. It has nothing to do with the DBS surgery.

My suggestion to Gail that we move to Canada? Yeah. Blame that on the DBS if you want. But not this rant. I said what needed to be said, and I feel better.

Thank you.

AUGUST 9, 2007

All right. Yesterday, I wrote the following words…

“Tonight I will leave the office at 3:30, get to the METRO 10 minutes later, arrive at Union Station by 4:15 and catch the MARC Camden Line train at 4:39, which is supposed to have me to Dorsey Station by 5:22 p.m”.

Hubris! Pure, unadulterated hubris! Excessive self-confidence to the point of arrogance. I really, really thought I could leave my office and get home in a time frame much like I described above.

I am a fool.

Oh, I did leave the office at 3:30. And I caught a shuttle to the METRO Station just about the time I walked out the front door. That part of the trip home went very well.

When I arrived at the Medical Center METRO Station and rode the longest escalator in the world (I think it really is!) down into the bowels of the Earth, only then did I learn what horror awaited.

Someone was making an announcement over the loudspeaker. It sounded like this:

"Attention, METRO Passengers. (Static) until further notice. Trains on the Red Line will (static) at Farragut North and at Van Ness. Shuttle busses have been (static, unintelligible syllables). Thank you for riding (static) and thank you for your (static)."

Just then, a train rolled up. I got on and sat down. The driver spoke to us on the intercom.

"Attention passengers getting on the train and those already on the train. There is a major delay on the Red Line. Because of a suspicious item at the DuPont Circle METRO Station, METRO trains will only operate between Shady Grove and Van Ness. The METRO Stations at DuPont Circle, Cleveland Park and Woodley Park are all closed. If you are going anywhere downtown, you will need to make other arrangements. Shuttle busses have been requested. I said, 'requested'. That doesn't mean there will actually be any shuttle busses. I would suggest getting off at Van Ness and getting a taxi. But this train will stop at Van Ness and will return to Shady Grove."

I sat there, wondering if the $11 I had in my wallet would be enough for a taxi from Van Ness to Union Station. The train started rolling.

When we got to the next stop, the driver made much the same announcement. I still hadn't figured out what I was going to do. When we got to the next stop, Friendship Heights, the driver was a bit more helpful.

"There is a major bus line at this stop. It runs down Wisconsin Avenue into the city. I would suggest getting off this train and getting on that bus, or you could get a cab. But this train will stop at Van Ness and will return to Shady Grove."

So, I got off the train at Friendship Heights with a couple dozen other hapless folks. We took the elevator to street level and found the bus stop. At length, a bus rolled up. The driver looked bamboozled at seeing so many passengers waiting to board her bus. I asked if the bus went anywhere near Farragut North (where the Red Line would be running again) or Union Station.

“Farragut? Yes,” she said. So I gave the woman a bus transfer and 35 cents and climbed aboard.

The bus was now jammed. We slowly made our way down Wisconsin Avenue, stopping at all the bus stops so the driver could open her door and shout at the bewildered passengers waiting for a ride, “THERE’S ANOTHER BUS RIGHT BEHIND ME.”

(After yesterday, I have placed that statement into the pantheon of Utter Lies and Deceptions – along with “I mailed the check yesterday” and “Honest, the truck just left the dock!” There WAS no bus “right behind us.” And the looks on the passengers’ faces showed they knew it and understood the lie for what it was.)

The bus continued to crawl down Wisconsin Avenue into Georgetown and made a left onto M Street, which soon turns into Pennsylvania Avenue. Ahead of us at a bus stop was a bus clearly marked as having Union Station as a destination. I got a transfer from the driver, got off the bus, risked my life by running in front of the other bus, and got on board.

The first thing I noticed was the smell.

When I was a boy, I had a blind uncle who lived in a small house on the north end of our little hometown. My Uncle Fred was a bachelor. He lost his eyes when, as a child, my grandfather (as the story goes) struck him in the right eye with a makeshift arrow launched from a makeshift bow. (Boys will be boys.) Well, the eye got infected and the infection spread to the left eye, and both were eventually removed. Uncle Fred lived into his 80s in his small house with no indoor plumbing. He had an outhouse on the east side of his property down by the river along the railroad tracks. On hot, muggy summer days, you could smell the outhouse blocks away.

That is the smell that assaulted my nostrils as I got on the bus. Also, there was no appreciable air conditioning. It was a nauseating blend. Other passengers sat there, discreetly holding their noses so as not to offend the source of the stench… an apparently homeless man sitting in the back of the bus, wearing an Army fatigue winter jacket in the 102-degree heat, his urine-soaked-and-dried-with-God-knows-what-else clothes giving off a toxic funk.

I managed to stay on the bus for about 10 minutes, during which it went about two blocks. Then I recognized where I was and knew that there was a METRO Station nearby, so I bailed.

After walking three blocks (during which the aforementioned bus with the malodorous homeless man had managed only about a half a block), I found the Farragut West station. I had hoped to find the Farragut North station since that was a station on the Red Line and I could just take that to Union Station without changing trains. But I decided to just go with the Orange Line train I could catch at this station, switch to a Red Line train at Metro Center, and glide into Union Station… and maybe still make the 5:18 Camden Line MARC train since the 4:39 train was now already on its way north.

The platform for the train heading toward Metro Center was jammed. I found a spot near the edge and stood there, dripping sweat. Again, no air conditioning. A train rolled up. It was likewise jammed. The driver shouted on the loudspeaker, “There’s another train right behind me.” But knew the lie for what it was, and was able to force myself into the train car before the door slid shut. We stood shoulder to shoulder, belly to backside for two stops. Then the majority of us disembarked at the Metro Center stop.

I took the escalator to the upper level to catch the Red Line train to Union Station. That’s when I saw the multitudes. Thousands upon thousands of people were waiting for the same train. Each time a train rolled up, a vast group disgorged from the packed interior only to be replaced by the squirming, sweaty mass of humanity on the platform. As each train rolled in, unloaded, reloaded and rolled away, I found myself getting closer and closer to the edge. After four trains came and went, I was in position to actually get aboard the next one to arrive. That’s when I heard the announcement that the “suspicious item” at the DuPont Circle Metro had turned out to be safe, and that the stations that had been closed were now reopening to regular traffic.

I didn't care. The next train arrived, I braced myself against the side of the train, extended my right arm so no one could shove me out of the way, and forced myself aboard when the opportunity presented itself. I stood, jammed into the aisle, as more and more people tried to get on board.

"There's another train just behind this one," the driver said over the intercom, lying the damnable lie. Nobody believed him, and for a moment the train door resembled the chaotic scene atop the American Embassy in Saigon as the last American helicopters evacuated the city. But soon, the doors managed to close and we were on our way.

I was now just two stops away from Union Station. I didn't need to hold onto the bars, since sheer pressure from other bodies was sufficient to keep me upright. We arrived first at Gallery Place, then Judiciary Square, then… at long last… Union Station.

This was also the destination for several thousands of passengers on the train, as the doors opened and we surged out onto the platform. I got through the turnstile and took the escalator to the main portion of Union Station. There was a huge crowd of people standing, staring at the TV terminal that posted track numbers for the MARC trains. I never did find out what manner of fresh hell awaited these people or what train delay had resulted in such a huge crowd of angry commuters. The next train to Dorsey had been posted… Track 13, leaving at 5:51. It was 5:40. Plenty of time.

I found the train, got on board, called Gail to tell her I was safe on a train, and relaxed.

Because of the heat restrictions on the Camden Line, we made our leisurely way north, stopping first at Muirkirk, then Laurel, then Savage, finally – 15 minutes late – Dorsey.

By the time I drove the short distance to the trailer park, checked the mail, and walked into our trailer – sweat soaked and stumbling from exhaustion – it was nearly 7 p.m. My commute had taken nearly 3-1/2 hours.

But hey… the electricity stayed on all night. That's something, I suppose.

AUGUST 17, 2007

"Well, my hands are shakin' and my knees are weak. I can't seem to stand on my own two feet."

Up to that point, Elvis could have been singing about Parkinson's disease. But then, he turns it into a love song… kinda.

Just as well, I suppose. It's hard to imagine a hit song about PD.

"Shake, Rattle and Roll?"

"Shake Your Groove Thing?"

"Twistin' the Night Away?" (Dyskinesia, y'know…)

"Shake Your Booty?"

"Dazed and Confused?" (Sometimes the dementia gets ya!)

Now, I'm no musical composer. But after 30 years in the radio business, I think I have an ear for hit music. And perhaps if I could spin out some winning lyrics… who knows?

How about a song for someone who broke up with his or her love because of the disease? A country song, perhaps?

"I've Got a Pill for Everything – but You!"

By Bill Schmalfeldt

Each morning when I open up my eyes,
And I feel familiar cramping in my thighs,
I sit up on the edge of bed, that last weird dream still in my head
And give myself a motivating shove.
I stand and brace myself against the wall.
I turn and slowly stagger down the hall.
At last, I reach the kitchen sink, fill up a glass and stop to think
About the time when I still had your love.
(CHORUS)
I've got a pill that helps to calm my shaking.
I've got a pill that cheers me when I'm blue.
I've got a pill that helps me walk and makes it easier to talk.
I've got a pill for everything – but you!
(VERSE)
I take these pills to get me through my day,

To fix the things that PD took away.
Not perfect, but it's close enough. The thing that makes it extra tough
There's no one here that I can lean upon.
You cried and told me that you needed more.
This Parkinson's ain't what you bargained for.
You said I didn't fit your plan. You need a strong and steady man.
It's still hard to believe you're really gone.
(CHORUS)
I've got a pill that helps to calm my shaking.
I've got a pill that cheers me when I'm blue.
I've got a pill that helps me walk and makes it easier to talk.
I've got a pill for everything – but you!
(SECOND CHORUS)
I've got a pill that helps my constipation.
I've got a pill that stops the drooling, too!
There's pills of every shape and size, but none can help me realize
I've got a pill for everything – but you!
I've got a pill for everything… but you!

Damn… that's depressing! Maybe next time I'll write a funny song about the damn thing.

(And then, yet another day trip to Nashville for programming.)

AUGUST 21, 2007

A crazy Elvis lady, a pain in the butt New York lady, a fellow traveler in the clinical trial, and – dyskinesia? These are the things I want to write about in connection with my second DBS programming trip to Nashville yesterday.

Let's take up that last one first.

At first I wasn't quite ready to declare this dyskinesia. And it certainly was not caused by the hiking up of the wattage in the old fuse boxes yesterday, and here's how I know. I felt this way yesterday morning, in the Baltimore airport, while waiting for the plane to Nashville. I attributed it to nerves and the two candy bars and bottle of tea I had just consumed. But it got to the point where I had to get up and walk around a little because sitting still just was not an option.

Then, after the adjustment yesterday, I took a Stalevo 150 at about 4pm. An hour later I was sitting in a restaurant at the airport and the feeling came over me again. This time, I was less successful at forcing myself to hold still. It lasted for about 15 or 20 minutes, and for the first time I began to wonder if this was the dreaded onset of that bastard side effect of levodopa therapy.

How to describe it… are you familiar with what they call "restless leg syndrome", where it feels like your legs want to just jiggle and dance, and you wanna get up and walk because it's driving you nuts just sitting there with your legs NOT moving? Imagine that feeling in the entire body. Right now, it's 8:51 in the morning. I took a 150 mg. Stalevo at 3:30 when I got up. It's almost time for another pill. And about a half hour ago, I started getting that "higgledy-jiggledy" feeling where I just… could… not… hold… still!

OK. I took a few minutes there to call Gail. She says she's noticed in my sleep (I take a Stalevo 150 right before bed) that I've been unusually restless lately, with a lot of fidgeting and such in my sleep.

It's subsided somewhat now. At this point, I'm just sorta rocking in my chair, sliding back and forth in my seat, readjusting my position, and missing the keys on the keyboard which calls for much backspacing and correcting as I go along.

I don't think it's noticeable yet. If someone were to see me right now, they might think I was acting a little – antsy? But I don't think they would notice anything really out of the ordinary.

So… the race is on. And the stakes have just increased. As we kick up the stimulation, we'll decrease the Stalevo pills. And that will take care of the dyskinesia. Now, instead of four Stalevo 150s each day, I'm directed to take three Stalevo 150s and one Stalevo 100 for the late morning dose.

I just shot an e-mail to Chandler down at Vanderbilt asking her to pass this info on to Dr. Charles. We'll see what they have to say.

OK. It's 9:15 a.m. and the feeling is almost gone. My typing is better, and I don't feel like I want to jump out of my skin and run around in my skeleton anymore. Now, what were we talking about?

Oh yeah, the trip to Nashville.

Possible dyskinesia aside? It went well. The flight down was jammed – what flight isn't during the summer months? There was one squealing child on the plane, and I was jammed up against the bulkhead in a seat that is far too small for the immense likes of me. But that's air travel.

On arrival at Nashville I had a bit of time to kill, so I dined on some boneless chicken wings at a little restaurant at the airport. A three person combo destroyed some of the American standards for my entertainment. It made me a little sad to think that this group harbored any misconceptions about being talented. I figure if you're playing for tips at a public area in an airport – especially in "The Music City" – then I think it's safe to say you're not fated to "make it big" in the music business.

Got a cab to the Vanderbilt Clinic and made my way to the Neurology Clinic where I found myself chatting with an older guy with PD. The topic? Gun control, and how the only reason cops don't want us to have guns is because they know we'll use them. On cops. Sometimes, I find myself limited in conversation to just nodding and smiling. This was one of those times. I smiled and nodded and smiled, all the while my mind crying, "Chandler? It's my appointment time. Come and get me, Chandler! Rescue me, Chandler!"

Sure enough, Chandler stuck her head through the door and invited me back into the exam room. She asked the usual questions… still taking the same meds? Any adverse events lately? (I didn't mention the "thing" at the airport, as I was still convincing myself that it wasn't dyskinesia.)

A few minutes later Dr. Charles came into the room and asked if I had any objections to meeting another patient in the clinical trial. I said I would love to, and in walked a gentleman wearing a white t-shirt with the name of some company or other on the front and "Job Well

Done!" on the back. His name is Ronnie, and he had his surgery back in November 2006. In fact, he was featured on the TV show about DBS that was aired on a Nashville station last spring. We had a nice, spirited chat – compared scars and stories – and he left. He'll be there for the eight-day droolfest same time as me, so that should be fun.

Dr. Charles came back and pulled out the neurotransmitter programmer, which looks like a big, old fashioned hand held electronic game. He put a transponder over my left neurostimulator and began taking readings.

I mentioned how I had set off a theft protection device at a liquor store last week. "Yeah, I see that on here," he said.

"No you don't," I said. "That thing tells you if the unit has been turned off and back on, but it can't tell you whether or not it set off an anti-theft device," I said.

"You're right," he said. "I like telling people that I can tell where they shop, what they buy, what movies they've seen."

"Santa Claus is watching you," I said. He smiled.

A few minutes later, we were all done. He had upped the wattage, but just a little. We agreed to change my medication as I described earlier. Soon thereafter, I was in a cab on the way back to the airport.

After my second episode of suspected dyskinesia – while eating a cheeseburger at O'Charley's (as Dr. Charles will no doubt see on the programmer during our next visit in September) – I started getting that "can't hold still" feeling again. I found myself shifting in my seat, moving my arms and head, and generally acting like a person with ants in his pants, so to speak. Like I said, it lasted about 15 to 20 minutes, then subsided.

This time, I had a "B" boarding pass… my first one ever for a Southwest flight. Passengers can print out their boarding passes online 24 hours before takeoff. I didn't print mine out until 23 hours and 50 minutes before flight time. So, instead of the "A" line, I found myself waiting among the second class citizens in the "B" line. Not as bad as the "untouchables" in the C line, however, one of which was a woman carrying bags of Elvis paraphernalia. She and her granddaughter had been celebrating the anniversary of Elvis Presley's death by swinging through Memphis and Nashville. She struck up a conversation with the lady at the head of the “B” line about her adventures, including following a tour of Elvis impersonators and sleeping in the $600-per-night “Elvis” room at the “Heartbreak Hotel.” I mentioned that if I was ever going to pay $600 for a hotel room, I would expect room service… served by Elvis, himself. That made the Elvis lady look sad, so I decided to keep my yap shut about the late King of Rock and Roll. The woman in front of me, heading to Albany, New York, covered for me – talking about how if someone got $600 worth of happiness by sleeping in a hotel room that Elvis once slept in then it was money well spent.

Then the Elvis lady mentioned downloading the new album in which, through electronic means, Lisa Marie Presley sings with her late father. The New York woman asked how much it cost. The Elvis lady said, “Nuthin’. I knows a place whar you can git songs fer free.”

That set something off in the New York woman, who began what, I’m sure she felt, was a very polite lecture about how downloading free music was cheating the artists, and in this case, the homeless – as Lisa Marie had promised a certain portion of the proceeds from this new album would be going to feed the homeless or to house the hungry, or something like that, and for just a minute I feared this small but rotund and powerful little Elvis grandmother would launch herself over the retractable strap that separated the “B” line from the “C” line and all hell would break loose with hair pulling, screeching, punching and cries of “ELVIS WOULDA WANTED ME TO HAVE THAT THERE ALBUM...”.

Thank goodness they started loading the plane and hostilities were soon forgotten.

Once again, I was crammed into a window seat. The flight home was delayed as we sat on the runway for about 30 minutes – first, waiting out a “hold” on takeoffs because of congestion in the northeast, then waiting for planes to land so we could get on the main runway without getting killed.

90 minutes, two old-time radio shows on the iPod, and a double scotch on the rocks later, the plane landed at BWI. Gail picked me up at the departing flights area (yep, departing flights! That time

of night, the arriving flights area is jammed with vehicles. So I generally have Gail pick me up at the departing flights area. Less hassle that way.)

In four weeks, I'll do it all again.

And now it's 10:50 in the morning. The "higgledy-jiggledys" (a much nicer way to describe it than dyskinesia, don't you think) are just a memory. No response to my e-mail to Chandler yet, but they're an hour behind us. I don't know what they can really say, anyway, other than, "Yeah, sounds like dyskinesia. See you on the 17th."

But I do want them to know about it.

(And yet, another trip!)

SEPTEMBER 18, 2007

And now, a new feature --

Bill's Helpful Tips to Get You Through the Day.

First a travel tip. Want to ensure an empty center seat on the airplane, giving you a little bit of elbow room? Try this. Oh, a disclaimer. For this to work, you will need to be overweight , bald, and have recently undergone Deep Brain Stimulation surgery or some other procedure that leaves multiple., visible scars.

1. When you get on the plane, do a quick scan for OTHER fat passengers. Look for one in a window seat. Then sit in the aisle seat on the same row, leaving a space between you and the other chubby flyer that only a circus rubber man could possibly squeeze into. This works even better if the other passenger also has visible scars or some other noticeable disability.

2. Take off your hat. They're YOUR head scars! Show 'em off! Few people will willingly sit down next to someone with visible head scars. They don't know how you got them, or what you're likely to DO on the flight as a result.

3. As people make their way down the aisle, shooting evil glances at you for daring to be overweight, smile at them. In a slurred voice, say "you can sit here if you wanna." Rub your scarred, bald scalp when you say it. I'm not saying you should go so far as to drool

on yourself… but it works. And you're probably never going to see these people again, so what the heck?

And now… a tip about how to cover up that pesky dyskinesia. Get an iPod. They've just lowered the price, so now's the time. When the twisting and writhing come over you and everyone in the subway car is staring at you, put an expression on your face that indicates you are merely grooving to the music. If you want to, say something to the person next to you like, "there's an audition for one of them iPod commercials where they show them silhouetted morons hoppin' around like savages as they's listenin' to them iPods. I'm just gettin' my MOVES down." And the side benefit will be that you'll have pretty much that whole section of the subway car to yourself after that! So enjoy!

So… there you go. I came up with both of those ideas yesterday during my trip to and from the Vanderbilt Clinic in Nashville to get my DBS unit adjusted. And here's where I helped myself to a heapin' helpin' of hubris.

Doctor Charles, the lead investigator for this clinical trial, is one of my favorite people in the world. While I was holding the little transponder over the neurostimulator buried in my left chest, he turned the screen of his programmer so I could see what he was doing and he explained everything about it.

"Can you play Tetris?" I asked.

"No, and for what this thing costs, you SHOULD be able to," he replied.

Both stimulators were previously set at 1.0 watt. I watched as he set the left one to 1.3 watts. As this was the third and final adjustment according to the study protocol, I asked if that's where we would leave it.

"I'd like to go to 1.5, but that represents a pretty big jump for someone without advanced PD," he said.

"What the heck," I said, "let's give it a try."

So, he jumped 'em both up to 1.5 watts. Then he asked me to hang around the clinic for about a half hour so we could make sure he hadn't bounced them up TOO much. He told me what to expect, and what to do, if I should run into trouble with the adjustment after getting home. He said it would feel like I'm overmedicated, and it it's something I can't deal with – turn them off. Simple enough.

So, I went to the cafeteria and sat until about 3:10. I felt a little "antsy in the pantsy" but not particularly dyskinetic. And, as we will recall, I had dyskinesia LAST time after an adjustment. After balancing out the meds, the dyskinesia went away. So, I called a cab and went to the airport. I swallowed a Stalevo 100 and went to the gate.

And then they hit.

Not horribly so, maybe only slightly noticeably so… but there I was, with a case of the flibberty gibbets while waiting for an airplane.

And they lasted all the way home, despite my attempt to drown them in a double scotch on the rocks. And then, as I tried to fall asleep, my flibberty, jibberty legs would NOT let me drop off.

So, at about 10:30, I got up and walked out to the kitchen where the remote control was… and for the first time since Dr. Charles turned on the neurostimulators in July, switched 'em off.

I slept like a LORD! But when I got up this morning, I was really off. So, back to the kitchen, and on with the neurostimulators.

Good morning, flibberty gibbets!

So that's where we are now. I took a Stalevo 100 at 4 this morning. Nothing since. I'm still bouncing around a little, but not nearly as bad as earlier today or last night. It seems like my legs are the most affected… I can't remember them ever feeling so… loose! No stiffness at all. Arm swing? I've got THAT! Don't stand next to me while I'm walking.

I'm gonna just let the whole thing sit and stew awhile. If it's still doing this tomorrow, I'll shoot Dr. Charles an e-mail asking for advice. I really don't want to turn the whole thing off for four weeks. And it's not THAT bad. We'll just hope that things eventually wind down. I'll let you know what happens next time.

(Then there was some downtime leading up to DROOLFEST II! There was a grand total of 5 of these droolfests, but this is the last one

I'll write about since they were all pretty much the same after this point.)

OCTOBER 15, 2007

Well, here I am — same room as last time I was here for an 8-day stint. I'm all checked in. Nurse Eunice has strapped the wrist band on. I have officially begun the 8-Day Droolfest II.

I'll write more in a bit. Dinner just got here. And it's meatloaf. Mmmmmm. Meatloaf.

———

Well, I made quick work of that. Wasn't really hungry... pigged out at McDonalds at BWI before getting on the plane.

Ah, the plane. There's usually at least one major annoyance per plane trip. This time it was the yammering, nattering old lady in the seat behind me. This easily offset the bonus of having an empty middle seat next to me. I employed one of the "How to Get an Empty Seat" techniques I defined in a recent blog entry — find a fat guy sitting by a window, grab the aisle seat, leave an impossibly thin space between you and the other fat guy. It worked again. But the yammering, nattering, high-pitched old lady behind me who talked and talked and yammered and nattered and WOULD NOT SHUT HER MOUTH THE ENTIRE TRIP ruined it for me. That, and the fact that it seemed for a moment that the plane might crash on landing here in Nashville.... The pilot seemed to be riding the controls pretty hard, but we got all the wheels down at roughly the same time and... well, here I am.

It's warmer here in Nashville than it has been in Maryland. Mid 80s today. A bit on the muggy side. It matches he weather I understand will be coming to Maryland in a few days. Gail is keeping busy by painting the bathroom and our bedroom. Girlfriend knows how to PARTY!!!

Anyway, Eunice reminded me that I can continue to take my meds until tomorrow, when Dr. Charles tells me to stop. OK. That's why I'm here.

Oh, another DBS-buddy dropped by. Donnie's bald, too, but his head looks like it healed without dents. You could use the divots in my skull as ashtrays. But please, don't.

Now to sit and chill and watch TV and... I guess... chill some more.

OCTOBER 16, 2007

7:40 am

Got up about an hour ago. Felt a keen desire to take a Stalevo. May as well take them while I still can, right?

We're about 20 minutes away from the first appearance of our old friend, "Lump o' Egg." That is, if they don't cross me up and put an OMELET on there today. That could happen. I won't know until it gets here.

Met the other three DBS dudes here for their own 8-day assessment. Two have had the surgery, one is in the control group. Those guys are the real heroes, I think. They devote themselves to coming here and taking part in the study, even though they haven't had the surgery. But without them to compare the surgery patients to, this whole thing is a waste of time from a research point of view.

Oooooh. The CNN weather guy says we might be in for severe weather here. Cool. But I do need to dash out to a convenience store today to get some basic staples... soap, shampoo. I forgot. This ain't a hotel.

Having my first cup of the pale brown water they call coffee. It's not horrible... it's like what you might expect at a Denny's. Of course, when I make coffee, one generally has to cut off a chunk... but that's me.

Eunice dropped by. My first "Arm Purpling Blood Pressure Torture" will be at about 9:30. That's the thing where they have to take my BP 16 times, once every 30 seconds, etc.

Then at some point, Dr. Charles comes in, does my Hoehn and Yahr scaling, turns off the DBS device, and let the fun begin.

12:20 pm

Lunch was just here. Country Fried Steak, mashed taters, green beans, cornbread, pecan pie, orange jello. Not bad. Tonight? Grilled chicken breast.

Eunice came in and performed the "Arm Purpling Blood Pressure Torture." Gee. Just seven more days of that! My next door neighbor, Don, dropped by. Nice fella. Nice head of hair to hide the DBS scars. He and Wayne are probably gonna head to the golf course this afternoon. I think I'll pass. Supposed to rain this afternoon.

Had my Day 1 videotaping done. Wore a hat to disguise my readily apparent head scar from the independent analyst who will review the tape. With my meds and current settings, my PD is virtually non-noticeable. That will change over the next few days. After 4 pm, no more pills, no more neurostimulation. Whee.

I'm waiting for Chandler who said there was something she needed to go over with me, then I'm gonna dash across the street to the drug store to get some stuff I need.

3:25 pm

Chandler came and went. We did the test with the finger tapping on the counters. Both hands had the same score... 42/41. Then she asked several UPDRS questions and timed my walking and sitting.

And that's all for now!

Went to the CVS across the street and got some snacks and shampoo and such.

Took my last Stalevo 150 at about 12:30. That makes 300 mg for the day.

And now, since I don't suppose a half hour will make that much difference in the scheme of things, I'm going to turn the stimulators off. Let's get it on!

First the one in my right brain... off.

Now the one in my left brain... off.

Okee doke. Let's rock and roll!

OCTOBER 17, 2007
9:19 am

What I want to know is, whose brilliant idea was it to conduct overnight construction projects here in the Medical Center North area? Since about 10 pm last night, someone (it sounds like he's one floor below me) has been running what sounds like a pneumatic paint chipper. Forget getting any sleep. The grinding, grinding, grinding and grinding have put an end to all hopes of that!

I have to wonder... did whoever authorized this overnight work realize that there is a Clinical Research Center here on the third floor, with PATIENTS, some of whom might want to actually get some SLEEP at some point during the night?

I'm sure it seemed like a great idea to someone. We'll chip paint, or remove plaster, or grind up drywall or whatever the bloody @($#! they're doing down there at almost 2:30 in the morning while all the offices are empty.

I know we PD patients are not the only ones here in the Research Center tonight. Sorta makes you wonder what sort of shape we're all going to be in during the day. It also makes you wonder — is this just the first night of some ongoing project and we can look forward to six more nights of this?

It's too late to ask for an Ambien now... but I'm damn sure gonna ask for one tonight!

———

9:42 am

The drilling or grinding or whatever the hell they were doing went on until just after 3 am. All the while I lay there, fantasizing about going down there and showing the operator a new use for his equipment — mostly involving his ass. But it would have been too much work to walk the hallways looking for him, and besides — I'd be in jail right now.

Got up at around 7, got coffee, took a shower, got dressed just in time for the arrival of breakfast. Sausage, French toast, and the ever-present "Lump o' Egg," which no longer has that "burned rubber" taste I remember from my first 8-day assessment.

Just had a nice visit with Nurse Sheila, who administered the "Arm Purpling Blood Pressure Torture."

I feel somewhat crappy — lack of sleep, tightening muscles, bit of a headache... I'll live.

——

12:50 pm

Just had lunch. BBQ pork sammich, beans, pineapple chunks. Not bad.

I miss my Stalevo and how it makes me feel.

Ahhhhh.... Stalevo! Click here to see how I feel when my stimulation is on and my Stalevo is working!

(Yes, I do have too much time on my hands this afternoon...)

———

6:19 pm

Well, looks like dinner with my DBS chums is going to be the order of the day. That's great. These are some nice fellas — I hope I have the names right... Dwayne and Ronnie, both of which have had the surgery, and Wayne who is in the control group.

They hipped me to the fact that they like to gather in the patient dining room for the evening repast last night. Everyone looked a little more ragged than they did last night. Dwayne wasn't there — he was out golfing still. Wayne and Ronnie had their wives with them... delightful ladies. We had a nice dinner and a very nice chat.

Symptom-wise, I'm not feeling it too much in my hands as of yet. My legs, however, feel slow and stiff. And my right arm isn't swinging when I walk.

So, on to tomorrow then. Hopefully the demolition on the second floor is put on hold.

OCTOBER 18, 2007

8:47 am

Slept like a lord last night. Two Ambien before bed did the trick. I don't think there was any construction going on, but really they could have torn down the hospital and built a new one around me and I probably wouldn't have noticed.

Just had brekky... bacon, omelet, a tiny Danish, cereal and coffee.

Typing is beginning to get challenging. Perhaps it would be instructive in one of these posts to just leave up what I originally type without going back to correct it. Maybe by Sunday or Monday I'll give that a try.

Other than my morning visit with Dr. Charles and the "Arm Purpling Blood Pressure Torture," really not much on the agenda today.

———

7:30 pm

Man, I really have been out of it today.

Really nothing to write about today. I took a 45-minute stroll around the campus this afternoon and have been wiped out since. My legs ache, my arms weigh a ton, and even my FACE feels tired.

Talked to Gail for awhile this afternoon, and she noticed that I'm slurring my speech a little. Right now, I feel like I could just sit motionless in my chair for hours.

Maybe tomorrow will be better. Sorry, just don't feel much like sharing today.

OCTOBER 19, 2007

8:34 am

We're halfway through. Huzzah!

Actually feeling slightly peppier this morning than I did yesterday. Maybe that was the low point and it gets better from here. We shall see.

Slept great, thanks again to Mr. Ambien. I understand there were severe storms that rolled through Nashville last night. Couldn't tell by me. Closed my eyes at around 10:30 and didn't open them until about 7.

Killing time during "Droolfest."

Just had a shower, followed by breakfast. Not quite feeling "energetic" or anything like that, but I do feel like I'm in a better mental place today than I was yesterday.

So... we await the "Arm Purpling Blood Pressure Torture," the visit from Dr. C, and then a visit with my little brother tonight.

——

8:18 pm

I think I've figured out why my BP has been trending high during the "Arm Purpling Blood Pressure Torture."

When we do the sitting part, I generally sit on the edge of the bed, which presses into the back of my thighs, cutting down on the flow of blood in my femoral arteries. It finally dawned on me that's what was happening, so I moved and my diastolic pressure dropped about 15 points in subsequent measurements. Then tonight, I had my BP taken sitting in the chair here, and the diastolic was in the 70s.

Anyhoo...

Just got back from dinner with my little brother Joe. He's the chair of the Phys. Ed. Department at Lane College in Jackson, TN. We went to the Long Horn restaurant and enjoyed tasty porterhouses. Good stuff.

Now I'm back in the room... time to wind down for the night, then the fellas and I will hike over to the PD Symposium here at Vandy tomorrow.

OCTOBER 20, 2007

7:39 am

It sure is hard live blogging ANYTHING when you just don't feel like writing...

I passed on taking the Ambien last night because I had a drink with dinner. So the night was spent flipping and tossing and having wild dreams about driving a tanker truck and getting it stuck in sand and having minor accidents banging the trailer into things and getting dispatched to far off odd locations...

I think I'll have the Ambien tonight.

In about 20 minutes, the lads and I will toddle over to the PD Symposium being put on by the VUMC Neurology Department today. Should be interesting. Maybe I'll feel like writing something about it.

———

4:40 pm

Well, right now the lads are off enjoying themselves with one of the original DBS guys... and I'm sitting here in the room waiting for a phone call from my little brother cuz I dropped my Blackberry in his car last night.

I noticed it was gone when I put my jacket on. Then I recalled how I heard a "clunk" when I sat down in Joe's car as we left the restaurant. I felt around, but only found the seat belt thingie. But the "clunk" had to be the Blackberry.

I eventually got hold of Gail who got Joe's number from Mom and left a message. Now we wait for him to call. Hopefully he can swing by on his way home tomorrow and drop it off.

It was an excellent symposium. About 250 PD patients and their families were gathered to hear from four neurologists, including Dr. Charles. We DBS dudes got a round of applause as we were introduced.

Ever want to be in a really slow buffet line? Do so with a bunch of PD patients with bradykinesia as they slowly and stiffly pick through the bacon, eggs, etc. If I didn't have PD myself, I would think it cruel to smile at the thought.

Met Dale, the first guy to get the surgery in the clinical trial. He's the guy the other fellas are out with now as I wait for Joe to call. And wait. And wait.

I did find time to stagger to the convenience store and get some provisions. I'm exhausted.

OCTOBER 21, 2007

7:43 am

Whew! That's a load off of my mind. Joe got in touch with me last night and will be here with the Blackberry around 9-ish. I'll take him out to breakfast for his trouble. I knew that the blackberry was in his car, but still there's that little bit of uncertainty...what if it isn't?

Yes, I am typing wihtout correcting my mistakes this morning. Just want to see how far the hand coordination has gone. Not too bac, actually.

Dr. Charles will be in around 8:30-ish to do the daily UPDRS thing, then my breakfast with Joe. The other fellas are heading off to church and then for lumnch over at Wayne;'s place. I'd go alonmg, but I really, really meed my Blackberry back — it's government-issue, and hey don't look kindly on little boys who lose their Blackberriues!

Ten, an afternoon of waching football. Thjey actually have a Redskins game on down here today. Now that the Packers have beaten the Skins... go Skins! (Tbhe Pack has a bye week...)

More later...

———

7:47 pm

Had my morning visit with Dr. Charles and my daily Arm Purpling Blood Pressure torture. Then Joe got here around 9:15 and we went to breakfast. Thank God he did have my Blackberry. That would have been a real embarrassment, losing it so soon after getting it.

Spent the afternoon lounging around, watching TV.

One more full day, then I get to go home. Yay!

OCTOBER 22,2007
10:29 am

It occurs to me that this would be far more interesting to "live blog" if there were more interesting things HAPPENING!

Sadly, it's just another day at the GCRC. Had my breakfast (spilled my cup of coffee all over the floor, thanks), had my visit with Dr. C, had my Arm Purpling Blood Pressure Torture, and now I'm sitting in my bedside chair, getting caught up on some work, and deciding to write something in the blog about how there's really nothing interesting going on.

Let's face it. This has been like watching paint dry.

I'm entirely washed out. I feel slow and stiff, my typing sucks (I'm correcting it as I go, because otherwise you wouldn't be able to understand it...) but I don't know how this compares to the LAST droolfest in April. I guess we'll see tomorrow when I take the final UPDRS tests before turning the devices back on and taking a Stalevo.

So, it's about 90 minutes until lunch. It's Fried Catfish today. Uh, yay? Then we wind up back where we started with our meat loaf dinner... just like a week ago tonight when I first got here.

This afternoon at 5:30, I gotta get a computer with a printer so I can check in to tomorrow's flight and get the "A" boarding pass. Gotta get that "A".

* * *

7:20 pm

It doesn't get any more exciting than THIS!!!

Spent the day lounging around, watching TV, feeling crappy.

Had my final meal with the rest of the Gang of Four. They're all splendid fellows and I will look forward to seeing them again in April.

Got my boarding pass. It's an "A".

I'll get my final UPDRS tomorrow, get videotaped, and be on my way!

OCTOBER 23, 2007
7:56 a.m.

I get to go home today. Yaaay! This has been a long week. But in a way, I think it's a good thing — not just for the fact that the researchers need this week to measure our progress. I think it's good for each of us to know how bad the disease is, unmedicated or unstimulated. It can't help but make us appreciate how good we have it when the devices are turned on and the meds are working.

Dwayne, Wayne, Ronnie and I will go our separate ways today after we each get our final UPDRS check on videotape. Then we can take our pills and (except for Wayne, who's in the control group, God love 'im) turn our devices back on. I wonder how long it will take to get back to "where I was" symptom-wise.

Brekky will be here in a minute. Then the final "Arm Purpling Blood Pressure Torture." Then we wait for Dr. Charles and Chandler.

Oooh! It's HERE!!! With RAISIN BRAN!!!

———

8:55 am

OK. Odessa (Chandler's helper) came in and had me drink from a cup of coffee and button my coat. I did both to perfection. She asked how I felt, and "mildly impaired" seemed to fit best. But I do feel better, if memory serves, than I felt on Day 8 of the last droolfest.

Then Chandler came in and we did the finger tappy test... On Day 1 I scored 42/43 on both hands. Today, it was 25/25 on the right (a 40% decrease) and 35/35 on the left (a 19% decrease). Last time, I was reduced by half on the right and a third on the left. So there's a measurable improvement right there!

I also did the stand and walk test, but I have no idea how I did or how it compares to last time.

Now I'm just waiting for Dr. C and the videotape. But first? THE ARM PURPLING BLOOD PRESSURE TORTURE!!! That's next!

——

9:49 am

ALL DONE!!!

I'm turned back on and I've taken a Stalevo 150. I changed my flight (at a cost of $63) and will be in Baltimore an hour before I was supposed to leave Nashville.

Gonna pack, have the ladies call a cab for me, and be on my way.

And this endeth the Droolfest II.

OCTOBER 24, 2007

Thank God this day is nearly over with!!! I've had about 30 minutes of sleep since yesterday morning.

Got home a little after 6pm ET last night, got my bag, and Gail picked me up and took me home. Saw the beautiful job she had done on remodeling the bedroom and bathroom — fresh coats of paint, new photos, fixtures, etc. The lady has an eye for that sort of thing.

Went to bed at 9. Got back up at midnight. Went back to bed at 1:30. Got up for good at 3:30.

Just could not shut off my head.

I don't think PD has anything to do with this. Anything that screws up my schedule is likely to give me a little bit of insomnia. If I don't sleep tonight, that's a problem. But betcha I will.

(From this point on, with the major programming over with, it was time to segue into the next part of my life - the rest of it.)

3. LIFE WITH AN ELECTRIFIED BRAIN

(In this part of the story, we notice that my disease progression is accelerating. After the final programming session, I continued to have problems with the settings. My right side was just fine, but my left side tended to be wiggly and floppy. It wasn't long before I was freezing, festinating and falling.)

SEPTEMBER 24, 2007

Well. Darned if THIS isn't turning into something of a mystery!

As I mentioned in my previous entry, I had planned to just let this thing sit and stew awhile in the hopes that the dyskinesia and other side effects would just calm down. Then, on Wednesday, I had a revelation. An incorrect one as it turned out... But still...

As I stood on the train platform waiting for the Maryland Amateur Railroad Club to arrive, collect its passengers and whisk us all to DC, I realized that I could NOT get my left knee to lock and allow me to put my weight on my left leg, stiff-legged.

That's when the light went on. Left side. Controlled by right brain. Both sides of the brain getting the same, new setting of 1.5 watts from the adjustment on the 17th. As I am primarily RIGHT sided with my symptoms, this MUST mean the RIGHT brain (which controls the LEFT side, which is NOT as badly affected by my PD) is getting -- TOO MUCH STIMULATION and that HAD to be causing loose muscle tone in my left side!!!

Right?

So, I turned off the stimulation in my right brain. Badda bing! My right side felt fine, and my left side no longer felt loosey-goosey!

I got to work and fired off an e-mail to Chandler and Dr. Charles informing them of this great discovery and, no doubt history-making revelation.

That night, Gail almost had to get up and sleep in another room. My right side, all stimulated and such, was trying REAL HARD to flip over in bed, while my unstimulated left side was having none of it.

Thursday I got an e-mail from Chandler. She and Dr. Charles had been discussing my situation and suggested that I TURN THE STIMULATOR BACK ON! My little "loose muscle tone" theory was something the good doctor had never even HEARD of in connection with DBS.

So, as directed, I turned the stimulator back on. And within minutes, I experienced the worst case of dyskinesia I have ever had, before or since. It hit as I was walking down the hallway towards the elevator to go down to the little snack bar we have on the first floor. All of a sudden – and bear with me, because it is difficult to describe – my legs didn’t want to do what my brain was telling them to do, and my upper body began to twist and bend at the waist. I had to quickly place by back against the wall to keep from falling. Once I felt secure enough to try walking again, I could only take small, halting steps. And just then, the elevator door opened and several people I knew stepped into the hallway. Now, everyone here who knows me, knows I had the operation in June. And for the most part, I haven’t given folks much to gawk at. On

Thursday, we made up for lost time in the gawking department. Other than the usual greetings, no one said anything as once again I flattened by back against the wall to try to stop the bouncing and twisting, so I could let these folks walk past without having to see my twisting, turning and writhing efforts to get back to my office where I could sit down without being looked at. It took some doing and some real concentration, but I made it back to my office and plunked down on the chair behind my desk. My head and neck were bobbing and twisting as if I were some sort of curious chicken trying to see everything around me, and my arms… especially the left one … were not at all interested in holding still.

I managed to punch the correct buttons on the phone to call my wife. I told her what Dr. Charles said, and what was happening, and she suggested that perhaps, until the dyskinesia settled down a bit, I should use a cane when I walk. I laughed out loud at the thought, as I explained to her how my arms were flailing in the hallway, and how a cane at that time would do nothing more than help me to cut a swath through the onlookers.

I shot an e-mail to my boss and begged off of a meeting we had scheduled and was soon on my way home. Folks on the Metro subway and the MARC train, especially as we stood and waited to be let onto the train, looked at me and looked away quickly when they noticed I was checking them out. Their expressions said it all – "kinda early on a Thursday to be quite so shit faced, ain't it, fat boy"?

I stayed home from work on Friday. Dr. Charles called me at home that evening. He said the fact that I'm having dyskinesia is, in a way, a good sign. It means the electrodes are where they're supposed to be. Now it's just a matter of finding the right balance between medication and stimulation.

He suggested I try half a Stalevo 150 when I get up, then half a Stalevo 100 at 9, half a Stalevo 150 at 3, then half a Stalevo 100 at bedtime. I tried that on Saturday with minimal success. By Sunday, the dyskinesia was bad in the morning, not quite so bad in the afternoon, and almost gone in the evening, except for when I went to bed and my left leg developed the worst ever case of "restless leg syndrome."

Now it's Monday, and I'm taking even less medicine. I took half a Stalevo 100 at 4 this morning. In a few minutes I'll take another. Then another at 3 before I go home. Then another at bedtime. I will, by this evening, be taking about a third of the Stalevo I had been taking before the surgery.

As I write this, my upper body isn't quite so affected. An occasional twitch in the trunk causes me to rock back in my chair. While seated, my legs are just dandy. But as soon as I get up to walk, the dyskinesia kicks in – but not as badly as before. My right leg feels just fine. My left leg feels like a spaghetti noodle.

On the way in this morning, another co-worker asked why I was limping. I winked and said, “Interesting weekend.” So now, no doubt, the nice lady thinks I hurt myself having sex. Let her think that.

So... What have we learned?

I am not a neurologist. I don't even play one on television.

And… since I have been spending a great deal of money for travel to and from Nashville to take part in a clinical research study with a top notch neurologist… Therefore, I should DO what the neurologist SAYS!!!

Which I will do from now on. With one caveat. When I go to bed at night, and I cannot sleep because my left leg wants to get up and run up and down the hallway by itself, and no relaxation technique I know of will FORCE it to just lie there and go to sleep with the rest of the body, I will turn OFF the stimulator. I’m sorry, I love my wife and do not want her to get used to being kicked. And, I need my sleep. I’m assuming as we go through the “getting used to it” process, the leg will eventually come to terms with the rest of the body and stop acting like the renegade puppy that wants to keep the rest of the litter awake all night – bouncing and flipping and jiggling -- when all the other puppies want to do is get some shuteye.

At least, that’s what I hope will happen. You can always give away a naughty puppy. Not so, a naughty leg.

Oh, and since you’re no doubt wondering? I’ll put this as delicately as I can.

Dyskinesia sex? It’s not… good.

That may come as a surprise to you. Sure did to me.

But it is not… good.

And that’s all I’m going to say about that.

OCTOBER 9, 2007

Yesterday was Columbus Day. That being one of those phony baloney government holidays, it meant I had the day off as I am a phony baloney government employee. As we are in the midst of the most ungodly hot and humid October on record here on the Eastern

Seaboard, I was lounging about in my summer "at home" uniform. Underpants.

Shortly after noon, the phone rang. It was Dr. Charles. He was in Washington. He had brought the DBS programmer along with him. And he offered to fix the problem I was having with the stimulation in the right brain if I could get to his hotel at 6 that evening.

Now here I had been expecting to just leave the right brain electrode turned off until the end of the upcoming 8-Day Droolfest. But the good doctor said he preferred that I have the thing turned on and set at a comfortable level, even though in a week we will be shutting the whole thing down for eight days.

So, I put on some clothes (after a nap), got into my non-air conditioned car, and headed DC-ward. I drove to the Grosvenor Metro station, just north of where I work, parked the car there, and took the Metro to the Woodley Park station. The doc's hotel was right across the street.

The hotel lobby resembled nothing less than one of Saddam's presidential pleasure palaces -- marble floors, wide-screen TVs, plush furnishings, and pleasant perky uniformed folks. OK, that part was different than what you would see in one of Saddam's palaces, but you get the idea.

Dr. Charles greeted me and we walked to sit in adjoining chairs in a discreet part of the lobby where a neurologist could adjust a fella's DBS units without making a scene.

I described what had been happening to that point, what my current Stalevo intake is, and Dr. Charles did the rest. He reset the right brain electrode to 1.0 watts -- right where it was before I went to Nashville last time. And I was good as new. He watched me walk a bit, and we decided I was good to go.

As I was leaving, Dr. Charles introduced me to the young lady who was coordinating the neurology event he was in DC attending. The lady smiled, shook my hand, then she said to Dr. Charles that he would be seated at Dr. Howser's table at that evening's dinner.

"Doogie? He's here??" I asked.

They both managed a quick smile at my idiotic comment.

I sure do think I'm funny sometimes.

(After this entry, I blogged at length about further "Droolfests" and other events in my life. I left NIH and went to work at the US Department of Agriculture, only to return to NIH in September 2008. I took a prolonged break from the blogosphere when my older brother, Jack, died from lung cancer in January 2008, and I realized I was likely to be the first male member of my family to reach the age of 55. I started blogging again one November morning when I fell and broke the shower curtain.)

NOVEMBER 28, 2008

It was Monday morning, Nov. 24. Shower time. Time to scrape off the scuzz of the weekend and make myself dainty for the first day of the work week.

I woke up that morning feeling particularly unfocused. It's one of the symptoms of Parkinson's disease. It's called bradyphrenia. Loosely defined, it means "slowness of thought."

I get that a lot. My limbs move slowly before the first pill of the day. The deep brain stimulation (DBS) devices are always turned on, but they're not sufficient in and of themselves to control all the symptoms. And, usually, I take that first hit of levodopa/carbidopa an hour BEFORE getting into the shower. But I woke up late that morning.

The shower proceeded with no problems. It's a small shower, so I am able to keep one hand on the wall and stay steady.

I turned off the water, opened the curtain and grabbed the towel from the nearby table. Slowly and carefully, I dried myself. Making sure my pins were under me, I gingerly stepped over the rim of the tub. Right leg first. Then the left. So far, so good. I slipped on my underwear and shaved the undergrowth from my neck and lower lip. I picked up the towel from the toilet seat and — much as I've done at the conclusion of a shower for DECADES — flipped it over the shower curtain bar.

My wife, God love her, slept through the crash. I didn't even know what had happened, but somehow I was plastered against the far wall of the shower, the towel — and most of the shower curtain bar, in my hands. The brackets that were supposed to keep the shower curtain bar fastened to the wall? In pieces on the floor and in the tub.

"Gail's gonna notice this," I thought. "Better leave a note."

I stepped out of the bathroom into the hallway — a passage that, at this time of the morning, is generally strewn with dogs. Our two beauties — Raven and Shiloh — tend to present themselves as obstacles to my progress at this point of the morning. I've long since learned not to try to step over them, as they tend to wait until I have one leg over their prone bodies before leaping to their feet in their daily attempt to kill me.

Now I stand there and growl a single word.

"Move!"

And they do. Grudgingly. They get up, stretch, shoot me an evil glare, and make their way either to the couch or the recliner. Now I can just kick the dog toys out of my way and step safely — first into the living room, then into the kitchen.

Coffee's ready by this point. So I pour a cup, dispense my morning pills, and sit down at the lap top at the kitchen table to check the morning headlines and e-mail.

After about 10 minutes, it was time to get back into the bathroom, brush my teeth, then finish getting dressed for the day. I felt foggy, cloudy-headed, unconnected, and apathetic. I thought about leaving the empty coffee cup on the table, but decided against it. I stood up and turned on my left foot to put the cup on the counter top near the sink.

I meant to just turn around and take a step. Instead, with my left foot stuck to the floor — a condition Parkies know as "freezing" — I found myself wheeling around nearly 360-degrees. I grabbed the back of the chair and steadied myself, preventing a fall.

Twice now. In the span of a morning. This was going to be a FUN day. I just KNEW it.

I've been aware for awhile now that I am not the steadiest fellow in town anymore. I've nearly fallen quite a few times… getting into the car, getting out of the car, walking up stairs, walking DOWN stairs, and almost always when I least expect it. There's no sense of dizziness. There's no sense that something isn't quite right. There's just that sense that the top half of my body is just about to go over the lower half to a tipping point past the center of gravity and if I don't GRAB SOMETHING, I'll go ass-over-teakettle into somebody's lunch at the cafeteria.

That's what the cane is for. I figure I actually only need it once out of every several thousand steps I take. But I'd rather have it and not need it than need it and not have it.

So… where were we?

Right. My balance issues.

I sent an e-mail to the very nice lady at Vanderbilt University Medical Center — where I'm taking part in a clinical trial testing the safety and tolerability of Deep Brain Stimulation in early Parkinson 's disease. I told her what happened that morning. I also explained the fogginess I had been experiencing. How I sometimes lose track of a TV show because I zoned out for a few minutes and missed a plot point, or how I can watch a football game and not remember why the score had changed. I explained how my speech had been more slurred than usual, and how Gail was noticing my face wasn't showing its usual range of expressions.

That evening I went to bed shortly after 8. I was practically incapable of holding a conversation and just wanted to let my brain reboot.

On Tuesday, I was slightly better. Still feeling foggy, still wobbly. But I didn't fall. Gail had replaced the shower curtain with a nice new one.

When the neurologist called me back on Wednesday, I was actually feeling better. Not as foggy, not quite as wobbly. But still stiffer than I would like to be. Still slower. And still having moments where, if I weren't hanging on to something, I would probably fall.

He explained it clearly. Parkinson's is a progressive disease. Mine is progressing. We noticed during my last 8-day stay at

Vanderbilt as part of the clinical trial that my balance was becoming an issue. Postural instability is one of the cardinal symptoms of the disease. Like bradykinesia (slow movement), rigidity and resting tremor. (I have three of the four… although tremor is the symptom most people associate with PD, it is not the most disabling… and I don't have much. Which is why, when I tell folks I have PD, they invariably respond, "but you don't LOOK like you do!")

We decided against changing my meds for the time being, and I said I would keep a daily track of "how I'm doing" and we'd discuss it when I go back down to Vandy in April for my last 8-day stay in the clinical trial.

(Then, shortly after Thanksgiving, we learned that my older sister had been diagnosed with a terminal case of esophageal cancer. That's the day I wrote this next entry.)

DECEMBER 12, 2008

I recall an episode of "The West Wing" where, after the death of an assistant and long-time family friend, President Bartlett walks into a church and curses at God.

President Bartlet (Martin Sheen): You're a son of a bitch you know that? She bought her first new car and you hit her with a drunk driver. What, is that supposed to be funny? "You can't conceive nor can I the strangeness of the mercy of God," says Graham Green. I think I know who's ass he was kissing there, 'cause I think you're just vindictive. What was Josh Lyman, the warning shot? That was my son, what did I ever do to yours but praise his glory and praise his name? There's a tropical storm that's gaining speed and power. They say we haven't had a storm this bad since you took out that Tender ship of mine in the North Atlantic last year, sixty-eight crew. You know what a Tender ship does? It fixes the other ships, and, delivers the mail, that's all it can do. Gracias Tibiago Domine. Yes, I lied. It was a sin, I've committed many sins. Have I displeased you, you feckless thug? Three point eight billion new jobs that wasn't good? Bailed out Mexico, Increased foreign trade, 30 million new acres of land for conservation, put Mendoza on the bench, we're not fighting a war, I've raised 3 children. That's not enough to buy me out of the doghouse?

Hace credam a deo pio? A deo iusto, a deo scico? Cruciatus in crucem. Tuus in terra sertvus, nuntius fui. Officium perfecti. Cruciatus in crucem. Eas in crucem.

(Translation: Am I really to believe that these are the acts of a loving God? A just God? A wise God? To hell with your punishments. I was your servant here on Earth. And I spread your word and I did your work. To hell with your punishments. To hell with you.)

A nice piece of writing, and it really goes to show the anger and frustration and powerlessness we confront when faced with bad news… when things happen that are beyond our control… when bad things happen to good people.

We wonder why God permits evil to exist while the righteous suffer. Is that fair?

We wonder why God allows decent people — children, adults — to suffer from dreadful diseases while those who prey on others enjoy long, healthy lives.

We wonder, sometimes… "God? What the fuck are you doing up there?"

If you're of the Judeo-Christian tradition, your mind turns to the book of Job, where God visits his good and faithful servant with death and disease and poverty to win a bet with Satan. And when Job finally turns his eyes skyward and asks the Almighty to explain, "Why me?" God answers — "Because! That's why! And by the way, where were you when I created the universe? Huh? So, which one of us is God and which one of us is YOU? Ah ha! I thought so! Piss off." Of course, God does replace everything He took from Job, but still…

If you're a Steven Sondheim fan, you think of the lyrics to "Epiphany" from "Sweeney Todd."

We all deserve to die. Tell you why, Mrs. Lovett, tell you why. Because in all of the whole human race, Mrs. Lovett, there are two kinds of men and only two. There's the one staying put in his proper place, And the one with his foot in the other one's face. Look at me, Mrs. Lovett, look at you!

So, I have to wonder. Are we to blame for the bad things that happen by virtue of the fact that we are mortal? Does God cluck His almighty tongue in contempt for humanity when we plead for mercy, for forgiveness, for special treatment, for a cure to disease? Does He flip us the Eternal Bird when we ask him to protect the airplane we're riding, when we beg him not to wipe out the city we live in as the hurricane approaches, when we pray for the Queen to come up as we draw to an inside straight?

Or is the problem merely the way we think of God?

Could it be that God is NOT a cosmic "Daddy Warbucks" — to be called on for rescue when we're in trouble?

Why would God divert a hurricane from New Orleans to have it strike in Houston? Are the people of Houston less righteous? Why would God answer YOUR prayers to cure YOUR cancer and not answer my father's prayers to cure HIS cancer? Why would God allow a plane carrying good and decent people to crash into a mountain when planes carrying wicked people fly cross continent unharmed? And why would God kill the GOOD people on that plane at any rate, even to get at the Mafia Don who happens to be sitting in first class on his way to commit wicked deeds?

Could it be that God created a universe that is random in nature… that things sometimes "happen" for no good reason?

Could it be that we are as capable of understanding eternity or the rationale of an omnipotent being as my dogs are of understanding why water is falling from the sky and why their fur is getting wet and why I — as their master — can't STOP this nonsense?

I don't know what lessons are meant to be learned when we or our loved ones are dealt shitty hands in the card game of life. Actually, I wonder IF there is a lesson to be learned. I wonder if we're not supposed to just pick ourselves up, dust ourselves off, and get back to work with a smile on our faces and a pound of lead in our hearts.

I do know that there are times when I've found I can handle things better when I ask God to just give me a bit of strength to DEAL with misfortune.

And frankly, as a finite being keenly aware of his own mortality, I think that's all we really have any right to ask for.

So, in the words of the National Lampoon parody — Deteriorata…

Therefore, make peace with your god
Whatever you conceive him to be—
Hairy thunderer, or cosmic muffin.
With all its hopes, dreams, promises and urban renewal
The world continues to deteriorate.
Now pick yourself up, dust yourself off, and get your ass to work.

(My sister Cindi, ever graceful, ever optimistic, had surgery for her condition. She did everything she was supposed to do, with the help of her loving husband and her devoted kids. She died on November 4, 2009.)

JANUARY 28, 2009

Wanna know how happy I am right now? I had almost a full entry typed when, all of a sudden, my right pinky finger hits a key that highlights everything on the screen, and before I can recognize that this has happened, I hit another key — ALL GONE!

Vanished.

Into that black computer hole from which nothing emerges.

But I'm too pissed off to just say "fuck it" and quit at this point. I feel like bitching, and goddamn it straight to HELL if I'm not gonna do it, if for no other reason than to indulge myself!

(He hits the "save and continue" button.)

Felt relatively decent when I got up this morning. Then Raven showed me a puddle of pee on the carpet. Shiloh saw me looking at it and ran behind the couch. She's been "demonstrating" lately… when Gail leaves to go to the store… Shiloh pees on the carpet. When we go to bed at night and leave them alone, Shiloh pees on the carpet. Sometimes, when she's really upset with us, she poops.

Gail just shampooed the carpet yesterday.

I waited for Shiloh to peek out from behind the carpet and called her over. I put her collar on and attached her leash. She figured this meant she was going outside. Which she was.. but not quite yet.

I started walking toward the puddle. She realized where she was being led and put on the brakes. I am stronger than she is, so I dragged her to the spot, laid her on her side, and — just like the Dog Whisperer says to do — I assumed the position of a dominant dog correcting the behavior of a subordinate. I put my face over hers and growled. I rubbed her little snout in the pee. Then I smacked the palm of my hand on the carpet like a referee pounding out a three count at Wrestlemania, accentuating each slap with a “NO! NO! NO!” Then I dragged her little canine ass to the door, hooked her up to the outside leash and tossed her out into the cold, dark yard to consider her crime.

I will do this every morning from now on if there is pee on the carpet. SHE will get tired of it looooong before I do.

So now, it’s almost time to go to work. Gail notices I am limping. I tell her that it’s because my right Achilles tendon hurts, which is true. But walking out to the car, I notice that the leg is having trouble obeying simple commands, like “step”. (Great, something ELSE that won’t listen to me. At least it hasn’t peed on the carpet. Yet.)

(He hits the “save and continue” button.)

No problem driving to work, except my head feels like it’s stuffed with lead. So do my bowels. Every morning for the past week or so, I manage to crap out a hunk of granite — after struggling like Hercules for 10 minutes or so. I ate a bowl of Cream of Wheat last night. That USUALLY results in a steady, flowing stream of poo right away in the morning — followed by a sense of “gotta go and I mean right NOW“ urgency when I’m in the car, stuck on the Beltway, 10 miles from the office. Not so this time. If I were to die today, I would feel very, very sorry for whoever has to do my autopsy. I must have four or five days of backed up crap in there.

I get to work, get out of the car, and my leg is still acting stupid. We get to the office, I get inside, take off my coat, take a seat, and chat with some co-workers. This is when I discover that my mouth is set on “stumblebum.”

(He hits the "save and continue" button.)

I wonder what my co-workers think about the normally well-spoken and eloquent Bill as he stammers through simple conversation.

(And suddenly, my right hand hits SOMETHING that causes the blog program to close. He begins again with this paragraph.)

9:45 — I have a 10 o'clock appointment to discuss podcasting with a potential interviewee. I throw on my coat and drag myself to the Clinical Center… a 10-minute walk that takes 20 on days like today.

I get there, meet the person I'm supposed to chat with, and stammer and stumble my way through a description of the podcast, what I'm looking for in a subject interview, etc. The person I'm talking to is a nurse. She looks concerned. Or worried that this babbling idiot sitting before her thinks he can INTERVIEW someone. For a PODCAST???

(He hits the "save and continue" button.)

I drag myself back to the office, And this is a problem. Most days, it's tiring to walk from Bldg. 61 to Bldg. 10 and back again. Today? I feel like I'm ready for bed. My head feels heavy. My thoughts feel like they're being strained through thick layers of gauze. My fingers are practically mashing the keyboard — especially on my right hand.

I notice I'm leaning to the right as I type, and mayhaps that's why my back hurts.

To sum it up… I rarely despair. Parkinson's isn't a death sentence, it's a life sentence.

There are far worse things.

But still… if I may be allowed a brief, profane explosion of anger?

(He hits the "save and continue" button.)

FUCK YOU, Dr. James Fucking Parkinson and your FUCKING DISEASE!!!

FEBRUARY 16, 2009

It was a wonderful day! We stayed at a 4-star hotel in DC, I yelled at a protestor, had our picture taken with "The President", fell down while walking, helped a kid get his football back, and somehow bled all over the sheet on our bed and the hotel bathroom floor.

It really was a great idea! Who needs to drive long distances to "get away" for a night when you have a world-class city like Washington, DC, just 30 miles away. Saturday morning, I went on to Priceline and Bill Shatner got me a great deal on a 4-star hotel… the Renaissance Mayflower Hotel.

We checked into our room and took a stroll. The White House was about two blocks south.

After walking for awhile, I was getting pretty tired by this point, so we had to stop and sit from time to time on our way back to the Hotel. This was taken on the right in front of the White House.

We got back to the room and rested awhile. Then we went out to see if we could find a restaurant that was open. We couldn't find a thing! Even the sandwich shops closed at 6! As we walked, I fell. Just, WHOOP! Straight down to the ground. It's like I put weight on my leg and it just wouldn't hold me. Skinned the hell out of my knee.

Gail was ticked at me for "pushing myself too hard," but we both know that the day will come soon enough that we won't be able to take long walks together. We went back to the room and ordered room service.

Then we hit the hay for a much-needed night's rest.

I got up once at 5 or so to go potty. Gail got up at 6:30 and came right back out of the bathroom.

"Do you have any idea how blood got all over the bathroom floor?"

I got out of bed, almost lost my balance, and staggered into the bathroom. It didn't QUITE look like OJ Simpson's driveway, but there were blood smears all over the tile floor. I looked at the scab on my knee, and there was no leakage. Gail asked to look at my feet… and there it was. Somehow, during my sleep, I had gouged out a small hunk of the back of my right heel, probably by kicking myself with a toenail during the night. There were streaks and smears of blood on the bed sheets as well.

We made coffee, Gail slept for about another hour, we got dressed, checked out and went home.

Best Valentine's Ever! Except for falling down, that

APRIL 14, 2009

Had a visit with a nurse practitioner this morning. Talked about the depression (apathy, etc.) symptoms and got a prescription for Zoloft, which I will start taking tonight. Also got my Maryland MVA request for a handicap placard signed.

I'm not really bummed out about any of this… more of a sad resignation that things aren't ever really going to be any better, physically, from this point on. And they will get worse.

APRIL 20, 2009

After originally being told that he didn't have any openings until the summer, I managed to get on the cancellation list and — viola! Dr. Stephen Grill of the Parkinson's and Movement Disorders Center of Maryland had an opening this morning. Excellent!

We had a very nice visit, and I'm looking forward to an excellent doctor/patient relationship.

We did all the standard tests and he seemed pretty encouraged about the condition my condition was in. Balance problems, yeah. A very minor tremor… but with the DBS and my meds, no sign of rigidity.

We did some speed tests… walking a certain distance, putting blocks on pegs, putting dots in squares and the like. I was thrilled to hear that I'm either as fast or faster than I was when I saw Dr. Goldstein in Feb. 2007 — until I realized that I wasn't on meds when I last did these tests for Dr. Goldstein. That was the visit where I went back ON the meds after being off for several years.

But still — for someone who has had this thing for more than 9 years now — not too shabby!

He stressed getting more exercise, so I think Gail and I will get a treadmill — provided I can find one of those "fold-up" models so it's not out in the open all the time.

We'll get together twice a year unless I need additional attention.

APRIL 21, 2009

6:15 am. I've been up since 5. One cup of coffee down, another to go. Gail will likely get up in about 15 minutes. She'll ask me if I slept OK.

Nope.

I think I maybe got about an hour's sleep. Total.

Just couldn't shut my head off last night. Not so much worried about anything… just couldn't stop thinking about stuff. Stupid stuff. Like the fact that a recent CT scan shows I have a 2mm unobstructing kidney stone. I started to wonder if that would present a problem down the line. Then I wondered what can be done about that sort of thing. Then a thunderstorm came and I started wondering how the dogs were holding up. They hate storms. Then I started wondering what we would do if a tornado whipped up. What kind of warning would we get at that time of night? Probably none. Then I laid there with various tunes running through my head. Over and over and over and over.

This is nothing particularly new. I've had nights like this in the past, well before starting the Zoloft. But I think I will indulge myself with a sleeping pill tonight.

Today? Should be a LOT of fun.

Right.

APRIL 22, 2009

Amazing what 10mg of zolpidem tartrate can do! (Generic name for "Ambien." Consider yourself enriched.)

After going the whole day with wide, staring eyes (but no strong urge to fly — and my powers of observation were far from amazing…) and an audible 60 hz buzz in my ears, when 8 pm came last night, I downed a Zoloft and an 5mg Ambien and waited for the sleep angels to caress me in their soft, feathery wings.

When 8:45 arrived, the only thing I noticed was that the 60 hz electric buzz was louder. So… to the kitchen for one more Ambien. You can HAVE 10 mg. My doctor TOLD me so. So SHUT UP about it!

That, gentle friends, did the trick. Went to bed at 9 — still not feeling that gentle send-off you get with a sleeping pill… then…

BOOM BOOM! OUT GO THE LIGHTS!!!

Woke up once when Gail got up to go potty. It was nearly midnight. "I WAS ASLEEP!!!" I exulted to myself. "I SHALL RETURN THERE MOMENTARILY!!!"

And I did.

Got up at 5, let the dogs do their thing in the yard, made coffee, took a shower, shaved (as much as I shave) and now I'm sitting here, feeling fresh and ready to face the day. Better living through chemicals.

I get these little insomnia spurts now and then. Then, shortly thereafter, I will have days where I fall asleep milliseconds before my head hits the pillow.

All part of the grand and rich pageantry of Parkinson's.

Now… on with the day.

MAY 13, 2009

I just walked to and from the Clinical Center for lunch. And I'm bloody, damned exhausted. My legs ache. My arms feel heavy. My legs just don't friggin' wanna DO this anymore.

I am the same man who, during the East Coast Blackout of 2003, walked from midtown Manhattan to Astoria, Queens — with a BACKPACK filled with t-shirts and other giveaways for our listeners at XM Satellite Radio… and I was 50 lbs. HEAVIER then.

Now, a 10-minute walk to the Clinical Center leaves my legs feeling like lead. I don't seem to have a "low gear" anymore… a slight incline causes me to have to force myself to keep taking steps, and one of these days I will likely go ass-over-teakettle from picking up speed going DOWN a slope.

The guy on the right? Sisyphus — in Greek mythology, condemned to push a boulder up a hill — forever and ever.

Seems like they could have named Parkinson's Disease after THIS guy, instead of the mook who first wrote about the disease in 1817.

Just call me "Sissy Puss!"

MAY 20, 2009

Last night, right before bed, I had a drink of water from an onion-shaped cocktail glass. As I tilted back my head to drink the water, I lost my balance. I didn't fall — but it was a close one. During the night, about 11 pm, I woke myself up violently shaking in bed. It stopped right after I woke up. This happened either Saturday or Sunday night, too. This morning, I'm wobbly, wiggly and altogether unsteady on my feet. I almost fell over one of my dogs. I don't feel safe driving or walking. So, this is a good day to just sit at home.

DAMN you, Parkinson! AND your disease!!!

LATER THAT DAY

I got my first driver's license when I was 17 and living in North Dakota. For awhile, I had a CDL and drove a tanker truck. Until today, I spent nearly 4 hours each day commuting to and from work. It ends today. After getting up this morning feeling wobbly and unsteady, after discussing the situation with Gail, after doing some reading up on the subject of driving with Parkinson's disease, I've decided it is in everyone's best interest to hang up the keys and rely on Gail and public transportation from now on.

The worst part (so far) is making the decision and realizing it's necessary. I haven't noticed any real difference in reaction times, but I have noticed that I sometimes step on the gas and the brake at the same time and my foot will — from time to time — slip off the gas pedal. Better to make this decision now on my own than to wait until after an accident.

So, starting tomorrow, it's the MARC train to DC, then the Metro Red Line to Bethesda.

Yay!

MAY 26, 2009

Tomorrow makes one week since the day I gave up driving. So far, so good.

Gail has been wonderful about taking me wherever I need to go. She drops me off at the train station in the morning and picks me up in the evening. We went clothes shopping on Saturday (needed new pants because of the weight loss) and grocery shopping on Sunday. On those occasions I choose not to go into the store with her (like Sunday when she went into the Wal-Mart to get a new BBQ grill grate), she refuses to park in the handicapped spots, since she can walk just fine… a less moral person would use the placard. I admire the woman.

As far as the train ride goes… again, so far, so good. I get the 6:45 am train to DC at BWI, jump onto the Red Line Metro as soon as I get to Union Station, and ride it back out to the Medical Center station in Bethesda. It's out of the way to have to go all the way down to DC and then slingshot back out to Bethesda, but until they put in that new Purple Line Metro — sometime in the next century — my choices are limited.

Once I'm at the Medical Center station, it's up the longest escalator in the world, about a 150-yard walk to the NIH Campus Shuttle, and they bring me to within about 300 yards of my office.

The only problem so far… my stability. I almost tumbled out of the shuttle bus this morning, and the walk to and from the shuttle bus stop is over a small hill… and I don't have a low gear these days, it would seem.

But all in all, compared to the very real chance of a car accident if I kept driving — it's been a fair tradeoff.

For now.

MAY 29, 2009

The last thing I want to do on a blog like this is come off as "whiny." When I came up with the idea for a manuscript about my experience with deep brain stimulation (and that manuscript turned into this blog), the intent was to describe in as non-maudlin fashion as possible what it's like to experience the gradual loss-of-control that accompanies a progressive neurological disorder like Parkinson's. The idea is to bring folks in on — and, hopefully, help them understand — the experience. Sometimes, however, I'm not sure I understand it myself.

Since having the operation nearly two years ago, I've noticed that my "slowness of movement" in my hands and arms is almost gone. I can do finger taps with the best of them when the devices are turned on and my meds are working. But my walking, my balance, my coordination? All seem to have suffered over the past year. And from what I've seen in a VA/NIH study on DBS, that's pretty much par for the course. According to the study, "The authors caution that the benefits need to be weighed against the risk of complications related to DBS surgery. "As with many effective therapies, there may be a price to pay in terms of increased risk of adverse events," said Dr. Moy. The total number of adverse events was 3.8 times higher in the DBS than the BMT group. The most frequent adverse events in both groups were gait disturbance, falls, motor dysfunction, balance disorder, depression, and dyskinesia and dystonia, which cause involuntary movements. There were more falls in the DBS group, often resulting in injuries (fractures, dislocations, head trauma) requiring surgery and other interventions. It is not clear whether DBS increases fall risk directly or patients are at higher risk of falling due to their improved overall function and greater activity level. "

For myself, I think it's the former and not the latter. My activity level is about the same as it was before the surgery. But before I had this done, I was able to stand at the toilet in the morning and not be in danger of resurfacing the wall with wee-wee because I can't seem to hold still at times when I need to. I'm probably walking LESS than I did before the surgery because I didn't suddenly feel my upper body shifting to the left or right when I walked before — and even if it did, it was easier to keep my balance than it is now. Before I had the surgery, I could stand on an escalator stair without bouncing and shifting from one foot to another. Before I had the surgery, I could reach for a coffee cup with my left hand and not feel the need to kick with my left leg. Before I had the surgery, I could lie in bed without my entire body jumping and twitching as if someone were touching me with a live wire every few minutes.

Now, is this a result of the surgery? Or is it just that SOME of my motor functions have been improved by the DBS, while others have declined at the same rate they would have if I never HAD the operation? I guess there's no way to tell.

I'm not complaining. I'm glad I had the surgery, especially since it was an experiment to see if DBS can be safe and tolerable for those of us in the earlier stages of PD. Hopefully, if the clinical trial bears out that this thing has benefits that exceed the risks, then folks will have it offered to them sooner while they can still preserve some motor function.

All I can say for sure is that 2009, so far, has seen this thing really picking up steam in my life. And it puts a little bit of the fear of the future in me as I wonder if this is just a momentary acceleration in the downspin and things will eventually level off for awhile — or is this just the beginning of a slide towards total infirmity.

Time will tell. And I'll talk about it — here and elsewhere.

JUNE 1, 2009

I'm having a miserable morning. My arms feel like lead weights. My fingers are missing the keys when I type. When I try to walk, my feet freeze to the ground and for a few seconds I'm motionless and frustrated. Freezing of gait is another delightful part of Parkinson's. Fortunately, at this point when it happens to me it's generally for just a second or two and most of the time it happens when I'm trying to start walking, or when I try to navigate a turn, or when I find myself going from an open space to a narrow space (or vice versa), or when I go from a smooth surface to a rough surface (or vice versa). It's hard to describe — think of walking up to the edge of a diving board and your legs just don't want to take that next step. That's really about as close as I can get to describing it.

Experts on the subject say that when freezing gets to be a major problem, a person could find himself frozen to the spot for as much as 30 second. They say that visual or audio cues may help a person get un-stuck. There are special canes and walkers with lasers that give the Parky a visual cue to "step over" something. Even just telling your foot "one, two, three, MOVE!" can help.

My wife, Gail, however, has a "better" idea.

I stayed home from work this morning because I'm having real difficulty with walking — and other motor activities. A little while ago, I started walking down the hallway to the bathroom. As I got from the wide-open living room to the narrow hallway, I froze. "THIS IS SO FUCKING FRUSTRATING!" I yelled.

Gail came up behind me. "Maybe I should follow you with a cattle prod, and when you freeze up, I could just give you a little jolt and then you could get going again," she said in a sweet, caring tone of voice. I started laughing and continued towards the potty.

My wife. She always knows just what to say. I sure do love her.

JUNE 2, 2009

It's a little after 5 am as I sit in our little home office. I have a black border collie curled up behind me in the corner and cup of coffee on the desk to my left as I try to figure out what the hell I'm going to do about today. It was a much easier decision yesterday —

not only was I wobbly and “freezy”, but I felt like crap — like my stomach was still full of food from the night before, headachy and just plain “bleh.” Not quite so clear cut this morning. I’m wavering back and forth in the seat as I type, my fingers are hitting the wrong keys, and I am not so much “walking” as “stutter stepping” when I maneuver around the house.

But I slept pretty good last night — weird dreams about buying an old clunker car and witnessing a shootout between cops and armed citizens and then reporting about that shootout for a radio news station… but when I woke up I still had my covers on the bed, so I’m guessing I managed to stay more-or-less still during the night for once.

So, as I see it, the question is — do I go to work on days when my main difficulty is in the area of walking? Ordinarily, I would say yes, even though it’s getting tougher for me to get from where the shuttle bus drops me off to my office about 300 yards away. Then there’s the matter of having to walk to and from the Clinical Center for lunch. Today, that’s complicated by the fact that I have to add two extra trips to and from the CC to escort a filmmaker doing a project on the early days of AIDS research.

Am I up to that today? And if I am not, am I admitting to myself that I may be getting closer to the day where I just can’t work anymore? It would be an entirely different matter if I were able to take a train/subway to work, get to my desk and just sit without having to walk around so much. But that’s the job.

No answers. So, I guess I’ll probably just go in today and see how it goes.

UPDATE: It’s 9:45, I’m here at work. So far, so good despite almost falling on the train and shuttle bus again. Such is my life. May as well just get used to it, cuz it ain’t gonna get any better — physically speaking. Mentally, mood-wise, I feel just fine. So… up and at ‘em.

JUNE 3, 2009

Got to Union Station in D.C. a little earlier than usual yesterday, so I had an opportunity to ride an express train on the Penn Line to the BWI station. As the conductor came by and checked tickets, he told me that BWI-bound passengers needed to be at least three cars up from where I was sitting, as the entire train would not fit at the platform at BWI.

So, cane in one hand and the seat hand-grips in the other, I made my wobbly way three cars up. The train was full, but there are seats that are clearly identified as being reserved for the elderly and handicapped. Surely someone would see the wobbly guy with the cane and twin scars on his bald noggin and, at the very least, be shamed into giving up a seat.

The handicapped-reserved seats were all taken. The oldest passenger appeared to be in his mid-40s. Now, I don't know if they had heart conditions or any other sort of disability that would render them as officially "handicapped," so I can't really judge. But one thing stood out to me. You never saw people try so hard NOT to see someone. After giving me a quick glance as I hung on to a hand grip — wobbling and trying to keep from falling as the train jostled on the tracks, you could almost hear the neck bones snap as heads turned away as faces suddenly found something interesting out the window to look at, or something on their cell phone that caught their eye, or a scuff on a shoe tip that needed immediate buffing.

I stood there, wobbling, clutching my cane, clearing my throat, hoping that common decency might kick in. No such luck. As the train continued to roll north, all I could do was sit on the stairs.

I'm not going to be so nice about it next time.

JUNE 10, 2009

I'm finding that when I walk with people who aren't used to walking with me, I scare the hell out of them. When motivating by myself from point A to point B, I generally do OK, slow and clumsy, but OK. However, walking and carrying on a conversation is becoming very difficult. So when I'm walking with someone and a foot sticks to the floor, or digs into the tile and I almost trip, it invariably elicits a shriek from my companion. I've told everyone that it's all part of my ordinary day-to-day existence now, I've grown quite used to it, and unless I fall — in which case, they should at least offer to try to help me get back on my feet — it's nothing to worry about.

One such occasion was Monday. A young colleague and I were walking back from a podcast interview when my left foot dug into the floor and I stumbled. A few minutes later as we made our way down a long hallway, another gent with a cane approached from the opposite direction. He notice me and my cane (and the young lady I was walking with, no doubt), and brandished his cane as if it were a sword. I stopped and did likewise. "YOU WANT SOME OF THIS?" I said with a smile. He smiled, too, and continued on his way. "Manchild," my wife would say. Nice to know I'm not alone in that respect, either.

Yesterday was particularly difficult. I needed to get from our building to the one next door and as I opened our door and pivoted to exit, I lost balance and slammed my right shoulder into the light switch. "God dammit," I said. The ladies in the office thought someone had opened the door in my face… but it was just Willy the Weeble crashing his bulk against the wall.

I believe I'll try to make it through the day with a modicum of grace. That is, get to work, get in my chair and stay there until it's time to come home.

UPDATE: After writing this entry, I went into the kitchen to load up the "man bag" for the day with lunch, Gatorade and a Mountain Dew. Bending over to get the Gatorade, I misjudged how far I was away from the wall and busted my skull on the corner next to the fridge. It left a bump. Just what I needed.

JUNE 11, 2009

Gotta say, this new way of commuting since I gave up driving last month is really wearing me out. By the time I get to my office, I'm exhausted — and generally in need of a shower, given the recent spate of warm, muggy weather. But I don't trust myself behind the wheel and just don't want to risk it.

Of course, it would be extremely helpful if folks on the MARC train and Metro subway could READ the freakin' SIGNS! Like these two jolly fellows featured in the photo on the left. I got on at Union Station and stood there, staring at them — cane in hand, as they both looked for other things to look at. Just when I was about to say something, a gentleman behind me (in a seat NOT reserved for the elderly or disabled) stood up and offered me the seat. But I thought I'd just go ahead and immortalize these two assholes for you.

Anyway, like I said, it's a wearying experience.

Yesterday afternoon, after walking 15 minutes to get to the shuttle that would take me to the Metro, then a half hour on the subway, then a long walk (up a broken escalator) at Union Station to the MARC train, I finally had a minute to relax. With my iPhone cranking tunes through the headphones, my mind started to wander. I thought about my nephew, Matthew, who is in the Navy in the Middle East and how he invited me to take part in a "Tiger Cruise" when his ship comes back to the states. And I wondered to myself "how many other folks can say they've been in the Navy three separate times?"

I pondered that thought for a moment — and then snapped out of my reverie. I wasn't IN the Navy three separate times. It was TWICE. Once from 1973 to 1977, then again from 1981 to 1985. See, this is significant because one of my frequent, recurring dreams at night is that I have re-enlisted for a third time. So, for a few brief moments, my dream world and real world had melded.

This is a clear warning sign that I need to try to stay focused — and ask Gail to let me know if I ever babble on about anything that she knows did NOT happen. With my "acting out" at night and vivid dreaming, this is one of the symptoms of incipient Parkinson's psychosis. So far, it's just the one episode. But for the last few nights, I've woken up and have not been clear as to where I was or if I was awake or asleep… eventually, I realize I'm awake and look at the clock to see if it's time to get up yet. It generally is around 1 am or so when this sort of thing happens.

I think this will bear watching.

JUNE 12, 2009

Yesterday was a bit more strenuous than I generally like 'em. Since hanging up the car keys, I'm doing considerably more walking than I used to, and that's a good thing. My neurologist stressed that the last thing I need to do is sit around and grow sluglike — or MORE sluglike, as the case may be. But yesterday, I'm pretty sure I overdid it.

It used to be I would walk out the front door to the car, then from the car in the parking lot about 20 steps to the office. Then I would repeat the process coming home.

Now, I walk from the car when Gail drops me off at the train station, to the elevator at the BWI Amtrak Station, across the catwalk over the tracks, down the other elevator, then to the train. When we get to Union Station in DC, I walk from the train into the station, down to the Metro station. When the Metro gets me to the Medical Center station in Bethesda, I walk from the train to the escalator (the longest such contraption I'VE ever seen…) and up to the front gate, after which I step onto the campus to await a shuttle bus. The shuttle drops me at the bottom of a hill, about 300 yards from where I work, and I walk the rest of the way.

Considerably more walking than I used to accomplish.

Add to that, yesterday, an additional walk from my office the quarter-mile or so to and from Bldg. 1 to take part in a Communications Director meeting, and I was POOPED when I got home yesterday.

Got up at 4 this morning and decided I just didn't have the steam to go in today. I need to fill out that "work from home" paperwork so I can stay home on days like this and not have it charged against my leave balance.

JUNE 13, 2009

Gail and I went to the mall for awhile this afternoon… I got some see-gars at the tobacco store, then we had lunch at Chili's. This was followed by a trip to get groceries and some wine. Walking was difficult, with frequent episodes of freezing.

So, after getting home, Gail suggested that we could go out more places, stay longer and have a better time if I had a wheelchair she could fold up and put in the trunk of the car.

So… the model shown here has been ordered and is on its way. Not gonna use it for every day getting around — not yet. Not quite ready for that.

JUNE 14, 2009

Sitting here in my home office on an early Sunday morning after having just consumed two cups of excellent coffee, just contemplating the overall “goodness” of life. I know I bitch and moan a lot, but that’s with the full knowledge that I’m not really all that bad off and there are folks with this disease who are suffering far worse than I am. I’m not in any particular pain, except for the odd leg cramp that comes on at night and wakes me up. I haven’t fallen in quite some time, although I attribute that to an abundance of caution on my part. The “freezing” episodes are merely an annoyance at the moment. The things the deep brain stimulation were MEANT to do are all where I would expect them to be — I have no tremor, my hands (although clumsy) aren’t particularly stiff or slow. I walk slowly, but I’m not in any particular hurry at the moment.

So on those occasions where I seem a bit crabby or quick to complain, bear with me. I’m probably just blowing off steam. I have a wife who loves me and takes EXCELLENT care of me. I have two very entertaining and loving dogs. I have a wonderful, intelligent step son.

So, frankly? Life is pretty darned good.

JUNE 15, 2009

Sitting here on the MARC train at the Seabrook station. Already, it’s been an interesting morning. First, I almost decided to stay home again because I felt foggy and wobbly. But as the morning coffee and levodopa kicked in, my head cleared up and I decided to push ahead.

I’m still extremely wobbly, however, and prone to episodes of freezing. Taking little baby steps when I walk. And I fell in the yard this morning.

(New Carrolton, everyone. All off for New Carrolton. Next stop, Union Station.)

I was making my way, slowly and cautiously to the driveway. As I passed under the tree, a leaf brushed my hat and startled me. I turned my head quickly to see what touched me and lost my balance.

Didn't go straight down but took a few staggering steps attempting to regain my balance. Saw that my head was about to impact the tree, so I deflected it with my left hand, then went ass-over-teakettle down into the grass. Didn't hurt anything other than my pride. I think I should stop doing stuff like that in front of Gail, though.

Almost to Union Station. Into the subway. More later.

JUNE 17, 2009

OK, we all know that I've developed problems with gait and balance. When I come up to a narrow opening, like the gate between the kitchen and living room (which we had to put there to enclose a German Shepherd who was peeing FAR too frequently on the living room rug at night), I will freeze up.

Problem enough, right? Add to it… herding dogs.

Raven is a Border Collie. Shiloh is a German Shepherd. Their instinct? Herd! When Mom tells them they're going outside, they will circle around behind her and HERD her to the front door — because OTHERWISE, we would NEVER know where it is! When she does her household work, Raven will follow the vacuum cleaner around the house, point out the spots that need attention, then lead Mom to where the vacuum is supposed to go when she's done with it.

When we need Shiloh to get her lazy teenager hiney out from behind the couch, Raven will trot back there and get her for us.

Now, the dogs have decided that Dad doesn't move around the house as sporty as he oughta! They will both tend to walk beside me, one on either side, until I get where I'm going. If I freeze up at the hallway or the fence leading into the kitchen, I will feel a cold, wet nose on my leg or butt HERDING me through the opening.

They are good, good girlies and their Mom and Dad love them to pieces. But if I FALL over one of these mutts, they're gonna be really, really sorry! And likely, squashed.

JUNE 18, 2009

Yesterday I filled out the paperwork to work at home on an ad hoc/situational basis. Frankly, due to the wonders of modern technology and stuff, there isn't all that much I can do at the office that I can't do here at the home office. So, assuming the paperwork is approved (and I'm sure it will be, since it was my boss's idea), on days where I feel my PD is making walking "problematic," all I'll have to do is shoot an e-mail to my boss and let her know that I will be working out of the Elkridge Annex that day.

JUNE 19, 2009

Did my first unofficial "work from home" dealie yesterday. (I still have to get it officially approved, but since it was my boss's idea, that shouldn't be a problem.) It went pretty well. Wrote a story for the CC News, wrote some podcast scripts, checked the media line about once an hour. All in all, a successful day.

My "interns" however? Less than helpful. Shiloh came in from the yard yesterday morning (freshly de-pooped and feeling sassy) and stood at the office door barking at me. I told her she was interfering with the work of the Federal Government and was subject to disciplinary action. She gave me a look that seemed to say, "Federal, Schmederal. Throw the friggin' ball!" I reminded her again that this was WORK time, not PLAY time. She would not relent.

"President Obama called, fat boy! He said throw the friggin' ball!"

She gave up after awhile. This morning she just sat and stared for awhile… before barking at me.

She did come to my rescue this morning, however. I got out of the shower and was talking to Gail in the living room before going in to get dressed. As I turned, my foot stuck to the floor and I wobbled towards the wall. Gail, who is very quickly becoming VERY GOOD at telling when I'm gonna topple, reached out and grabbed my right hand. That steadied me for a moment, so I let go and started falling again. Gail grabbed my right hand again, I threw out my left hand… which Shiloh jumped up and grabbed! She wrapped my hand in her front paws and held on. So I had Gail holding my right hand and

Shiloh holding on to my left as I regained my footing and kept vertical! Good dog!

Next time, it will be Raven's turn. Today, she's sitting here barking at every little sound she hears outside.

On the "new symptom" front, I had a little trouble swallowing yesterday. We were having some chicken for lunch and a hunk went most of the way down my esophagus… and stayed there. This has happened once before, and it's very uncomfortable. I just had my food tube scoped recently, so I know for a fact there's no obstruction in there. Trouble swallowing — or, "dysphagia" as the docs call it — IS a symptom of Parkinson's disease. Most of the time, it leads to choking or aspiration of food into the windpipe. But it can cause problems with the valve allowing food to leave the esophagus and enter the stomach. We'll hope this doesn't become a regular thing.

Stayed home again today. Got up at 4:30 to let the dogs out, took a few steps, foot froze to the floor and I decided, "Screw it. Not gonna chance a fall." So, I'm taking a break and then it's back to work.

JUNE 22, 2009

Had a very pleasant and productive discussion with my boss this morning about the concept of working from home a few days a week. It makes sense on so many different levels — no walking from the car to the MARC, from the MARC to the Metro, from the Metro to the Shuttle, from the Shuttle the 300 yards up the hill to my office, then vicey versey at the end of the day. And I can get as much done there as I can here — especially since I've been authorized to find a cell-phone recording device for podcast interviews.

My boss wonder why I'm not more freaked out about the recent decline in walking ability. Simple answer? I've known I've had PD since 2000 and being a curious kinda fella, I tried to learn as much as I could about what to expect. And this is one of the things I've always known was coming. Unless there's a cure, it's gonna get one HELL of a lot worse! And it's not going to get any better. So, knowledge is power!

She also suggested that having this formal "work at home" agreement in place will be of benefit when the time comes (as it will) that I have to take disability retirement. When we can demonstrate that we've done all we can do to keep me working, and that I can't do it anymore, it should be easier to get that retirement approved.

No time soon, of course.

Had some lunch with friends, one of which noticed the recent changes in my voice (they ALL noticed the recent change in my walking). To the untrained observer, I suppose I sound the same. My friend is a broadcaster and she can hear that I'm getting a bit on the "breathy" side when I talk — especially when I'm tired. It's called "hypophonia." Some folks get it much earlier in the disease process… but since I'm a loud guy and a trained broadcaster who talks from the diaphragm (most folks talk from the throat), it's been late in coming.

I'm about 9-1/2 years into this thing. Frankly, even with the stumbling, freezing and falling, I think I'm doing fairly well for a guy who is this far into it.

JUNE 26, 2009

As I drifted off to sleep last night, my mind was in a pretty good place. (I don't suppose the three glasses of port had anything to do with that…) As I contemplated the sad news about Michael Jackson and Farrah Fawcett, it dawned on me — again — I have it pretty easy.

I think the thing about sudden and unexpected celebrity death that hits us so hard is, if it can happen to THEM, it can happen to US! If someone with Michael Jackson's fame and wealth can keel over and die at age 50, then what sort of guarantees do WE have that we won't be sitting in the front car of the DC Metro the next time they have an accident? How do we know that there isn't a clot in a cardiac artery or a tumor in the colon or a weak blood vessel in the brain, or some clown on his way home from the bar who will get to the intersection the same time as us?

There are no guarantees. Like my Dad used to say, "you pays yer dime, you takes yer chance!"

I lay there for awhile contemplating this truth, which first occurred to me back in 1977 when Elvis died (and I'm pretty sure with each passing day, the similarities between the King of Pop and the King of Rock and Roll — at least in their manner of "check out" — will become even clearer). We never know what we're gonna get smacked with. A speeding car while crossing the street? Cancer? A stay bullet?

Unless you're suicidal, you don't get to choose. The wheel spins and lands where it lands. That's why otherwise healthy folks drop dead while jogging, while others — my grandmother, for instance — live into their 90s on a diet of pork chops and creamery butter.

When you wake up in the morning, you agree to spin the wheel again. If you're lucky, you'll make it home that night. If not, you could be in that Metro car I mentioned earlier. For my father, the wheel stopped on Pancreatic Cancer in 1983. He was 54. Same age I am now. Same age my older brother was when the wheel stopped on Lung Cancer. The wheel stopped for my twin brother in 2004 when he was 49. Stroke.

I may live to be 100. I might die on my way home from work today. We never know. And when things like this happen to famous people, even when it was clear that MJ was FAR from the healthiest person in the world — mentally OR physically — many of us take a little inventory of ourselves.

For me, the wheel stopped on Parkinson's disease. But I got a free spin. I don't think I will die from PD. Unless cancer or that aforementioned Metro car gets me, I probably WILL die from a complication of it… pneumonia, choking on my food, falling and breaking a hip — something. Whatever. No idea.

But, as I said about seven paragraphs ago, I have it pretty easy.

I have a wife who loves me and who I trust to take care of me as my condition gets worse. I have a supportive family. My boss is incredible. The feds have a great "work-at-home" policy that I will use on an as-needed basis until the time comes when I can't work at all… and then, early disability retirement at 60 percent of my pay awaits.

At this point of my dance with the disease, Parkinson's doesn't hurt. It doesn't make me feel ill. Sitting in a chair with my meds working and my deep brain stimulation devices turned on, you wouldn't know there was anything the matter with me — until I stand up and start walking. (I carry a card in my wallet in case I ever get stopped by a cop wanting to know why I'm weaving and walking — it's not P.I. [public intoxication], officer! It's P.D.!)

My biggest day-to-day worries now tend to center on questions like will there be a seat available on the Metro or will the "reserved for the disabled and elderly" seats be filled with 20-year old slackers again?

I'm doing OK. I'm a "Weeble." Remember them? "Weebles Wobble but They Don't Fall Down." Except for now and then. But not often.

Every night when we go to bed, my wife gives me a kiss on the lips, then a kiss on the forehead. She says she's trying to make my brain "better." I love her so very much and I know I couldn't manage without her.

I think of the folks with PD and other diseases who don't have that kind of support or assurance. The folks who lose their jobs when employers can fabricate a "reason" that has nothing to do with the disease. The broken marriages when a spouse just can't handle the PD symptoms or the stress of being a "caregiver." The folks in nursing homes who are left to "go it alone".

Taking stock of what I have and what I haven't, what do I find?

Not only do I have the Sun in the Morning and the Moon at Night…

I have Parkinson's. I've had it for almost 10 years.

And I'm a lucky, lucky man!

JULY 2, 2009

At first, I had every intention of going in to work today. For one thing, this is the final day before the 4th of July holiday and then I'm taking a week of vacation. (Some vacation, I'll be sitting around the house…) But when I got up this morning, I decided against it. I make the daily determination based on whether or not I feel comfortable walking that last 300 yards, uphill, from the shuttle bus to my office. Today, I did not…

Of course, it didn't help that there was dog poop on the floor that I had to clean up. Gail says I can wake her up when that happens if I get up before she does. Yeah. Right. I'm gonna go wake up this woman who is doing SO MUCH for me already and tell her, "Honey? The doggie went poopie on the kitchen flooooooor… come clean it. And then, you can make some coffee. OK?"

Nuh-uh. Not yet.

So here I sit, in the Elkridge Annex of the NIH Clinical Center Office of Communications. I've already gotten an interview request cleared today and have had a nice phone chat with the boss. She tells me that my cell phone recording device has arrived and will be waiting for me when I come off vacation.

I love my job. I really do. So — back to work!

JULY 24, 2009

"ODE TO A FROZEN FOOT"

As I sit down to write this, I am feeling pretty good.
Having had PD for 10 years, I feel better than I should.
The stiffness and the slowness are well handled I confess
All thanks to Levodopa and that thing called DBS.
I don't have dyskinesia and I have no trouble dressing.
I'm grateful every day and thank God for every blessing.
I work at home more oft than not, in that way I'm in luck!
There's just one thing to gripe about — the way my feet get stuck!
At lunchtime Gail and I go to the store to browse the deli
To get some ribs or chicken or something else to fill my belly.
She parks the car and we get out and I hobble towards the store.
My feet freeze to the ground as I get close to the door.
I look down at my shoes and they're stuck there on the floor.
"What are you sissies scared about, it's just a stupid door?"
My brain sends down a signal to my hesitating feet.
"Come on, you lazy tootsies, let's go get something to eat!"
I think they are embarrassed as they turn loose of the floor

And they make their cautious way and proceed right through the door.
And now our goal's is nearer as I hobble down the aisle
"I hope they have some meatloaf," I say with a hungry smile.
We're making decent progress as we get close to the food.
I can almost taste the mac and cheese when… BAM! My feet are glued.
"So what's the problem NOW?" I ask the feet I walk upon.
"The pattern on the floor has changed. It scares us," they respond.
I roll my eyes and start to rock to free my frozen feet.
My wife holds out her hand to help. (She loves me, ain't she sweet?)
My feet, at last, break free from their invisible detention.
I hobble to the counter and make clear my lunch intention.
With food in hand we make our way to the checkout for to pay.
I'd like to take our food and go, my feet decide to stay.
"I've really had it with you guys," I say through gritted teeth.
"But there's a RUG there on the floor," they whisper from beneath.
With mental calculations that would make an Einstein strain
My legs receive commands from my confused, beleaguered brain.
"YOU'VE NEVER SEEN A RUG BEFORE?" My brain begins to shout.
"IT'S JUST A STUPID RUG, YOU DOLTS! STEP OVER, AND GET OUT!"
My feet may be reluctant, but they know my brain's the boss.
They free themselves and step into the street so we can cross.
Gail, she walks behind me ever ready to assist
To gently jab me in the butt if my feet again resist.
We're almost to the car when the rain begins to fall.
It's not a gentle shower, it's a sudden summer squall.
I'm getting soaked, I cannot move, I'm frozen to the spot.
I look down at my soggy feet, I whisper "thanks a lot!"
Gail runs on ahead so she can bring the car around.
She opens up the door and I get in without a sound.
I'm wet, I'm miffed, my shirt is soaked, my feet squish in my shoes.
I'll say this about Parkinson's. It always does amuse.

JULY 26, 2009

Cruising around the web today, I stumbled upon an objective test for balance — the One Leg Stance Test. Basically, you stand on one leg — take your pick — keep your arms folded across your chest or at your side, and see how long you can stand there without moving your arms, dropping your leg, or falling.

The only tests I've taken for postural instability in Parkinson's disease that I know of are the reach test and the one where the doc stands behind you, gives you a little tug and jumps out of the way in case you fall like a redwood.

Curious, I grabbed Gail and a timer and we went into the bedroom so I could fall on something soft if things went haywire.

The average dude, my age, can stand on one leg for 38.1 seconds with his eyes open. My average of 5 attempts… 6.5 seconds. My best attempt… 9.1 seconds.

Average with eyes closed, my age, 4.5 seconds. My average after 5 attempts, 2.54 seconds. My best attempt, 3.5 seconds.

This was on my right leg, left leg lifted. Other way around? Far worse. Eyes open, 3.08 seconds. Eyes closed, 1.92 seconds.

According to the averages, these would be GREAT numbers — if I were in the 80-99 year old group.

THEN… we did the "Timed Up and Go" test. I measured off 10 feet, then sat down… started the timer, walked to the spot, walked back to the chair, sat down, stopped the timer. Average after 2 tries? 16.7 seconds.

According to the test guide… A score of more than or equal to fourteen seconds has been shown to indicate high risk of falls.

Gail sniffed and rolled her eyes. "I could have told you THAT! All I have to do is LOOK at you. You're WOBBLY!"

Just call me "Steady Eddie!"

JULY 29, 2009

Yesterday around lunch time, as we usually do, Gail drove me up to the supermarket so we could get some eggs. We had all the ingredients for ham, egg and cheese sammiches… except for the eggs. So, off we went. I love going to the store these days. Since I work at home almost every day, it's a rare opportunity to get out of the house and test my feet and legs to see how well they're working that day.

As usual, I was slow and freezy. There really is no way to explain what that's like to someone who hasn't experienced it — it's easy to describe losing your balance because it has happened to almost everyone. But how to make somebody understand what it's like when you're walking and your feet stick to the floor?

Anyhoo…

We got the eggs and started making our way to the checkout. There were obstacles ahead — a shopper at the service desk, a clerk stocking a shelf, and a guy with some sort of pushcart filling most of the aisle. Gail weaved her way through and kept going. I got as far as the ice cream freezer and stopped.

My feet… would… not… MOVE!!!

Gail was getting further and further away. I tried rocking loose. No go. Gail was getting smaller and smaller and I was stuck FAST to the floor.

"Um, Gail?"

She's a little hard of hearing, but I didn't want to cause a scene, which I surely WOULD have if I did what I WANTED to do, which was…

"GAAAAAAAIIIIILLLLLLLLL!!!!! Don't LEEEEEEEEEEAVE MEEEEEEEE!!!! GAAAAAAAIIIIIILLLLLLL!!!!!!!"

So, I repeated — a little louder.

"Um, Gail?"

She turned around and saw me standing there, smiling sheepishly, trying to work my feet loose and she came back for me. A touch of her hand and I was free.

I guess I shouldn't panic about stuff like that. She SURELY would have missed me at some point… hopefully before bedtime.

AUGUST 2, 2009

It's been quite awhile since I've taken a spill. I'd have to do the research to see what day it was the last time I actually fell, but it's been awhile.

Until…

Gail and I were playing with the pooches last night, and we were looking for a particular toy — a rubber bowling pin that gives off a peculiar sound when it's squeezed. I thought it might be under the recliner, so I stood up and tipped the chair forward. I took a step back and…

YIPE!!!

…stepped on Raven's paw.

Startled, I immediately lost my balance. Rather than try to stumble my way towards regaining it and getting hurt even worse in the process, as soon as I realized I was gonna fall no matter what I did, I just did a quick tuck and let my upper back take the brunt of it. See, last time I fell I was in the yard and I ended up staggering several feet trying to get my feet under me before finally toppling. If I did that in my house, I might have gone through a wall or creased my head on the exercise bike or an end table.

I'm fine. My butt was a little sore last night, but it's OK now. Raven, who is remarkably perceptive about such things, felt very bad about what had happened and spent the rest of the evening looking at me very sadly.

Gail said, "I guess we can't call you a 'weeble' anymore."

Weebles wobble, but they don't fall down.

I — it would seem — am no weeble.

AUGUST 7, 2009

I've been experiencing the phenomenon known as "freezing of gait" or "FOG" for a couple months now. For the longest time, I've found it difficult to explain what it feels like when you're walking along and — all of a sudden — you can't take that next step.

I finally hit on it.

Do a little test with me.

Stand up.

Lift your left foot off the ground.

Now… without lowering your left foot, lift your RIGHT foot.

Can't? Of course not.

Imagine BOTH feet feeling like that when you come to a small incline or go from tile to a rug or there's a pattern on the floor or someone suddenly cuts in front of you in a crowd or for whatever reason your brain and legs lose contact with each other.

Now you know.

AUGUST 8, 2009

After going in to the office on Wednesday, I was just exhausted all day Thursday. Unfocused, listless, more difficulty walking. Friday? Not so bad. Of course, I barely walked at all Friday… for lunch, we went through a fast food drive thru. Today? Not too shabby. Gail and I went to the mall, and we left the wheelchair in the trunk. I really do want to push myself as much as I can for as long as I can. So I decided to walk.

I did almost end up kissing the floor at the Chili's when my feet froze up solid at the entrance. See, the floor changed from a LIGHT tile to a DARK tile. My feet were having none of it, but my forward momentum was such that I started tipping over and was saved when Gail grabbed my left hand and held on.

After eating, we went looking for a new pair of shoes for Gail. Crowds are another thing that scares my feet, causing them to stick tight to the floor, so we made our way slowly to the shoe store. I sat on a bench and waited. Then, after she found a pair that she liked, we made our way back to the car. I froze up solid again when we got to the mall exit and the floor changed from tile to rug, and there were PEOPLE coming in through the door. DOUBLE scary. But a couple seconds later, I was free and we got to the car and made it home.

Weird dream again last night. Again, a Navy dream. I was my current age, in the Navy, on a battleship heading for the Philippines. I needed a bathroom and there were lots of 'em with a variety of toilets from the Japanese benjo style to an ultra-modern toilet on a retractable skid that would pull you back behind closing doors so you could poop in privacy. But the floors were filthy and all the toilets were clogged with poop and toilet paper.

I needed new uniforms, but I wasn't sure what rank I was so I had to check with the personnel office on the ship. Then I went to meet the guy I'd be working for, just as we learned a typhoon would be arriving in the Philippines at the same time we did.

The night BEFORE, it wasn't a weird dream that stands out… but the fact that I woke up at 11:11 pm shaking like a leaf on a tree and grasping for the clock radio — which is how I knew what time it was. I laid there for awhile trying to figure out what had just happened, but couldn't. So, I went back to sleep.

Ah, Parkinson's disease. Many and mysterious are your ways!

AUGUST 17, 2009

This feels like one of those days where I am going to have to be especially careful.

(And right now, in my mind, I can hear Gail saying, "You should be especially careful EVERY day." Let's pretend we can't hear her.)

("Typical male thing," Gail says. We'll pretend we didn't hear that, either.)

What was I writing about? Oh. Yeah.

Got up this morning at about 6:20 a.m. Took the dogs out. (It dawns on me the first words I speak out loud on a given day will likely be, "Raven, go potty." This is because Raven — our nearly 5 year old border collie whose birthday is tomorrow… same as Gail's, but Gail is a little older than Raven is… just sayin' is all — will tend to dilly dally around first thing in the morning, smelling grass, looking around, doing her "fierce dog" pose in case anyone is watching…)

Walked into the kitchen to check e-mails and make coffee. Looked to see if there were any new comments on the blog from the previous day.

Went into the bathroom to go potty. (No one has to say a thing to me to make ME go potty. I'm all BUSINESS as far as that daily chore goes…)

Finished my business. Stood up. Turned around. Lost my balance. Fell against the wall.

Boom.

Gail says she heard something, but as it wasn't followed by cursing or screaming — she went back to sleep. Good. Save the emergency reactions for actual emergencies, says I.

Still… I feel exceptionally wobbly today. And these are my choices.

1. Turn off the DBS devices, be immobile, withdrawn, unresponsive and feel like crap. (See the video on the blog's front page. That was after 36 hours without DBS or L-dopa.)

2. Suck it up. Leave the devices on. Take the L-dopa. Be wobbly, but alert, responsive and mobile. Rub some dirt on it, as my father and Peyton Manning would say.

Great choices.

Am I done whining yet?

Yeah, I guess…

AUGUST 24, 2009

Funny, the things you need to consider when you have Parkinson's disease…

I was taking my shower this morning, sitting there on my sturdy little shower seat, when I noticed I didn't get the shower curtain all the way in the tub. There was a growing and spreading puddle of water on the floor.

I called for Gail to see if she could bring an extra couple towels so I could clean the mess… but she couldn't hear me. (Her hearing is starting to slip at the same time my voice is getting softer — really funny there, God!)

I got out of the shower, dried off, dropped the towel on the floor and cleaned it up to the best of my ability. But it dawned on me if she couldn't hear me hollering, how would she know if I had an actual emergency? Other than the vibration she might feel from the "thud" of my hitting the floor, that is.

This afternoon, we're gonna pick up a couple baby monitors — one for the bathroom, the other for the living room.

OK — so far this year, I've gone to using a cane full time, double beds to keep from hurting Gail when I lash out at night, a shower seat to keep me safe in the tub, I've given up driving forever, I work at home because my walking is getting more and more difficult, my balance is that of an 80-year old man, I have a wheelchair for long-distance motivation at the mall and such, and now… a baby monitor.

I suppose diapers will be next?

Damn you Parkinson! And your stinking disease!

AUGUST 27, 2009

Yesterday, as I started soaping up in the shower, I noticed I still had my glasses on.

Last week, I nearly put Listerine on my face after shaving, thinking for a moment it was aftershave.

Practically every night now, I have bizarre vivid dreams and lash out. This is referred to as REM Sleep Behavior Disorder, or RBD.

When I wake up during the night, I often have difficulty figuring out what was the dream and what is reality.

The fog lifts, generally, by the time I waddle into the kitchen to make our morning coffee and let the dogs out. But not always.

If I don't jump up and take my pills the moment my iPhone tells me it's time to do so, I forget if I've taken them. I've solved that problem by putting the day's supply in a shot glass. If they're still IN there, that means I didn't take them.

I had to pay for two months of cable this month because I forgot to pay the bill last month.

Yesterday, I saw a squirrel almost jump in front of our car as Gail was driving. Gail didn't see it. It might not have actually been there.

On Sunday night, Gail was talking to me and I zoned out on her twice causing her to have to raise her voice and say my name to get my attention. I told her I didn't know she was talking to me.

I notice simple mistakes in spelling and grammar and punctuation that I would have never let reach a final product before. (Update – For instance, I first wrote this entry 7 hours ago, and just now noticed I wrote "TBD" instead of "RBD" in the paragraph about my sleep problems.)

I often find myself sitting here, staring at the computer screen, trying to force myself to think.

It's pretty clear to me.

I'm slipping.

AUGUST 28, 2009

Sorry if this seems either mundane or like I'm whining, but I want to keep track of these things as they happen.

Gail drove our neighbor to her job, then she came home, told me what mail we had gotten today, then she went back into our bedroom.

My stepson, T.J., came out of his room and said he was heading out. I told him to have fun, drive carefully and we'll see him later. Then I made a mental note to tell Gail when she got home from taking our neighbor to work, that T.J. had gone out of the night. I thought for a moment about being home alone with the dogs, and decided to stay in my chair and not risk falling and cracking my skull with nobody home to see me do it.

Then Gail came walking down the hallway. And for a moment, I wondered how she could have come home and I didn't notice it…

Then I remembered… I did see her come home. I had just forgotten.

Whee!

AUGUST 20, 2009

Not a great day for me yesterday. Other than being my usual bumbly, stumbly self, the enormity of this whole situation kinda came crashing down on me yesterday afternoon.

It started, as these things generally do, stupidly. Gail was getting irritated with the dogs. Shiloh, in particular. Our 3-year old German Shepherd has been very annoying as of late… making you think she HAS to go OUTSIDE and go POTTY and RIGHT NOW! And then, when you take her out, she pokes around, chases bugs, sniffs the air, stares off into the distance, does everything but go potty and that would be FINE if it weren't so bleeding HOT and

MISERABLE! Gail's scleroderma causes her to have difficulty with heat. My Parkinson's does the same.

So, she hooked Shiloh and Raven — our 5-year old border collie — on their leashes and set them out in the yard… which would be FINE except for the fact that Raven thinks everyone is Osama bin Laden and will bark her foolish head off if someone walks down the street. And if you bring RAVEN in and leave SHILOH out in the yard, then SHILOH will stand on the porch and bark because she doesn't want to be ALONE in the big, scary yard where somebody — perhaps that bin Laden fellow Raven is scared of, might come STEAL her.

So, I decided to slip on my shoes and sit outside with the doggies so I could be there to bring Raven back into the house if she started barking.

Gail, annoyed with Shiloh, objected. She told me it was just too hot for me to sit out there, baking my brains in the sun, just to keep an eye on our neurotic dogs.

She was right, of course. But as I sat on the recliner, I felt this wave of sadness come over me. The realization that, at THIS MOMENT, I am as "able" as I'm ever going to be. Parkinson's is, of course, a progressive disease. It doesn't ever get better. And it's going to get worse. Much worse. And if I'm too frail, too "feeble" to help Gail with the mundane crap NOW, what's it gonna be like when the day comes when I can no longer do the mundane stuff — shower, shave, brush my teeth — for myself?

I know Gail will take excellent care of me when that time comes. That's not the issue. The issue is — I guess — I have this lingering "machismo" about "taking care of my wife, like a man should." And Parkinson's is stealing that from me, bit by bit.

After a considerable bit of feeling sorry for myself, I got up, went into the kitchen, and did something I knew I could do and it made me feel marginally better. I whipped up a tuna-noodle casserole. Got cooked noodles all over the floor, but that's what dogs are for, right? To clean up the spills of a Parky cook?

I'll be OK.

SEPTEMBER 2, 2009

Inasmuch as I generally need an excuse to get out of the house at least once a day, as we generally do on weekdays, Gail and I took a drive up to the grocery store to get a bite of lunch. I'm not having the best of days today — my leg and hand and foot muscles have been cramping (as has my right butt muscle — but try not to think about that too much).

Some days are worse than others with Parkinson's disease. Today, I'm freezing more than usual, and I almost toppled over walking into the store when I tried to get my left foot unstuck from the pavement by rocking back and forth. Then, getting back into the car, I turned to sit on the passenger seat. I can't just raise a leg and climb in like I used to… I need to turn so my back is facing the inside of the car, bend my knees, sit, and then rotate and bring my feet into the car. This time, my knees would just not bend to allow me to sit. I stood there, wobbling, trying not to fall forwards or backwards. Gail came around and took my hand. I unfroze and sat.

Anyway, on a wobbly day, a few close calls, but no falls.

Until…

The car pulled into our driveway. I rotated my body, put my feet on the pavement and stood up. I started leaning to my right. Ordinarily I would just thrust out my cane to stop the lean, but my right arm didn't answer the signal and I began to slide to the ground. I leaned back onto the body of the car so I could slide rather than just drop to the rough pavement and I grabbed the car's frame through the open door and held on. I looked to see if Gail was watching. She was walking around towards the back of the car and hadn't seen me yet.

"Uh, Gail?"

She turned and saw me through the car's windows. My right hip plastered against the car's body, my left hand clutching onto the door frame for dear life, my cane having skittered uselessly under the car.

She came to help, and I realized it would be easier to just use the car's body to control my descent the rest of the way to the pavement, then I could roll over onto my knees and get up without my wife of nearly 20 years having to tear every muscle in her lower back trying to lift me from where I was currently dangling.

I assured her it was a “controlled descent” and that I was fine. She gave me her arm to hold onto, and eventually — slowly — haltingly — I made it back into the house.

Then I ate some chicken and had a chocolate milk.

How’s YOUR day been so far?

SEPTEMBER 8, 2009

One of the nice things about living in such a small space — when I find myself starting to tip over, there’s usually something nearby to grab and keep myself from falling. A door frame. A wall. The arm of a nearby chair.

Parkinson’s disease has stolen the corners from my butt. When I’m in the car with Gail, I generally find myself slouching towards her. In my office chair, if I lean too far to one side or try to touch or pick up something from the floor, I feel like I’m gonna roll right out of the chair. Same in the recliner.

Even now, I feel like I’m hunched over the keyboard, stoop-shouldered as I type.

My left shoulder still aches from my almost-fall in the driveway last week.

Seems like only a matter of time before I take a serious spill and hurt myself.

My leg muscles are shrinking. My biceps and forearms are getting skinnier and I have flaps of saggy skin where triceps used to be. The backs of my legs look like half-empty laundry bags. When I try to stand still, I wobble. When I walk, I hesitate, freeze and festinate.

And did I mention that I kicked the bedroom wall next to my bed last night?

Oh, yeah. We’re having some fun now!

SEPTEMBER 10, 2009

I got this mailing from my friends at the Neurology Department at Vanderbilt University Medical Center a couple weeks ago. It was another revision in the standard consent form they keep on file for the clinical trial in which I'm involved — a Phase I trial of deep brain stimulation in early Parkinson's disease.

If I remember correctly, there have been a couple of these since I joined the trial in 2007. Pretty routine stuff — look it over, sign it if you agree, mail it back. So I didn't really rush to deal with the one I got a couple weeks ago.

Today, Gail is having a house dusting extravaganza. Anything not moving WILL be dusted! Anything not where it is supposed to be WILL be put WHERE it is supposed to be. One such item was the large manila envelope with the consent form update. So, I decided to take a look at it — finally.

Here's the update: (emphasis added)

"The following sentence was added: 'It is also possible that the use of DBS in early stage PD **may speed up progression of the disease** and may make you ineligible in the future for the FDA-approved DBS for advanced PD."

Um… OK.

I'm thinking that there must be a reason at this late date for adding that to the consent form. I'm wondering if I am not the only one of the 15 out of 30 people who had the surgery who is having a sudden downturn in symptoms. No way to know for sure until the study is published, since it would violate patient confidentiality to share that info.

The logical question is, would I have consented to taking part in the clinical trial if that part had been in the original consent.

Yes. I would have. And here's why.

If it turns out that doing DBS in early stage PD doesn't slow the progression of the disease (as was and is hoped), and — instead — speeds UP the progress of the disease… there's only one way to KNOW that… and that's to DO THE SURGERY!

And the only way to know whether or not DBS surgery is safe or effective in early stage PD is to have DONE the surgery on a few willing volunteers and then measuring their progress.

I'm only in sporadic contact with a couple fellas who are in the clinical trial. One was in the control group, meaning he did not HAVE the surgery. The other one, who DID have the surgery — last I heard he was doing very well.

So. This is just something else to think about, something to discuss with my neurologist when I see him next month

Having the surgery did NOT give me Parkinson's. If the DBS surgery DID speed up my disease progression, which no one is saying it did, then what the hell… I would have eventually reached this point ANYWAY.

You gotta break a few eggs to make an omelet. And I am still very happy to have been part of this clinical trial, no matter how it turns out.

SEPTEMBER 12, 2009

Right before 2 am this morning, I woke up to "the leg cramp from hell."

I've been troubled with these things on and off since earlier this year. At first, I thought I just needed more potassium in my diet. But now it's clear what's going on.

There is a demon in my right calf. It wakes up at night and torments me.

I think the demon (which I shall name "Chtulu the Cramper") dwells mostly in the peroneus longus muscle. During the day, he fidgets and twitches. But during the night, he comes alive in a hellish torrent of ouchiness.

Generally, the demon attacks when I mindlessly extend my right leg when rolling over in bed or while trying to reposition my top sheet and blanket. He comes on like gangbusters, creating a golf ball-sized lump on the lateral side of my shin. Usually he attacks once or twice a night. Recently he came and went six or seven times over the course of the night.

Last night he manifested himself for nearly a half hour.

I tried everything I could think of to drive the demon into submission. Pulling my toes toward my shin. Rotating my ankle. Bending my knee. Sitting up on the edge of the bed. All to no avail!

Oh, the DOGS were happy about it, having daddy sitting up on the edge of the bed at 2 in the morning could only mean GOOD things as far as THEY were concerned. Gail had just gotten back into bed after taking them out for their middle of the night lawn watering, and they were awake and ready to PLAY. But I was in no mood.

Raven jumped onto my mattress in the mistaken belief that having a warm dog lie next to the cramping muscle would help somehow. (Maybe it would, if she weren't inclined to lay there and PANT for a half hour before going to sleep, making my bed jostle and bounce like a sleeper car on a railroad train…) I appreciated her effort, but it was up to ME to silence the demon.

I rubbed. I flexed. I twisted. I got up and walked around a little.

And that quieted the demon. For awhile.

He's asleep now. Every few moments I can feel a twitch in the painful muscle as Chtulu the Cramper dreams of causing me further pain later tonight.

I wonder if self-amputation is an option.

Damn you, Parkinson! AND your disease!

(During the intervening time between the prior entry and the next one, my sister Cindi's condition worsened. It was hard to blog about my emotions at the thought of losing the third of my seven siblings – my twin brother died of a stroke in 2004, my older brother died from cancer in 2008, and now Cindi was fading. She died on November 4, 2009. I spent a week with my mom and my two remaining sisters in Milwaukee while my little brother Joe represented our family at the memorial in New Mexico. Soon, I felt up to the task of blogging again.)

NOVEMBER 21, 2009

I fell in the bedroom when I was getting up this morning.

Actually, it was more like I slid from the bed to the floor.

I woke up after a particularly crampy night and noticed Gail and Raven were already up. So I figgered I'd get up and get the cappuccino going. So, with some difficulty, I managed to swing my legs over to the left side of the bed and sit up. I put my hands by my side, grabbed the mattress to use them to push myself to a standing position, when...

Whoopsie Daisy!

My arms wouldn't support my weight and I slid to the floor.

For a few seconds, I laid there, my hiney on the floor, my upper back and neck braced against the mattress. I thought about calling Gail, but after realizing that I wasn't hurt, I figgered I could just slide the rest of the way to the floor, roll over, get on my hands and knees and get to my feet. Which I did.

Maybe it's time to start thinking about bed rails?

DECEMBER 1, 2009

Had another of those little uncomfortable moments today, much like one I had when I was at the store recently with Gail and I froze up -- mentally and physically.

I had just downloaded a series of sound files from a colleague of mine and wanted to go from my work server to my home server to piece them into a single podcast.

Suddenly, I had no idea what I was doing. I knew who I was, I knew where I was, I knew what my computer was, but the icons on the desktop suddenly made no sense to me. I couldn't even look at them without feeling frustrated. It was like, I knew what I wanted to do, but it was just on the other side of a thin sheet of drywall and if I could just break through that wall, I could get the info I was looking for.

I expressed my frustration to Gail as verbally as I could, then forced myself to look at the desktop on my computer again. After a few seconds, the icons made sense again, I realized which folder I needed and remembered just what it was I wanted to do.

I'm used to my body screwing up. I am NOT used to my mind doing this to me.

DECEMBER 7, 2009

Taking a sick day. Here's why. (And be warned... this post makes reference to bodily functions. If that kind of thing repels you, stop after the next paragraph.)

First thing, I've been getting kinda sloppy with "putting the caps back on things." The other day, a whole bottle of rum flavoring extract. It spilled. This morning, I made Gail's coffee and didn't put down the cap on her creamer. When she went for her second cup and shook the container of creamer -- the dogs had a delightful mess on the floor to lick up.

Then... (and here's where you should stop as forewarned).

I went to take my shower. As usual before a shower, I decided to go potty. It was a great success. I did the "post potty paperwork" and stood up to take some ibuprofen, cuz I woke up feeling headachey and head-cloudy today. I looked at my right hand and wondered, "Are those coffee grounds?" A quick sniff showed that they were NOT coffee grounds. So I washed my hands thoroughly and got the shower water running.

I sat down on my shower seat. Then I realized I had forgotten to take down the shower nozzle (we have one of those shower nozzle on a hose kind of things). It was impossible to reach from my seated position, so I stood up -- and instantly realized there was something amiss.

I turned around and looked at the shower seat. And there it was. A small dookie! Sitting there, mocking me... like a profane Hershey's Kiss.

So, I hosed down the shower seat, I hosed down myself, I finished off the rest of my shower, I shaved my cheeks and neck taking special care not to slash my own throat in the process. I got dressed, and sent my boss a note saying I'm taking the day off.

The only thing I feel capable of doing right now is staring at the wall. Maybe the TV, if there's something not-too-involved that requires a lot of thinking I can watch.

Fuck Parkinson's.

DECEMBER 8, 2009

Yeah, today is a much better day -- so far. Actually as the day went on yesterday, I got better and better.

I'm still feeling kinda logy and disconnected, but nowhere near as lobotomized as I did yesterday morning. I was able to perform my basic morning tasks with no real difficulties, except for a brief moment when I first got out of bed and relied on my walker to save me from painting the floor with my face.

I am noticing deficits, however. In the first paragraph of this post, for instance, I had to sit for a moment and try to remember how to spell the word "actually." Stuff like that used to come automatically. Now I have to sit and think about them.

I know I'm nothing special. Studies show that 70 to 80 percent of folks with Parkinson's disease show signs of dementia 10 years into their diagnoses. January 30 will make 10 years for me. The fact that I can still be a productive person and make a good income is a real source of pride for me -- especially since most Parkies hang up their spurs 3-4 years after diagnosis -- and I still plan to keep chugging along as long as I am able.

So there.

DECEMBER 9, 2009

I swear, my brain is turning into a soft pudding.

Some time ago, I set my iPhone to alert me when it's time to take a pill. Now, unless I get up IMMEDIATELY and take the pill when the alarm goes off, I forget.

Yesterday, I blew off two pills. I was sitting here at my keyboard, my iPhone alarm went off, I turned it off and instantly forgot. I've been doing that a lot lately.

I remember to take my pills when I get up in the morning cuz it's part of the routine. Check e-mails, take pills, make coffee. I remember to take my nite-nite pill, cuz it's nite-nite time. But my 11 and 4 pills? There isn't any other action associated with taking them, so I have to jump up from what I'm doing and take them, or I forget until I either start wondering why I'm so stiff, or it dawns on me that an hour or so has passed and I didn't take them.

This is one of the reasons why I got one of those daily pill compartment things. I load it up with the number of pills I need to take each day. That way, if I think I may have forgotten to take one, all I have to do is count. Like right now, I should have no levodopa/carbidopa pills in the Wednesday bin. Which I don't cuz I just took the last one... an hour late.

I think it's my brain...

JANUARY 6, 2010

One of the more charming things about having Parkinson's disease at this stage is how SLOW I am. Being a large individual, I imagine watching me walk from Point A to Point B is something like watching a huge, lumbering ship make its slow way through the Panama Canal. Whether I'm using my walker or my cane, I'm a slow and unsteady traveler.

Gail and I have joked about this very thing. She's suggested that I get one of those "slow moving vehicle" symbols and hang it from the back of my belt. I countered with a suggestion that I should put a "This Vehicle Makes Frequent and Sudden Stops" sticker over the back of my pants.

Gail is a godsend. She walks -- slowly -- by my side. When I use my walker, she's there to steady me if I begin to list to the port or starboard. When I'm using my cane, she gives me her right arm as we walk to steady me. I've lost count of how many times I would have fallen if Gail weren't there to grab me before reaching the tipping point.

Still, I can't expect the REST of the world to slow down to my pace.

On my birthday Monday, Gail and I went to a nice restaurant. The hostess greeted us and showed us to our table. Off she went, at what I believe was probably a normal rate of speed. I was using my cane, Gail had my left arm as I took slow, careful steps -- freezing once when I came to a downward slope in the floor, regaining my slow, unsteady pace as the hostess reached our table, turned around and wondered where the hell WE were. This happens a lot at restaurants.

Yesterday at my doctor's office, the medical assistant called my name and held the door as I ambled toward it. I cautioned her that I was a bit on the slow side (which is like saying Bill Gates is sort of "well to do") and she assured me that was fine. She got my height and weight and scooted down the hallway towards the doctor's office. I froze up once trying to get through the door to the hallway, almost lost my balance in the hall, and eventually made it to where the assistant was standing, by an open door -- bless her heart -- she smiled at the poor old man and his slow, slow gait!

These are both benign incidents. They are perfectly understandable. I certainly do not expect the world to slow down just because I have.

The thing that makes me want to climb a tall tower with a high powered rifle is the people who are in such a hurry that they either roll their eyes when they try to get past me at the mall, who cut in front of me and cause me to freeze up, or -- as happened on Christmas Eve, yet -- actually BUMP INTO ME and then keep walking while Gail and I try to keep my fat ass from falling into a row of mannequins.

Most people, I've observed, are very nice and respectful of a person with obvious disabilities. Thank goodness we have the jerks out there to keep my cynical streak alive!

JANUARY 9, 2010

I‘m getting to the point where I like my routine. And I generally look unkindly on those who would mess with it.

My general practitioner, for instance. Oh, it’s not his fault. He had no way of knowing that I had a set routine for taking my pills in the morning. Nor do I blame “Big Pharma.” It’s not THEIR fault that I had a set routine for taking my pills in the morning.

When I visited my GP on the 5th, he upped my Sertraline from 50 to 100mg and my Metoprolol from 50 to 100mg.

Fine.

But until now, it was EASIER to take my pills in the morning, cuz I had the COLORS memorized.

For instance, instead of a generic Sinemet (25/100), Metoprolol, Lisinopril, Sertraline and Prilosec…

"A yellow, a pink, a white, a blue — and a Prilosec."

Now that system has been messed up.

My new Metoprolol is WHITE! Like my LISINOPRIL! Sure, it's a little bigger and scored for breaking, but STILL! The feng shui is off!

And my new Sertraline? It used to be BLUE? Uh-uh! Now it's TAN!!!

My colorful little morning candy dish is now a bland assortment of Earth tones.

Damn you, Parkinson! AND the progressive nature of your disease!

Grrrrr….

JANUARY 11, 2009

As I write this, it's 31 degrees outside. That's about as warm as it's been this year so far. It's been cold and windy and not much fun for someone who hates the cold to be stuck outside.

Unfortunately, walking with me these days means getting stuck. Outside.

Gail and I just got back from the store where we bought some lunch. Because of our uneven sidewalk, I always tend to freeze up when walking to the car. (Thank goodness for Gail and my walker -- they keep me from falling.) When we got to the store, I found myself freezing up every few steps.

I try not to even think about the terrain. I try to make each step as automatic as possible. And it works, too! For about 5 or six strides. Then, I go to raise my foot for the next step and... nothing. Same for the other foot. I'm generally able to unstick myself by letting the walker roll forward just a little bit, and then I can follow it.

But on a windy, freezing late morning in a grocery store parking lot... freezing of gait also means freezing of mate! (I almost wrote Freezing of Gait means Freezing of Gail... but I think I like the previous version better. How about you?)

It's OK when I freeze up in the store. We're inside. It's warm. But to and from the car as the winter winds blow and howl (and sometimes, it's the wind itself that makes me freeze up...), it's frustrating on several levels. One, I know my wife hates the cold even more than I do. And she waits, patiently, for me to unstick myself. I would tell her to go on ahead and get into the car, but I know she wouldn't do that. She has this idea that she can stop me if I fall... which is true if she catches me just as I start to tilt (which I did, going into the store and we hit an upslope and I leaned backwards and my walker started to roll backwards -- but I was able to grab a cement post to steady myself). Many is the time when I've frozen up, started to tilt one way or the other and Gail has braced herself against me to stop the fall. God, how I love her.

Anyhoo...

It's all part of the colorful tapestry that is Parkinson's disease. Along with tripping over dogs, having trouble getting out of bed in the morning (and I mean that PHYSICALLY, not cuz I'm tired), the hassle of trying to roll over in bed, missing the car seat with my butt when I try to sit down, bumping into the wall in a narrow passage, needing an alarm to remind me to take my pills throughout the day, needing help to get out of a chair, having to sit while taking a shower, not being able to close my eyes while standing cuz I'll fall, being careful not to tilt my head too far backwards when taking a drink cuz I'll lose my balance, having to take little steppy steps to turn around instead of just pivoting, not being able to back up without falling, inhaling little hunks of food into my windpipe, having a runny nose all damn day, zoning out at the computer when I'm supposed to be working, forgetting what the hell it was that I was just about to do, having the "stares" (one reason why I stopped driving -- I will focus on something outside and STARE at it until I realize I'm doing it and stop myself) and my general stumblebummery.

But hey... it's nice and warm in the house! And lunch was good.

JANUARY 17, 2010

Parkinson's disease is a capricious bitch. Some days, you feel pretty good. Just can't seem to get my po' haid together this morning!

Sitting here, browsing the web. Find myself staring blankly at the screen. I pull my eyes away from the screen, and find myself staring at some doo-dads in top of the cabinet next to my desk. Even now, as I edit this entry, I find myself staring at individual words. Sitting here. Unmoving.

Blank.

It was a rough night. Very crampy. Woke up at 4 am and just couldn't get back into a deep sleep. Sorta drifted in and out until I pulled myself out at 7. Had to use my walker to get into a sitting position before I could even get out of bed.

Moving very slowly, both mentally and physically this morning. We're gonna head out to the store soon so Gail can get the fixin's for some Chicken Soup.

Maybe THAT'LL fix everything!

JANUARY 21, 2010

I must admit that, being new to this later stage of Parkinsonism, almost every day brings a new surprise. Like waking up in the morning with something hurting and having no idea what you did to hurt it. Taking your shower and seeing a scratch on your leg and not remembering when or how you got scratched. Looking in the mirror and seeing a scratch or a bruise on my head, having no idea who's beating me in my sleep. Having an ankle that's so sore it's hard to walk on it, but you don't recall having done anything to hurt it. There was one famous incident last Valentine's Day weekend when we were at a hotel and I left blood on the sheets and in a trail to and from the bathroom because I had somehow cut myself on the back of one of my heels.

This morning, it's my chest. Actually my ribs, right below the pectorals. More on the right than on the left. I feel like I've either been lifting weights or doing pushups in my sleep. Which, if I had, would be a good thing because medical experts agree that exercise is beneficial for those of us with Parkinson's disease. But I would think that if I were engaged in such strenuous exercise during my sleepy-time hours, I would have disturbed my wife and my dogs would have wanted to participate.

So, knowing that I did NOT do pushups or lift weights in my sleep, I'm left to wonder just what the hell I did that made the right side of my chest feel like I had been exercising past the point of all prudence.

Oh. And my ankle hurts, too, if anyone cares. :(

LATER THAT DAY

Gail and I just got back from our near-daily trip to the grocery store. I was standing there, leaning on my walker, deciding which frozen pizza I wanted to get. I made my selection and opened the freezer door, to hear a young voice behind me...

"Mommmmm! I can't GET a pizza! That MAN is in everyone's WAY!"

I turned and looked, and there was Little Timmy Asshole! So, I put my pizza on the seat of my walker and rolled away. That's when I heard Timmy's mom, Mrs. Asshole, speak.

"It's OK, honey. He's gone now."

I turned and glared at them, then just rolled away because I know that if I beat their skulls into a mushy pulp with a frozen ham and then hid their bodies in the freezer, it would be ME who went to prison.

Such is the state of fairness in America today.

JANUARY 24, 2010

One question I hear a lot from my beloved... usually when I'm seated in my recliner and my 1000-yard stare is focused on the TV and I haven't moved or blinked in awhile...

"Are you OK?"

I snap to attention and smile. "Sure. Just having a bad face day. Feeling Parky!"

She knows what that means.

To the uninitiated, the blank, expressionless, sometimes pissed-off looking face of a Parkinson's patient is mistaken for something else... like "The Lights Being On, but Nobody's Home."

In truth, it's more like "The Lights are All Out, but EVERYBODY's Home."

When I sit, staring what the experts call a "reptilian stare," that doesn't mean my mind isn't going a mile a minute or that I'm not in a good mood. A masked expression is usually one of the earliest symptoms of Parkinson's. It gets worse as time goes on, as shown by recent pictures of Muhammad Ali and later pictures of Pope John Paul II.

Here's the official explanation:

One way that we express emotion is via facial expression. Facial expression of emotion is made possible by the working of complex muscle groups in the face. In some people with Parkinson's disease, these facial muscles no longer work properly, and so facial expression of emotion is more difficult. The person's face is not as expressive as it once was and sometimes resembles a mask.

So, when you see me, and I'm just sitting there with that 1000-yard stare and I'm not moving or blinking or smiling or showing any emotion whatsoever... worry not.

I'm just having a bad face day.

JANUARY 26, 2010

Hmm. I finagled a free download trial version of the CNS Vital Signs neurocognition test battery. Gave myself a patient name, tested myself, and here's what we came up with.

In the verbal memory test, the computer screen shows 15 words that you have to memorize. Then, it shows a longer string of words and you have to hit the space bar when you see a word that was on the original list. Then, later in the test, they show another long string of words and -- once again -- you have to hit the space bar if you see a word you recall from the original list.

In the visual memory test, they show 15 different abstract symbols. Like the verbal memory test, you have to memorize the original symbols. Then they show a longer list of symbols and you have to hit the space bar if you see a symbol that was on the original list of 15. Later in the test, you repeat the process.

In the finger tapping test, you tap the keyboard with your right index finger, then your left index finger, as fast as you can for 20 seconds. (I scored 50 on the right [18th percentile] and 53 on the left [40th percentile].)

In "Symbol Digit-Coding" you see a line of symbols, each with a number under it. Then you get a row of symbols, and you have to match the symbol with the number.

In the Stroop Test, first you tap the keyboard when you see a color, spelled out as a black word -- BLUE, GREEN, etc. Then, you have to tap the keyboard when the COLOR of the word MATCHES the word... a blue BLUE, a green GREEN, a red RED, etc. Then, you have to tap the keyboard when the color of the word does NOT match the word... a green YELLOW, a blue RED, a yellow BLUE, etc.

In the Shifting Attention test, you see red or blue circle or square at the top of the screen, and a circle and square -- one red, the other blue -- at the bottom of the screen. If the computer tells you "Match Shape" you tap either the right or left shift key, under the correct shape. If the computer tells you "Match Color," you tap either the right or left shift key under the shape with the correct color.

In the Continuous Performance Test, you're shown a single letter, one letter at a time, two seconds each for 5 minutes. You press the space bar whenever you see the letter "B".

Afterwards, you see the results.

The Neurocognition Index (NCI) - An average of the five neurocognitive domains and a general assessment of the overall neurocognitive status of the patient. I scored "100" which put me at the 50th percentile for my age group.

They combine the Verbal Memory (which I scored a woeful "41" which put me in the 1st percentile [very low] and the Visual Memory, (in which I scored a slightly less miserable "38" which put me in the 7th percentile [low]) to come up with a Composite Memory score of 79, which places me in the 1st percentile (very low). Yaaaaay for my BRAIN!!!

In Processing Speed, I wound up with a score of 40, which put me in the 13th percentile (low).

My Psychomotor Speed, indicating problems with slowed information processing (i.e., perceiving, attending/responding to incoming information , motor speed, fine motor coordination, and visual-perceptual ability -- I scored a 146, which puts me in the 18th percentile (low average).

Everywhere else, I did pretty good.

Executive Function, which refers to the capacity for autonomous behavior beyond the structure of external guidance. In clinical terms, this refers to initiative, motivation, spontaneity, planning, judgment, insight, goal-directed behavior, the ability to operate in favor of a remote or an abstract reward, the capacity for self-monitoring, and the flexibility required for self-correction --I scored a 63, which put me in the 95th percentile (above average).

Reaction Time -- scored a 576 which put me in the 84th percentile (above average).

Complex Attention, which refers to attending to multiple stimuli at the same time. Ability to maintain focus, track information over brief or lengthy periods of time, performs mental tasks quickly and accurately -- I scored a 3, which put me in the 79th percentile (above average).

Cognitive Flexibility, which refers to shifting attention between two stimuli. Ability to adapt to rapidly changing directions and/or to manipulate the information, I scored a 63, which places me in the 96th percentile.

So, my Executive Functioning, Attention, Reaction Time and Cognitive Flexibility are doing great.

My Processing Speed and Psychomotor Speed are low average.

My Visual Memory is below average, my Verbal Memory is WAY below average, totaling in a Composite Memory Score of WAY below average.

So I can still figure things out, but it takes awhile to process the info, and then I'll forget about it.

What were we talking about again?

Where are my keys?

Did someone say "cake"?

JANUARY 30, 2010

It was 10 years ago, January 30, 2000. I was driving on Alligator Alley from Miami to Naples, Florida, trying to let it all sink in.

A doctor -- a preeminent one in the world of movement disorders -- had just diagnosed me with Parkinson's disease. He put his hand on my shoulder and said, "It's not a death sentence, it's a life sentence." He gave me a sampler pack of Mirapex and a prescription for more when I got home.

My eyes focused on the road, I couldn't even hear the music on the radio.

"Parkinson's disease. Well, it's official."

We had expected this would be the diagnosis. From that day in November when a neurologist at a Naples hospital told me the tests showed no tumor, no stroke, but the way I walked and reacted to other tests indicated PD, we were pretty sure this would be the result.

Still. Now it was official.

The doctor who broke the news explained that it was very early in the disease process, and that I likely had a number of "good years" ahead of me. How many? "No way to say for sure. It's different for everyone."

As the Everglades whizzed by on the left and right of the car, I did a survey of my current symptoms. The cramping, the dropping of stuff with my right hand, the occasional difficulty finding the right word. I tried to think ahead, wondering what the future would be like for me. Surely they'd find a cure for this thing by the time I would be disabled by it, right? I mean, all this new stuff with embryonic stem cell research and all... whoever wins the 2000 election will SURELY allow federal funding to continue and they'll HAVE to have a cure for this thing five years from now, ten at the outside...

Well...

Ten years. And the science has advanced. Not as far as it might have, given President Bush's bowing to superstition and the eight years we wasted by not funding ESCR. But there's been Deep Brain Stimulation, which I had in 2007. It only affects the areas that are also helped by levodopa/carbidopa, so it does nothing for my gait or balance, or the onset of dementia that I feel is beginning to insidiously creep into my frontal lobes... But as I said in an article in the July 2009 US News and World Report Online, I have no way of knowing how much worse I'd be if I did NOT have the DBS.

Ten years. Zipping across Alligator Alley, Parkinson's was a concept. A thing I knew that I had. But I had no idea.

No idea.

Ten years. Now I can't walk outside without a walker or a cane and my wife's hand to hold onto. I can't close my eyes when I kiss her because I'll fall backwards if I do. I have to take tiny, baby steps or I'll lose my balance. My libido is gone, we have to sleep in separate beds because of the REM Sleep Disorder that comes with PD, my face shows little to no emotion, my voice is getting breathy and hoarse and when I DO talk, I have to sometimes stumble and fumble my way through a sentence, going back to correctly pronounce words, and ensure I'm making sense. I can no longer drive the car, I'm having problems swallowing food, my nose runs like a faucet from the moment I get up until the moment I go to bed, I have to sit down to take a shower, I've had "accidents" in the realm of "continence", it's difficult to focus on work or anything else, I get the "stares", I'm repeating myself a lot, I freeze when I walk, and my chest is congested nearly every evening.

Sorta makes a feller wonder what the NEXT ten years is gonna be like.

FEBRUARY 1, 2010

Parkinson's disease, thou art a WHIMSICAL affliction!

Having a particularly Parky morning... if I didn't push myself, I would be completely satisfied to sit here, staring at the computer screen, motionless, listening to blues on Music Choice on the cable. But that ain't what they pay me the big bucks for, so I manage to force myself to log into my work e-mail account and update the press log to reflect some activity over the weekend.

I force myself out of my chair and make my slow, halting way into the living room to get my slippers. Gail volunteered to get them for me, but I told her no because "I have to push myself."

Got the slippers, turned to walk back to the kitchen and get back to work. My left foot was more than happy to comply. My right foot stuck to the floor. I managed to keep from falling. This is nothing new.

I noticed Gail looking at me with concern. I said, "Here in the house, that's how I come close to falling. I'll start to walk, one foot will move and... and... and... and..."

I forced my mouth shut and closed my eyes so I would stop saying the word "and."

"And the other foot gets stuck?" Gail added helpfully.

I felt flush. I got STUCK on a WORD! I knew full well what I WANTED to say, but like an old fashioned record in an old fashioned record player, the needle in my brain got stuck in the groove of my language center.

I looked it up on my NIH-linked computer. It's called "palilalia." It's a subset of "bradykinesia" -- or slowness of movement in Parkinson's disease.

Speech and swallowing may be affected. The speech may be slightly softer, muffled, and less distinct. In more severe disease, the speech is rapid, monotonous, and slurred. Palilalia, repeating the initial syllable of a word similar to stuttering, also can occur in patients with more advanced disease and can be a side effect of medications. Sialorrhea and dysphagia are common problems in patients with more advanced disease.

Swell. I am feeling slightly drooly this morning (dabbing at the corners of my mouth with a napkin to contain the overflow) -- no trouble swallowing yet today, but I am clearing my throat a lot and my voice is thin, hoarse and scratchy.

Oh, Parkinson's! How I DESPISE thee!

UPDATE: Seems like "palilalia" might be too specific -- what happened this morning seems to fall more neatly into the category of "repetitive speech phenomenon". According to an article in the National Library of Medicine:

In idiopathic Parkinson's disease repetitive speech phenomena seem to emerge predominantly in a subgroup of patients with advanced disease impairment; manifest dementia is not a necessary prerequisite. They seem to represent a deficit of motor speech control; however, linguistic factors may also contribute to their generation. It is suggested that repetitions of speech in Parkinson's disease represent a distinctive speech disorder, which is caused by changes related to the progression of Parkinson's disease.

So, there.

FEBRUARY 1, 2010

Gail and I have talked this over many times. Can you imagine the world of hurt we would be in now if I still worked live radio? For one thing, except for XM Satellite Radio, I've never worked for a radio company that had a decent insurance plan. I would be a "pre-existing condition" -- even if I could AFFORD the insurance.

And now, when it's become difficult for me to come up with an understandable sentence off the top of my head while speaking, I can't imagine being able to hold down a live airshift.

My boss just called with a simple question. I knew exactly how I wanted to answer her. But for the first few seconds, all I could do was "abba dabba dabba homina homina homina ha ha ha!"

Once I closed my eyes and concentrated, I was able to answer her. I just sent her a note explaining why I sounded like such a moron on the phone.

But at least I can still write goodly...

FEBRUARY 2, 2010

Ak! Ak! Ak! Ak! Ak!

My speech problems continue for another day. Last night as Gail left the bedroom to use the facilities, I meant to ask her if she wanted me to turn on the bedside lamp. What I said was...

"Would you like me to turn the... the... the... the..."

I pointed at the lamp and Gail said, "No." Thank goodness, or else I'd probably STILL be saying the word "the."

So far, I'm noticing that the problems fall into a couple different realms.

1. When I talk casually, I'll start to say a word -- but begin it with the wrong syllable. For instance, instead of saying, "It's getting

dark outside..." I'll say, "It's getting nark...." and then I freeze up, close my eyes, concentrate on what I want to say... and then say it.

2. Also when speaking casually, I'll run words together until it's all garbled. I sound like Popeye. When this happens, I have to close my eyes, take a deep breath, and say the words I want to say with definite breaks between each word.

3. When under pressure to say something, I tend to just freeze up. It would be FINE if I just stayed silent, but I start making babbling noises with the "aaaaah" and the "errrrrrr" and the "uuuuhhhhh" and I sound like a moron. When this happens now, I force myself to shut up, then say "I'm trying to think of the right word."

So, what to do? Well, other than being breathy and hoarse, I'm not really having trouble with volume (hypophonia). It just seems like I've picked up a stutter (neurogenic stutter) in my old age.

Gail says we can make a little extra money by taking me on tour to do Popeye impressions. She LOVES me!

FEBRUARY 3, 2010

I may as well stop complaining about it. Seems like my Parkinson's disease-related vocal difficulties are here to stay.

After Gail took the photos that you can see in a previous entry from today, she asked if I could print one out so she could frame it.

"I'll see if we have any pho... pho... pho... pho... (shut my eyes, take a breath, concentrate) photographic paper."

There's been other examples throughout yesterday and today. Just now, Shiloh -- our neurotic German shepherd -- was nosing my elbow as if she needed to "use the yard." I went back to the other office where Gail was browsing the web and asked how long it's been since the animals have been outside.

"I just brought them in," she said. "I guess I could just hang Shiloh out on her cable for awhile."

"Tha... tha... that... tha... (close eyes, concentrate) That. Would. Be. A. Good. Idea."

I guess this is just something I'm going to have to get used to.

That's all, folks!

FEBRUARY 6, 2010

My wife and stepson have been out in the snow now for nearly two hours... taking breaks to come in and warm up a bit. I've been sitting here in my PJ's, making coffee, keeping an eye on the dogs, acting like the stereotypical frontier woman while her men do the dangerous chores outside.

It's been awhile since I could do any heavy snow shoveling. Until a year ago, I was able, at least, to help keep the porch clear and pitch in on the sidewalks and driveways.

This year, I am useless.

So, I do what I can do. I'll cook. I'll keep the cappuccino flowing as need be.

Maybe I'll make a quilt.

Damn you Parkinson! AND your disease!

FEBRUARY 7, 2010

The other night, my wife and I were conversing over one thing or another and I kicked into my newly found Parkinson's stutter.

Gail said, "I'm going to have to start calling you Elmer."

"Elmer? Why?"

"Isn't he the cartoon character who stutters?"

"No," I said. "You're thinking of Porky Pig."

"Oh, that's right," she said.

"Yeah, Elmer has problems with his "L" and "R" sounds. I don't have that problem."

"Not yet," she said without even looking at me.

My wife. She woves me vewy, vewy much!

FEBRUARY 10, 2010

Snowpocalypse II is underway. In about 2 hours, we officially slide into a Blizzard Warning. (That's when the wolves come out!) TJ is home from work. The Government is closed for the third day in a row. I had trouble hauling my butt out of the bed this morning (literally) and my left ankle feels like it's sprained... and I have no idea how it happened!

My Achilles tendon was feeling a bit tender last night where it hooks up to the heel bone. I woke up during the night, and my whole ankle was hurting. I couldn't find a comfortable position. After Gail got up to take the dogs out, I tried to haul myself out of the sack so I could at least help out by making coffee.

I was able to get to the edge of the bed and sit. I pulled my walker close to me. Now, usually, it's a combination of leg power and arm power that gets me out of the bed in the morning. But with my sore ankle, it was hard to put much weight on it, and I CERTAINLY did not have the arm strength to pull myself to a standing position without help from the legs.

I tried and tried, and I sat and sat. I contemplated calling for Gail, but decided against it. Finally, I got the foot that DOESN'T hurt under me just right and push/pulled myself into an upright position.

Now, a few hours later, after my meds and a dose of ibuprofen, things are better. TJ and Gail are fighting the storm and taking the dogs out when they need it. I'm sitting like a lump in front of the computer.

A big, Parkinsonian lump whose ankle hurts.

FEBRUARY 13, 2010

If the snow don't get ya, the Parkinson's Disease Dysphagia MIGHT!

The snowpocalypse is officially over! Just got back from the mall. Gail got a nice new set of glasses and sunglasses, which she will be able to pick up in 10 days because they have to order her lenses.

Then we went and got some lunch at Remomo's and had a long talk about my condition after I nearly choked on a piece of fried mozzarella. I seem to be developing what the doctors call "dysphagia" -- difficulty swallowing. It's worse with liquids, but this afternoon, I bit off a hunk of the mozzarella and part of it went down my esophagus and a small part, dangling by a cheesy string, slid into my windpipe.

I've been noticing this for awhile... when I swallow liquids, I notice (sometimes I don't notice it) that a little bit can leak into my trachea because the coordination of my epiglottis (the flap that automatically closes when you swallow so you don't die with a lung full of melted cheese while eating pizza) is affected by the Parkinson's. Then, at night time, I have this delightful experience of hacking and clearing my throat until Gail just wants to murder me to make it stop.

According to a website on the subject:

As many as 50% of people with PD develop swallowing difficulties. These problems may worsen as the disease progresses. Dysphagia can present with a variety of symptoms: coughing, choking, throat-clearing, or gurgly voice when eating or drinking; drooling; complaints of food “sticking;”

Another website:

Excessive throat phlegm is another common symptom of dysphagia because poor swallowing clearance will result in an accumulation of secretions in the pharynx (Murray et al., 1996; Warms and Richards, 2000). This is often mischaracterized by the patient as postnasal discharge or excess saliva production requiring frequent throat clearing or spitting.

Gail says she's gonna ask Dr. Grill on Thursday if keeping some Drano on hand would help with any of this.

She loves me.

Then we went grocery shopping for a few supplies and some stuff to make for dinner tomorrow evening.

It felt great just to get out of the house. And I took the opportunity to get a few shots of the outside world in suburban Baltimore/Washington in the days following "Snowmageddon."

Here we go!

FEBRUARY 16, 2010

I've been doing a lot of griping about my Parkinson's disease symptoms on this site as of late. It's been a rough few months -- from the death of my older sister (who would have been 58 years old today), to the recent horrible weather. I'll be seeing my neurologist day after tomorrow. New since my last visit in October? Trouble swallowing (dysphagia), voice difficulties (hoarseness and stuttering). I haven't fallen since then, so that's good. I don't feel like I'm any slower than I was, so that's good, too.

In fact, all things considered, I think I'm doing fairly well for a fella who has been diagnosed with Parkinson's for over 10 years now. I'm still working. Studies show that after 5 years, 25 percent of us can't hold down a job. That figure jumps to 80 percent after 9 years. I passed 10 years on Jan. 30. True, I'm not digging ditches, and I'm not doing all the duties I was hired to do (I can't do media escort anymore), I'm still able to do most of the stuff in my job description, and I can do it from home.

I have a wonderful caregiver, partner, friend and wife. All in the same person! She motivates me to do my best. I reward her by giving her a headache most evenings with my constant throat clearing. She is always there for me and I could not do this without her. My stepson, TJ, is great as well. During the recent snowpocalypse, he lent his hand and his back to keep us shoveled out. Gail helped, but TJ was the work horse.

THE PDQ-39

There's an excellent measuring device to show where you are in the progression of Parkinson's disease. It's called the Parkinson's Disease Questionnaire, or PDQ-39 for its 39 questions. I took it the other day (after researching how to score it), and it showed mixed results.

The 39 questions are broken into 8 different areas. Each item is scored from "0" (meaning "never" or "no problem") to "4" for "always" or "can't do at all.") You add up your responses to the questions, and the physician gets a good idea of where to place you on the progression scale.

The first 10 questions deal with "Mobility". I scored a "35" where "0" would be perfect and "40" would be worst-possible.

The next 6 questions center on "Activities of Daily Life." I scored myself at "6" where "0" would be perfect and "24" would be worst case. (I can still button me own buttons, tie me own shoes, cut me own food and wipe me own backside.)

The following 6 deal with the "Emotional" aspects of PD. I scored a 10 in the "0-to-24" range.

The next 4 are for "Stigma" -- meaning, how embarrassed are you by your symptoms. I rated myself at "4" on the "0-to-16" scale.

There are 3 questions dedicated to the "Social" aspects of the disease. Am I getting the support I need from friends, co-workers and family. I scored a perfect "0" on this one!

In the 4 questions dealing with "Cognition", I gave myself a "7" in the "0-to-16" scale.

There are 3 questions about "Communication." Gave myself a "6" on the "0-to-12" scale.

Finally, in the area of "Discomfort", I graded my 3 questions at "8" on the "0-to-12" scale.

Then, to get an overall PDSI or "Parkinson's Disease Summary Index", you total up all the scores from all 39 questions (76), divide that number by 4 (the most possible points for each question) times 39 (the number of questions), then multiply that number by 100.

My PDSI is 48.72. That would put me just a tad over the limit for the Stage IV area in the Hoehn & Yahr PD rating scale. (The dividing line between III and IV is 48.59.)

I'm guessing that's about where I should be after a decade since diagnosis.

ALL IN ALL...

Bottom line... my hands still work pretty well, thanks to the medication and the deep brain stimulation I had in 2007. My legs? Not so much. I take little steps, I walk slowly, I freeze when I walk. I need a cane in the house and a walker outside. Mentally, I'm just starting to notice some slippage in the area of cognition. My speech is just now becoming affected (oft times, it's the FIRST symptom). My posture sucks, and you could push me over with a finger poke to the sternum. (Please don't.)

But when I go to bed at night, before I fall asleep with a dog at my feet and the sound of my wife breathing in her own bed, I thank God that I have it as good as I do.

Whoops! iPhone alarm just went off. Time for my 11am Sinemet.

FEBRUARY 18, 2010

Had my four-month visit with Dr. Grill today. The guy is great.

We did all the little tests we always do, and it turns out my hands are actually faster than they were before he adjusted my deep brain stimulation devices in October. So that's good.

We did all the movement tests... the first time he did the pull test, I fell right back into his arms. He told me to really try to stop myself by taking a backwards step and we tried it again. This time, I took backwards steps until I hit the wall. They call this "retropulsion."

I did well on the open and close your hands, finger taps, turn your hands like flipping a burger thing. I had a HUGE problem with the heel tapping thing. With my left leg, I was tapping away like a pro! With my right leg, it was like "tap-tap- (pause) -tap-(pause) (pause)-tap-tap-(pause)". Dr. Grill said, can't you do that in a more regular rhythm? "I'll try," I said. And I tried again... my right heel would strike the floor, I'd raise my leg, I'd try to lower it and it wouldn't lower all the way... then it would finally tap the floor and bounce right back up, and down again, and up, then hang up again on the downward stroke.

"Hmmmm....." Dr. Grill said.

We discussed my gait and balance, my recent speech and swallowing issues. He prescribed a visit with a physical therapist who has been dealing with Parkinson's patients for 20 years. So, I guess she knows her stuff!

We discussed my medication, and decided to drop the Sinemet and replace it with Stalevo. The benefit of Stalevo is that it contains entacapone, which causes the levodopa to be delivered to the brain in a smoother, steadier, extended and more consistent manner. This will help the symptoms I have that are helped by levodopa. It won't help the gait, the balance, the speech, the swallowing. I also got a script for Ambien to help me get to and stay asleep at night.

Speaking of gait, I still have a slow, heel-to-toe walk, but my stride is short. Dr. Grill says physical therapy will help that as well as my posture. I'll also get a swallowing evaluation and a voice eval. The Lee Silverman Voice Treatment is designed to help Parkinson's patients speak louder.

"Forget the louder," Gail said. "We don't need the louder."

Dr. Grill smiled at Gail's other suggestions, such as a prescription for Drano to help clear out my windpipes at night, and for a cattle prod to get me moving when I freeze. Well, he shot down the Drano idea, but he didn't SPECIFICALLY nix the cattle prod, so Gail still holds out a modicum of hope.

We had a nice chat. I explained that the last thing I want to be is a "full time patient." Someone who lives next to the medicine cabinet, who needs a Sinemet at 6, a Mirapex at 7, Entacapone at 7:30, another Sinemet at 10, another Mirapex at noon, something for the dystonia, something for the depression, something for the cramps, yada yada yada yada...

"I realize there will never be such a thing as 'normal' for me again," I said. "I know this is a progressive disease, it will get worse. I just want to be able to function as best as I can and to go into this thing as gracefully as possible." He said he thought I had a good attitude about it.

I guess I do. It helps to have a partner like Gail.

"He didn't specifically say no to the cattle prod," she reminded me as we walked to the car.

I love her so!

FEBRUARY 24, 2010

One voice is stern and scolding. The other is soft and soothing.

When I visited with my neurologist last week, he gave me a gentle scolding for putting on some weight. "It's gonna catch up to you as the disease progresses," he said. He advised more exercise and less of what he called "the bad food."

And I know he's right. It makes all the sense in the world. If I were lighter and more muscular, I would still have Parkinson's disease, but it wouldn't be such a heavy bulk for me to lug around.

But the soft, soothing voice of ice cream tells me differently.

Yes. I can hear ice cream.

It happens when I'm waddling down the aisle at the grocery store, my walker in front of me. That's when I hear the voice. I turn to the freezer display, and at first I have to wonder how that tub of Ben & Jerry's "Cherry Garcia" knows my name.

It draws me closer. The pint of ice cream sparkles like a glittering diamond in a jeweler's display case.

"Hi there, Bill," the ice cream says. I say nothing, because I know the voice is meant just for me -- and besides, if folks see me holding a one-way conversation with a pint of ice cream, I'll be in "the home" sooner than I really want to be.

I decide it will be OK if I communicate with the ice cream telepathically.

The ice cream seems concerned about me. "What are you afraid of, Bill?"

"You're BAD for me," I think at the pint. "My doctor says I shouldn't eat you anymore."

"Oh, piffle!" the ice cream says. "You have Parkinson's disease. You're ALWAYS going to have Parkinson's disease. And even if you DO lose weight, you're still gonna end up in the wheelchair sooner or later."

Now, I know I'm the only one who can see this, but the ice cream slides just a little bit closer to the edge of the display case, nudging aside the frozen yogurt and sorbet.

"Now, if you buy me and take me home and EAT me, you'll STILL have Parkinson's disease. You'll STILL have trouble walking and balance difficulties. But for a moment -- just a BRIEF portion of your evening -- you'll have a cool, tasty, creamy treat that will make you FORGET about the stiffness, the soreness, the slowness. Think of it as a brief vacation from reality, Bill."

I have to admit. The ice cream is making sense. I begin to back away from the display case.

"No, no, no," I think at the tempting pint of deliciousness. "You're telling me what I WANT to hear, not what I SHOULD hear! You're giving me bad advice," I think as I slowly retreat.

"Ah! Ah! Your doctor said 'No backing up!'" the ice cream scolds -- but ever so sweetly. "You don't listen to THAT advice, but you WILL listen to advice that would deny you my rich, sweet, cold and creamy goodness?"

I feel something snap in my mind. Call it the "breaking of resolve" if you will. I prefer to think of it as "making an executive decision."

"No!" I shout telepathically. "I will NOT be ruled by fear! I WILL buy you, ice cream! I will take you home and EAT you at a time that is convenient for ME!"

I open the display case, withdraw the pint of Ben & Jerry's. It's cold and heavy in my hand.

"Wise decision," the ice cream says, as I place it in the shopping cart my wife is pushing.

So, spare me your lectures. I know it's bad for me. So is Parkinson's disease. I can exercise more. I can eat less. But none of that is going to make a WHIT of difference at the end of all things. When the end comes, as it certainly will at some point no matter WHAT I do -- whether it's from aspiration pneumonia (the leading cause of death for Parkies) or falling and breaking a hip (hey, if I'm padded well with adipose tissue, won't that make my hip HARDER to break?), I will NOT lie on my deathbed regretting that I enjoyed the cool, creamy, fruity goodness that lured me to the display case at a grocery store.

Death awaits us all. Some of us sooner than later. Will YOU lie on your deathbed wishing you had eaten one less cheeseburger, one less order of fries, one less pint of ice cream?

Not ME, Mister! Not ME!

FEBRUARY 26, 2010

Gail went to the store. She went without me today because the wind is really whipping out there.   There have been times when, hobbling along with my walker, a good gust of wind almost caused me to lose my balance. Gail figured "better safe than sorry," and I wholeheartedly agreed.

No sooner is Gail out the door when my two hounds decide they need to use the yard. I ignore them for awhile, because I'm putting together the second of two podcasts I needed to get done today. I locked the doggie gate so I could work unmolested. (If you ignore Shiloh and her incessant "rrrrrrrOOOOOOoooo-ing" she will come into my office space and physically attempt to insert herself between me and my computer. I wasn't having it.)

When I was finished, I turned and looked at my doggies. They were both VERY sad.

I said the magic words. "Do you have to POOP?"

Both of my darling little idiots bolted for the front door and bounced like little cartoon doggies. I put the leash on Raven first (she's got seniority) and cautiously stepped out on the porch. The winds were howling and gusting, but I got my feet under me and told Raven, "Go potty!"

Raven walked down the steps and turned to her right.

She saw the squirrel before I did. The squirrel saw us both and bolted. Then Raven bolted. Then I flew across the porch and jammed my right wrist against the porch railing as this bulldozer of a border collie reached the end of her retractable leash. If that rail hadn't been there, Gail would have come home to a missing dog and the sight of my two slipper-clad feet poking out of the snow.

Once was a time I could STOP Raven from bolting after rodents in the yard. Usually, I see the varmints before she does, and I'm able to cinch up on the leash. This time, she saw it first and very nearly caused me some serious injury. I bashed my chest against the porch railing, my right wrist and elbow hurt, and my right knee feels slightly twisted and hurty.

But she sure scared the BEJEESUS out of that squirrel, don'cha know...

And then, she pooped.

So there I was feeling low, slow, down and depressed. Then I an article on the Internet, and it cheered me right up!

Turns out we People with Parkinson's are making OTHER folks WEALTHY!

And who wouldn't feel good about THAT?

"The Parkinson's disease market is approaching maturity, with the threat of generic incursion evident in each drug class. Although growth will be stifled by generic launches, relatively successful lifecycle management strategies and new product launches see the Parkinson's disease market grow at a compound annual growth rate (CAGR) of 2.6% over the next 10 years."

So invest now in Parkinson's drugs! Then keep your fingers crossed that those damn GENERIC drugs don't cut into your profits by making the disease a little less EXPENSIVE for the people who SUFFER from it. And just hope that those GENES they're fiddling around with don't actually result in a CURE! That would REALLY hurt your investment! And you better get in now, because the market is approaching maturity!

Truthfully? It sickens me just a little bit to know that there are folks out there speculating on how much worse the current Parkinson's epidemic is going to be. It rankles me just a tad to know that there are people betting money that MORE people will come down with this damned disease and that the more people who GET Parkinson's the richer these investors get!

I know that these drugs don't make themselves. And I believe in capitalism. And I believe in the right to invest in a product if you believe its value is going to increase. But there's just something kind of shocking to see this disease being discussed in such cold, monetary terms. It just seems so... mercenary. Like finding a cure will end up in people losing money or something.

And that would be TERRIBLE!

FEBRUARY 27, 2010

One thing I like about Saturdays is that Gail and I usually do something fun together. Today, it was a trip to the Mall in Columbia, Maryland. For one thing, I really NEED the exercise. For another thing, I really NEED to get out of the house. For another thing, I really NEEDED some new jammies!

I also, it seems, need to expose myself to rude morons so I can truly appreciate nice people when I meet them. Last time we parked near Macy's and walked through the store, I was nearly knocked off my pins by a young chickie baby who actually bumped into me -- bumped IN to an OLDER MAN with a WALKER -- and just kept going. I was able to keep from falling, but barely.

This time, heading into the mall, there was the typical assortment of the walking dead looking for skinny jeans and skinny t-shirts to cover their fleshless asses and breastless chests. I saw a young, tattooed fellow trundling my way with a push cart. He saw me and stopped. Then he politely motioned me past him. I thanked him for being a gentleman, and we made our way through the store.

So, first we toddled to the food court. Gail ate Chinese. I ate Japanese. Mine had more teriyaki, but that about spells the difference.

Afterwards, we strolled in my typical leisurely fashion down towards the Big and Tall store. I try to keep close to the wall when I walk, because people -- being jerks -- just love to cut me off, bump into me and score points by making the old man fall so they have something to "ROTFL" and "LMAO" about when they text message their idiot friends. Gail veered away to look at something towards the center of the aisle and I had to veer around an obstacle. This young 100-lb. teen chickie baby darts right between me and Gail because GOD FORBID she should have to WAIT a frickin' second for some OLD MAN to dodder his useless ass out of her way. She was in a HURRY! She caused me to freeze, and I almost fell as a result. Had to throw the brakes on the walker and steady myself.

I told Gail what happened when she was looking at the sparkly things, and she said, "Just keep close to the wall, Rat Boy." (See, rats and other vermin tend to scurry along the baseboard of a wall to avoid notice.) "I can only protect one side of you at a time," she said.

She made her point.

We got to the clothing store, I got some new PJ tops and bottoms. ("What does this say about my life," I asked Gail. "I no longer shop for clothes to wear to work. I just shop for stuff to sleep in.")

After that, out to through the Macy's where young waifs, looking like the starving cat mannequins they strive to emulate, cut in front of me, around me, beside me, not so much as an "excuse me." That is, until an elderly African American gent needed to make a left turn in front of me. He waited until our eyes met, and he made his turn. "Pardon me," he said. "No problem! Have a great day!" I replied. "You do the same," he said as he walked away.

See? You need to expose yourself to the jerks so that you will really appreciate the nice folks when you meet them.

(The next morning, Gail and I went grocery shopping. I toddled out to the car while she went through the checkout. As she came out of the store, this young chickie baby in an Acura rolled past the stop sign, honked twice at Gail as she was in the middle of the crosswalk, then - without waiting for Gail to get to the other side - she curved around her and zoomed down the parking lot.

I don't understand why it's the young people who are always in such a freakin' hurry. They have all the time in the world. Us older folks - WE should be the ones in a hurry. Who KNOWS how much time WE have left…)

FEBRUARY 28, 2010

Did our weekly grocery shopping today. One thing I'm grateful for is the fact that my walker has a seat on it so I can sit and relax while Gail peruses the kidney beans.

So, I'm seated on the walker and after a few minutes of examining the kidney beans Gail walks up with a big smile on her face. "Well, don't YOU look like the poor beleaguered husband waiting for his wife?"

"Not at all," I said. "Actually, at the moment I was thinking about how grateful I am to always have a place to sit."

Gail understands the philosophy of Parkinson's disease "masking."

"I know," she said, "but nobody else does."

So after we got a few more things, she gave me the car keys so I could toddle out to the car and wait while she went through the checkout. And I decided to take a picture of myself to see just how bad of a "face day" I was having.

"Yikes!"

This is one of the hallmarks of Parkinson's disease. No matter what kind of mood you're in -- and I'm in a fairly decent one -- this is how you look when your face is relaxed. I can make myself smile and show emotion if I want to, but it takes effort. This is why people get the mistaken expression about Parkies that "the lights are on, but nobody's home."

Actually, the truth of the matter is, "the lights are out and EVERYONE is home." Behind the sullen, angry-looking, granite face of a person with Parkinson's disease, the mind is still working at full speed... more or less, in my case.

At least I didn't drool on my shirt.

(ADDENDUM: I just read this to Gail. "I still think a cattle prod would help that," she said. She loves me.)

MARCH 2, 2010

Had a delicious Wendy's "Frosty" with my lunch today. Being a dairy product, it tends to produce phlegm. I've been having trouble with that sort of thing as I've written in the past.

So, shortly thereafter I'm sitting here at my computer, hacking and hewing and making a general annoyance out of myself when suddenly...

I take in a breath and a phlegm clot goes right into my left lung.

I could feel it in there, rattling with each breath as my remaining breathing tubes closed in defense against this invader.

After a few minutes of coughing such as you've never heard, I managed to bring the offending clot up.

What a horrible, horrible feeling. But the Frosty was good!

MARCH 3, 2010

I've seen their commercials on TV from time to time, and I've always said to myself that I should get more information about it. Now, I have. And when the day comes -- as it surely must -- where I shuffle off this mortal coil, my body will be donated to medical science through a company known as "Anatomy Gifts Registry."

I just filled out a lengthy application, with repetitive questions, and put it in the mail. If I'm accepted, Gail and I will each get embossed cards that explain what to do with my mortal husk once my eternal soul has winged its way wherever it's going. Here’s what we’re supposed to do…

Once a death occurs and is pronounced, contact AGR ... An AGR representative will verify the consent method ... and will immediately make arrangements with a mortuary transport organization to pick up the body and transport it to our facility. Do not call a funeral home. AGR has contracted organizations throughout the US that are familiar with AGR’s process.

AGR, will make timely arrangements to register the death with your State Department of Vital Records. Experienced AGR personnel can assist family members with obtaining the certified copies of Death Certificates.

Not that I'm expecting that day of blissful escape to come anytime soon, but it never hurts to be prepared.

Since I was diagnosed in 2000, it's been my intention to donate my brain after I die for furtherance of the Parkinson's disease knowledge base. By donating my entire body, hopefully there is stuff to be learned about PD's effect on the rest of the body as well. And this agency has a new, state of the art facility. So it's not like I'm gonna get segmented at Satriale's Pork Store, like on “The Sopranos”!

The advantages of this new establishment are not limited to only the scientists and doctors utilizing the facility. The donors and their families, whose participation has helped advance science and medicine, will also benefit. Participation in the AGR program, throughout the many years it has been in existence, has always translated into being part of a new and innovative way of helping to advance medicine and allowing for donors to make an impact on the health and welfare of millions of people. The development of this new teaching tool will further advance medical and scientific learning and acknowledge and highlight the generosity and sacrifices made by donors and their families.

Whatever isn't used in research is cremated and sent to your next of kin.

If this sort of thing appeals to you, check out the website. I think it's a great way to leave a lasting legacy. And it's comforting to think that I'll still be assisting in the search for a cure even after I'm playing a harp on a cloud somewhere.

MARCH 4, 2010

The very concept of "faith" means believing in something you can't prove. It means you put your hope into something that you don't know for sure will happen. For instance, every night when I go to sleep, I have "faith" that I will wake up in the morning. I have no way of knowing for a fact that will happen. I could toss a blood clot into my brain. I could get a 2 a.m. blocked coronary artery. I do not know for CERTAIN that I will wake up in the morning. But I have faith.

The bottom line is, NOBODY can say with certainty what is or is not "out there" in terms of "the great beyond." Unless you have been dead and then came back -- and I'm not talking about "near death experiences", I'm talking about being DEAD... stone cold DEAD -- then you have no idea what you're talking about when you come right down to it.

That's where faith comes in. And whatever you believe, it's fine with me!

I have a belief system. I would bet a week's wages that it's far different from yours. I've adopted bits and pieces of the Judeo-Christian theology, mixed it with a Zen Buddhist and Unitarian philosophy, and it works for me. It helps me make sense of things. But can I sit here and tell you, with all certainty, that what I believe is ETERNAL TRUTH?

Lord, no!

It may be true that when we die, that's it. No afterlife. The big sleep. Nothing ever after.

It may be true that when we die, we're greeted in a shining light by those who have gone on before us.

It may be true that if we've been naughty, this all-powerful pure love known by some as God will torture us in unimaginable agony. Forever.

It may be true that we're each given an ice cream cone, a spiffy straw hat and a banjo.

I don't know. YOU don't know. You can believe. You can hope. But you can't KNOW! Not until you're there! If there IS a "there" there. Which there may not be.

Intolerance pisses me off. It matters not if you are an evangelical Christian who thinks that everyone who doesn't see the "path to salvation" the same as you do is hell-bound. It matters not if you are an atheist who mocks believers for believing.

If you are intolerant, you piss me off!

So, bottom line?

Be nice! Help others. Adopt the old scouting attitude of leaving the campsite better than when you found it. Do it because it's the right thing to do and you're making the world a better place. Not because you're brown-nosing your idea of "God." Do it because being nice is nice!

And isn't it NICE to be nice?

MARCH 5, 2010

It's early in the morning. I'm lying on my left side. Comfortable. Not quite asleep, but not quite awake. I notice a sound.

"heeeeeeeeeeeeeeee. heeeeeeeeeeeeeeeee."

It's a high-pitched, melodious sort of whistling sound.

"heeeeeeeeeeeeeeeee. heeeeeeeeeeeeeeeee."

And it's coming from my throat. Every time I exhale.

"heeeeeeeeeeeeeeeee. heeeeeeeeeeeeeeeee."

Right in the area of my voice box, something is causing the air to whistle when I exhale.

"heeeeeeeeeeeeeeeee. heeeeeeeeeeeeeeeee."

Well, that was it for sleeping. I got up and immediately started coughing. See, usually it's the NIGHT time when I get all congested and phlegmy from swallowing bits of food and drink and saliva down my windpipe during the day. But when I went to bed last night, I was about as uncongested as I can ever remember being in recent weeks.

The noise has stopped, but I've spent the better part of this morning hacking up nastiness from my lungs.

I've done a bit of research on this, and it seems to have something to do with my Parkinson's disease advancing, now affecting the muscle control of my larynx, vocal cords and epiglottis (the little flap that is SUPPOSED to keep food and liquid out of your air pipes). I was talking with my Mom yesterday and all of a sudden my larynx just plain shut down. It was hard to take a breath, and for about 30 seconds all I could do was croak. But it cleared up.

I guess I was just secreting mucus like a CHAMPION during the night, and didn't have the muscular control in my chest and larynx and trachea to do anything about it.

Gail has, again, offered to pick up some Liquid Plumber to "clean my pipes." She's thoughtful that way.

So, let's all add a new one to the symptom pile! And let's start a pool to pick a date when I finally choke to death on a piece of salami.

MARCH 6, 2010

Just got back from a lovely lunch with my beautiful bride. Went to the DuClaw's at Arundel Mills. I had the "Fun Guy" burger -- a juicy burger with provolone cheese and marinated Portobello mushroom. *(Get it? "Fun Guy"? **Fungi**? Haw!)* Along with the home made 'tater chips and a Pepsi, it was all just too grand!

Afterwards, we toddled towards the Tobacco Leaf to get a few nice stogies. About half way there this little kid, maybe 3 or so, comes zipping by to my left. As I will always when someone cuts by me at a high rate of speed, I froze up solid for a few seconds. The little kid reached his dad, and his dad turned him around and pointed right at me.

"SEE WHAT YOU DID! YOU ALMOST KNOCKED OVER THAT POOR OLD MAN!"

The youngster looked at me and for a second I thought he was gonna cry.

Then I thought I was gonna cry.

"Poor? I cleared $90K last year," I thought to myself. *"Old? I'm 55!!!"*

Then I caught a look at myself in the reflection of a store window.

"Oh, right..." I thought.

Then we went to the tobacco store.

MARCH 7, 2010

Rough day for Billy, and it's barely 10 am!

I've been congested and hacky all morning because I have trouble with my night time, shall we say, "secretions." We were at the grocery store and I had a throat spasm. I bent over and hacked like I had a lung coming up. And, to my horror, I watched in slow motion as a long string of drool cascaded from my lower lip to the floor. I looked up and saw the horrified faces of customers around me.

Gail suggested I might want to start carrying paper towels with me.

You can tell she loves me.

Then, on the way home, we approached the off ramp to US 1 from Highway 100. I saw a guy standing on the shoulder, between the highway and off ramp, and it looked like he was waving down a car. He watched as the car went past him, then he turned and walked onto the off ramp.

"Watch out for the guy on the off ramp," I said to my wife. She looked and looked and saw nothing.

I looked again, and the guy turned into a shadow on a light post. I swear, I could almost see face detail, tell you what kind of clothes he had on, and his hair color. I saw him waving and walking. And then... he wasn't there.

"God, I'm afraid to tilt my head one way or the other because my brains will come pouring out my ear," I said.

"Just make sure to have those paper towels with you," Gail said.

I can FEEL the love coming off her in WAVES! :)

Oh, Parkinson's disease. Truly thou art an ENTERTAINING affliction!

4. WEIRD DREAM THEATER!

(One of the more interesting things about Parkinson's disease – especially over the past year or so – is the amount of weird, vivid dreams I've had. They're rarely nightmares and they generally center on a specific group of topics – bad radio stations, being back in Japan, being back in the Navy and Dead Relatives. I share some of the more amusing ones here.)

MAY 30, 2009

Every night, it's the weird dreams with me. Last night, for instance, I had a very realistic dream in which Gail and I were living back in Iowa back in the 90s and she decided she didn't love me anymore. She wasn't mean about it, it was more of a "matter-of-fact" realization that we could keep living together, but there'd be no more hugging, kissing or any kind of affection between us. At one point, she unplugged the TV and said that she had just finished HER three hours of TV watching and now it was MY turn. She handed me the electric cord and I knocked it away, saying, "What the hell! We're not doing THAT!!!"

Only, I didn't just say that in my dream. I shouted it for real. Woke up Gail (who actually DOES still love me) and knocked my blankets out of the bed. If Gail and I hadn't have gone the twin bed route several months ago, I certainly would have smacked her when I lashed out. She went back to sleep. So did I.

Damn you, Parkinson! AND your disease!

JUNE 6, 2009

I was at my late older brother's house, but he wasn't in the dream. I was standing in the patio of the back yard, watching as a grey and white cat (which, apparently, was mine) was chatting with the next door neighbor (no, the cat wasn't talking — he was "brrrt"-ing and meowing). The neighbor was seated in a lawn chair. The cat walked into the neighbor's yard and started chewing on some herbs in the garden. The neighbor asked me to come collect the cat, but the cat ran back into my yard as I approached. Then I noticed two doves on the patio. The cat snatched one of them and started running to the back door. I reached out and tried to swat the bird out of the cat's mouth, and…

…knocked the bedside lamp off the table. I looked around, did a bit of a mental shrug, and went back to a very restless sleep. When I finally got up, my blankets were sideways on the bed again.

Oh, and Gail says that at some point during the night, I barked. A play bark, as if I were teasing one of our dogs. I don't remember dreaming about dogs.

Damn you, Parkinson! AND your disease!

JUNE 28, 2009

Hard to remember the last time I had 8 hours of unbroken sleep. I generally get off to a good start (because, by the end of the day, I'm generally exhausted by the basic effort of walking and moving). I usually hit the hay around 9-ish and — for the most part — go right to sleep and stay there until shortly after midnight.

For most guys my age, if they have trouble staying asleep it's because of their bladders and prostates. Not me! I wake myself up when I try to turn in bed.

When I go from my back to my right side, I need to raise myself off the mattress with my right elbow, then flop. When I roll from my right side to my back and then from my back to my left side, I do it in a series of bounces and wiggles. This not only wakes ME up, sometimes it will wake up Gail and SHE sleeps in a different BED.

Then, generally sometime after 2 am, the vivid dreams start. Rarely nightmares, but never really "pleasant" either.

General dream themes:

The Bad Radio Dream: I quit my government job to take a gig at a bad radio station with crappy equipment and low pay.

The Navy Dream: I've gone back into the Navy and am at sea — usually on an aircraft carrier.

The Dead Relative Dream: Usually it's my late twin brother. Sometimes my dead older brother. Sometimes my Dad. Sometimes they're "back from being dead." Other times, they never died. Sometimes, with my twin brother, it is part of a Travel Dream (see next). Sometimes, we're fighting.

The Travel Dream: I'm going somewhere. Sometimes I'm driving, either a car or a truck (see next). Sometimes it's a plane, which may or may not crash. Usually there's a defined destination. Sometimes, my dead twin brother goes with me.

The Truck Driving Dream: I've quit my government job to go back to driving a semi for a living. Sometimes Bob goes with me. And it's usually a broken down, crappy truck with many of the usual difficulties and delays a truck driver will experience.

The "WTF" Dream: The weird, unexplainable ones, like when I saw a blimp in the sky, and it turned out to be a huge, floating coffee pot.

These dreams usually happen late in the sleep cycle, and it's during these dreams that I will yell or lash out — which is why Gail sleeps in a different bed. They're very vivid, they're in color, and I can generally recall them in detail.

Then, I wake up — usually tired.

It's all part of the rich, colorful tapestry of Parkinson's disease.

JUNE 29, 2009

OK, let me start this essay with a comment on the title. For most of us, this list will be MUCH different than it would have been if I were writing this 20 years ago. In fact, that list would probably only have one entry… depending on how mad my wife was at being woken up.

Um… on second thought… she would ALWAYS be mad about being woken up. So maybe this list won't be so different after all…

If you're anything like me (and God help you if you are), then you know that one thing we Parkies have a LOT of time to do at night is think about stuff. The challenge is to find things to do that divert the brain from contemplating the negative and to occupy the intellect with something positive.

Or, at the very least, something shiny.

Here are some suggestions for things you can do as the hours tick away and the Sandman is caught in traffic.

1. Lay there very quietly and see if you can hear your hair growing.

2. See if you can think of a tune that is in the same tempo as your spouse's snoring.

3. Consider your toes. Wonder about how they're doing down there.

4. Run various scenarios through your mind about what you would do if a tornado were approaching or what you would do if a burglar tried climbing through your bedroom window. Bravely discard the ones that have you screaming like a little girl.

5. See if you can imagine what President Obama is doing — RIGHT NOW!

6. Run your favorite album in your mind. I like Gilbert and Sullivan's "the Mikado." If I'm in the mood for rock, Pink Floyd's "Dark Side of the Moon" works well. (For extra fun, try to sync it with "the Wizard of Oz" in your mind as you play it.)

7. Get out of bed, stagger into the living room, see if you can stare down the fish in your aquarium.

8. Wake up the dogs. Wait for them to fall back asleep. Wake them again.

9. Get back in bed. Stare at the digital clock. Start counting the seconds when the minute changes. See if you hit "60″ just as the minute changes again.

10. Lay there very quietly and see if you can hear your toenails growing. (This can be done in conjunction with #3.)

11. Try to come up with a list of things to do when you should be sleeping but aren't, and write a funny blog post about it.

Well? Anything to add to the list? Drop me a line via the comment form.

JULY 1, 2009

Let’s get this out of the way — I feel like crap this morning. I feel better than I did when I got up at 4:30 to take out the dogs and then get ready for work. But I had a headache, I was wobblier and slower than usual, and my brain felt like it was wrapped in gauze like a mummy. So I wrote a quick e-mail to the office — mashing the keyboard with my barely-responsive hands — telling my boss that I was taking a sick leave day.

After a couple more hours of sleep and a shower, then some coffee, I feel marginally better. But no way able to navigate the trains, subways and shuttle busses that I would need to get to my office.

This is one of the rare days where PD makes me feel “sick.” On days like this, usually by early afternoon I feel much better. But even now at nearly 9:30 in the morning, I’m mashing the keyboard with thick, fat fingers, misspelling words, and deleting whole lines and paragraphs after typing them, making me have to retype them.

It seems like the dreams I have before days like this are even weirder than normal. Before I got up, I dreamed that I was sharing a large house with an old guy with long hair (who may have been Ben Franklin) who was having sex with an old, chubby woman in the room next to mine. Then I noticed that a sheet in my bed, a mattress on the hardwood floor, was a sheet he had used before — stains and all.

Two weird dreams after I went back to bed. In one, Gail and I were on Main Avenue in my little hometown in Iowa. We were sitting on a park bench near a tree, and a little female sparrow was sitting on a branch very close to my face, holding a dandelion seed in her beak. I held out my finger for her, and she perched on it. I brought her close to my lips to give her a little birdie kiss, and she put the seed in my mouth. She flew away, and I turned to talk to Gail about the whole thing. But I felt the birdie land on my shoulder. We started walking up 3rd Street towards the house I grew up in (we were living there in the dream) and the birdie flew away again. It came back just as we made a right turn onto 26th Avenue North, and we noticed a bunch of costumed kids heading up the alley towards “our” house. Gail said, “Oh no! It’s Halloween, and we don’t have any candy.”

Then, the dream shifted to me sitting with a bunch of friends (very few of whom I recognized) at a party. They were apologizing for what happened earlier that night when another guest at the party was making fun of me. This guest was apparently using a candy dish — which looked like a white Mexican wrestler mask — and pretending it was me, making fun of my weight and my Parkinson's. I told the guests not to worry about it, that I wasn't sensitive about my weight, and if someone were so crass as to make fun of a guy because he had Parkinson's disease — well — what does that tell you about HIS character.

A former co-worker asked me when I was going to bring Gail down to SW Florida to live — so I guess this dream was centered in Naples, Florida, where I once worked at a radio station. I told her that Gail couldn't live there because the heat wasn't good for her scleroderma. And I had to drive home, but suddenly I wasn't in Florida but in California, and that meant I would have to drive across country.

Then, I woke up.

Staggered out to the living room. Gail had the coffee already made and a cup poured. I sat in my recliner, and a bright-eyed German Shepherd dropped a ball in my lap. The look said it all — "OK, fat boy, if you're gonna hang out here with us, you gotta pick up the slack in the ball-throwing duties."

Ah. Reality!

JULY 3, 2009

I've written here in past entries about my weird adventures in dreamland… but last night seemed to go above and beyond! I woke myself up trying to stomp on something, and I think I may have had some kind of seizure.

Or else, I was just dreaming…

The dreams last night, I remember as fragmented bits — jumping from the typical "bad radio" dream where I'm working at a crappy radio station, to the "I quit my good job for a bad one" where I was selling insurance on "commission-only" basis, to where I was traveling somewhere with my late twin brother, but we couldn't make progress because there was an accident blocking the highway, to finding myself on a bus where we had to get slips of paper from one of those "take a number" things when we got on the bus and the driver wanted them back when we got off… to being in my hometown in Iowa, to being in New York City, to being part of a government program where older women could fill out forms to let men know they were interested in them. Yikes.

I woke up at one point trying to stomp on something — I don't remember what it was, but my right foot was out of the bed and stomping on air. If I still shared a bed with Gail, I would have been stomping on HER.

And at one point, I either had — or dreamed I had — some sort of seizure. I rolled from my right side to my back, and then I couldn't move… and felt like I was going to vibrate right through the mattress, the box springs, and onto the floor.

At 6 am, the adventure ended. I laid there, sort of awake, sort of asleep, and I heard a plaintive "bark!" It was Shiloh, our German Shepherd. She hadda go potty. I crawled out of bed, more tired than I was when I tucked in last night.

Golly, but having Parkinson's Disease is FUN!!!

JULY 17, 2009

OK, so this one starts out with my late twin brother and me at City Hall in my hometown in Iowa, waiting for election results. Our local councilman is sitting there, his arms crossed over his chest with a dour expression on his face, because someone taped a yellow piece of paper on the mayor's door that said the councilman's opponent had beaten him. So, Bob and I decide to go home, which — as it sometimes is in Vivid Dream Land — is the little house on Cleveland Street we grew up in.

We head out of City Hall, and we see that there has been a snow storm. A bad one, maybe 5 or 6 inches on the ground. And it's night time. So, we alternately drive and walk towards our house, and we notice that there are a lot of power lines down. And trees. In fact, Bob tells me to "gun it" if I want to get over a tree on the road. This makes no sense to me, because if we gun the car, we'll either spin out or crash into the fallen tree. When we get to it, I see that there's room to drive around it to get past the fallen tree.

Finally, we're walking (no idea what happened to the car), and we turn from North 3rd Street onto 26th Ave North. The intersection of the avenue and the alley leading to our house is a tangle of downed wires. Bob has gone on ahead (for some reason) and I'm wondering if we're gonna have any power at the house, and — if not — how we're gonna stay warm. And there are fallen telephone poles. I see a woman laying face down on one of them, and I walk up to her and ask, "Are you sure you wanna be sleeping here, sweetie?" She wakes up, smiles at me and says, "No." She gets up and walks away. I turn north up the alley, and I wonder why there should be so much damage since there isn't really THAT much snow and I don't remember any wind or anything like that.

I get to the house, and I notice it's the only one with power. I wonder how that could be. Gail is there, and she has a bunch of small kids she's keeping an eye on. I want to go to bed, but then the lights start flickering and I ask if she has any candles in case they lights go out. She is annoyed that I asked her, and she shows me some candles that, for some reason, look like cupcakes. Oh, and Gail tells me the radio says that our current councilman WON the election, he didn't lose and whoever put the paper on the mayor's office door is a liar.

Then Bob comes in and says Mom wants to go up to Eagle Point Park. The sky is clearing (it's morning now) and the snow is melting, so we all decide to take Mom to the park.

Now, for some reason, there is a beach at this park. Iowa is not on an ocean, but now we're at a beach and Bob and Mom and Gail and the little kids are all sitting on blankets. So I decide to go look for sea shells. I find some really nice ones, like the kind you'd see in one of those tourist sea shell stores in Florida. Bob yells at me that I'm not supposed to take any living sea animals out of the water, and I yell back that these are dead, empty shells.

I get out of the water and go looking for the family. They went home without me, and this annoys me greatly. I start walking home.

Then I woke up, came out to make coffee, sat down and wrote this in my blog before I forget the bizarre details.

From the "We Move" Website:

Sleep disorders are very common in PD, ranging from insomnia to excessive sleepiness to vivid dreaming. A careful history and reduction of unnecessary or offending medications may be helpful. Treatment of depression may improve sleep. Psychosis may be a side effect of antiparkinsonian medications, as well as a feature of disease progression. Initial features may include vivid dreaming and nightmares, which may progress to delusions, paranoia, disorientation, and hallucinations.

Ah, Parkinson's! You never fail to be interesting!

JULY 31, 2009

Why do I feel so TIRED this morning? Gee? Could it be the combination of horrible leg cramps, weird dreams, talking and lashing out in my sleep? Christ! I think I get more exercise when I'm supposed to be sleeping than I do during the friggin' DAY!!!

Mostly the leg cramps come in my right calf. But last night, my left calf and both feet decided they wanted in on the action. And my hands. But the cramps in the right calf were the worst. (Even now as I sit here typing this, I can feel my calves, twitching and mocking me.) Almost every time I rolled over or tried to move my blankets last night, the evil calf would ball up — not so much in the BACK of the leg, mind you… but right there in the FRONT causing a big muscle knot just to the outside of my shin bone. My feet, when THEY cramp, feel like they are birds' feet trying to hold on to a tree limb. And it doesn't feel good. Not at all.

Then, there's the dreaming.

For instance, for a goodly part of the night I was working at a Naval Hospital (I used to be a hospital corpsman many years ago) and we were preparing for a presidential visit. I remarked that it was weird to see so many people there on a Sunday just to clean the place and joked that I remembered it was like that in the Navy when an Admiral was planning a visit — like the old boy would faint if he saw a scuff mark on the floor.

The president came through in a limo, smiling and waving, and a bunch of protestors had somehow gotten on the roof of the hospital and — like they were hooting at a bad guy at a wrestling match — started screaming, "YOU SUCK! YOU SUCK! YOU SUCK!"

We on the ground responded by pointing at the protesters and hollering, "YOU suck! YOU suck! YOU suck!"

And I thrust an indignant index finger and them and hollered, "If you don't like who the voters chose, LEAVE THE COUNTRY…"

And that's when I realized I was pointing at my wife in the twin bed next to mine, telling her to leave the country. Not sure if she heard me. She's still here, after all. Still in bed. I'll have to check with her when she gets up so she knows I wasn't demanding her exile.

Fun days. Better nights. You BETCHA!

AUGUST 18, 2009

OK, so this one falls into the category of the "bad radio dream."

I was program director of a crappy little radio station, possibly in my home town although that was never really clear. Our morning guy showed up late to sign on the station and he had an entourage of his wife, an African-American preacher with long jheri curls, and some other guy.

I assumed he was going to do his show, and went back to my office to listen… but there was nothing on the speakers.   I went back to the studio and discovered my morning guy had disconnected the control board and laid it on the floor. In its place he had a keyboard which he was playing. The preacher sat in the corner listening as my morning guy and his wife and the other guy were using the radio station's equipment to cut some sort of demo tape to take to a record label.

I blew up and told everyone to get the hell out of my radio station. They filed out peacefully and I put the control board back where it belongs and started doing the morning show myself.

During the show, my morning guy came back into the studio and threatened me with a lawsuit. I pushed him back against the wall, put my face right in front of his and shouted…

"GET OUT!"

And that's when I opened my eyes as I realized I was yelling at my wife across the gap between our twin beds.

She is still here, however, having long since learned to ignore me when I yell things at her during the night.

Ah, Parkinson's disease! You never cease to be entertaining, at least.

NOVEMBER 19, 2009

Before we begin, I should note that I use the generic version of Klonopin, but it's easier to fit the brand name into a headline than writing clonezapam.

That being said…

My nights have vastly improved since my neurologist prescribed clonezapam for my REM sleep behavior problem. No more shouting at night. No more punching or kicking the walls. And I generally feel more rested when I get up in the morning.

It hasn't done anything about the vivid dreaming that comes with Parkinson's disease, but at least I'm not acting them out any more.

Had a doozy this morning right before I got up.

My dead twin brother and I were in Japan together. It was his first visit, and I was showing him all the high points of Yokosuka — the town I lived in for 18 months back in the 80s. We hit all the bars, browsed all the stores, dined at a restaurant and went walking down the streets. At one point, I recognized that we were in my old neighborhood, near the house that my ex-wife Janina and I rented in 1984-85. I wanted to show it to Bob and get a photo of it. (Side note — I once DID actually find the house using Google Earth, which is a neat program, but has nothing to do with this dream, although I did mention to Bob in the dream that I had found the house once on Google Earth…)

But as we looked for it, I saw that we were actually on the EAST side of the Kanagawa peninsula, and our old house was on the west side, so we gave up looking for it. Bob saw some birds down on the beach and went down to give them some bird seed. Some ate the seed, others made a big deal of spitting it out in disgust.

We went back to our walking and Bob mentioned that he had tickets to fly home that evening. I mentioned that I did, too, although we were both flying United Airlines, we had different flights. We found ourselves in a residential neighborhood as it grew dark, and Bob was afraid to walk into it until I told him that street crime is practically unheard of in Japan.

Then I woke up.

Shiloh, being bored, had barked and that got Gail up. So I went out and sent her back to bed. Now I'm making coffee, sipping cappuccino, and writing this.

See how my life is? :)

NOVEMBER 22, 2009

As I've mentioned time and time again on this blog, vivid dreaming is part and parcel of Parkinson's disease. So, in many cases, is REM Sleep Behavior Disorder -- the lashing out, hitting and kicking while acting out dreams that caused Gail and I to move to twin beds earlier this year. Klonopin has done a fine job with the lashing and hitting and kicking, but I still get the wild, vivid dreams.

Dead relatives have been a staple of my dreams. (I have several categories -- the "Back in Japan" dream, the "Working at a Crappy Radio Station" dream, the "Back in the Navy" dream, and the "Dead Relative" dream seem to be the most common themes. Sometimes they will combine into hybrids, like the "dead relative visits me in Japan" dream.)

When I dream about a dead relative, it's usually my twin brother, Bob, who died in 2004. Sometimes it's my brother Jack who died in 2008. Every now and then, it's my Dad who died in 1983.

My sister Cindi passed away nearly 3 weeks ago. I had my first dream about her last night.

As always, my "dead relative" dreams were pleasant, non-scary, non-threatening.

In this case, my entire family lived in a single apartment. Cindi was there, but in a coma. Death was imminent. So Gail and I decided to leave her with her immediate family so they could have some privacy at that final moment. When we came back, we expected her to be gone. But instead, she was in her pajamas, up and playing with her grandchildren.

I rushed to hug her and told her how glad I was to see that she was feeling better.

"You know I'm still going to die from this thing," she whispered into my ear. "Yeah, just not today," I replied.

Then, we all laid down on a mattress on the floor at the foot of a couch. Cindi sat on the couch and we chit-chatted, about what I don't recall. Mom (looking much younger) joined us, and my Dad came into the apartment as if he were coming home from work. I wrapped my arms around his neck and can still feel the 5-o'clock shadow stubble on his cheek where I kissed him. I told him I loved him, he smiled that half-smile of his and said he loved me too. Then he reached inside his jacket and pulled out a little "Simpson's" Christmas tree ornament.

"Give this to Gail," he said. "I forgot about Mother's Day."

So, we all decided to head to a buffet. It was in a dark, crowded room in a restaurant in a mall. I found a seat, and a lady trying to get by me stepped on my right foot. She apologized.

"That's OK, lady," I said. "I walk on 'em, too!"

Then, I noticed she lost one of her shoes. I picked it up and held it out for her.

"Here you go," I said. "That'll be $5."

Then we looked at the menu and decided on the breakfast buffet. We all got up and got into line and I noticed folks carrying little Styrofoam cups for coffee. I considered whether or not I wanted a cup of coffee.

Then, I woke up.

Odd.

JANUARY 18, 2009

I was a corpsman at Bethesda Naval Hospital, and I wanted the base newspaper to run a classified ad letting folks know about this website. This one. The one you are reading now. Yeah, I was a corpsman in Bethesda 36 years ago, but I still had this website. Go fig.

Anyhoo...

I went down to the Public Affairs Office and asked to see "Donna" who ran the base newspaper. She was just about to leave for the day, so I told her this was something we could talk about tomorrow. She said she had time, and we went into her office.

"I wanna show you something," she said and she pointed to a small room with a chair and what looked like photographic equipment. Sort of like one of those photo booth things you see at "Glamour Shots" or something like that. I had a seat, because it was obvious she wanted to show off her new equipment and I could tell her that I only wanted a classified ad, not a display ad, after the demonstration.

These two glass discs on metal arms pressed against my cheeks. I could see myself in a mirror, and the discs lit up as they pulled my lips into a smile. Then, two robotic arms holding a harmonica came down. The harmonica was pressed into my lips. "Now, blow," Donna said. I did, but could only get a feeble reedy discordant sound out of the thing.

"I have Parkinson's," I said, "so I'm not able to blow as hard."

"It's gonna stay there until you blow a perfect 'D'," she said.

Then, I woke up.

I dream the neatest stuff, don't I?

I remember various other snippets from earlier in the night, mostly seeming to have to do with traveling somewhere by airplane... but nothing I can put together into an actual narrative. The one I described is the last one I had before getting up.

JANUARY 20, 2010

OK, so last night I was an altar boy -- or something -- at my old church in Iowa. And there was a funeral that I had to prepare for. And the funeral was for Teddy Kennedy. I had to set up the candles to line up on either side of the casket, and I had to decide between using electric candles or actual wax ones. They brought the casket in -- it was white and the lid was slightly askew and I made every effort not to look and see the corpse inside.

After the service (which I don't recall), before they took the casket out, a bunch of people dressed in Scottish kilts and uniforms started bringing in ANOTHER body, but this one wasn't in a casket. It was wrapped in some sort of baggy canvas. I told them they had to wait in the sacristy until they got Kennedy out.

I went outside and watched from the side of a hill (of which there IS none at my old church) as they brought Kennedy's casket out. The lid flipped open, and I could see Teddy in there. The undertaker grasped the corpse by the shoulders and sort of shoved him down further into the casket. They closed the lid, and that's all I remember.

JANUARY 31, 2010

Evil Nurses are Calling Me a FAKER!!!

It's an odd thing. When I have one of my bizarre, vivid dreams, I rarely dream about having Parkinson's disease. I'm usually either back in the Navy, or traveling somewhere, or in Japan, or conversing with dead relatives who are, suddenly, not dead anymore.

Last night, I dreamed about having PD.

I was in a hospital being tested, and the doctor asked me to sit on the edge of my bed and lean forward. I did so and fell forward, smacking my right cheek on the cold tile floor.

"AHA!" a nurse shouted! "That SOUND he made right before he fell. It PROVES he's FAKING his Parkinson's!"

I asked her what the hell she was talking about, but she started walking down a hallway and the rest of the doctors and such just dispersed. I followed her and shouted...

"I'm going to report you to the nurse supervisor!"

She turned around and pointed to her ID badge, which clearly said "Nurse Supervisor."

"Well, I'll report you to YOUR supervisor, then!"

She gave me a dismissive wave and walked away.

That's when I woke up. And it took me three tries, using my walker, to get out of bed.

Still angry at the nurse in my dream, I muttered to myself, "Fake THIS, bitch!"

Then, I went and made coffee.

FEBRUARY 22, 2010

Let me start by reminding new readers that vivid dreaming is part and parcel of the Parkinson's experience. Every now and then, I have a dream that is sufficiently weird to where I like to share it with my readers.

OK, so I find myself in a hotel in midtown Manhattan. I have an appointment in the morning at Sirius Satellite Radio where a pal of mine from my XM days is supposed to meet me and get me in for an interview for a program director's job.

I get there early and since I no longer have an XM ID badge, have to be buzzed in. They tell me to wait in this side room with a bunch of empty tables and chairs, so I do.

A few minutes later, a lady walks in and tells me that she told someone else HE had the first interview. Only, she was interviewing people to make waffles in the cafeteria, not for a program director position. So, I had to leave the room.

I went back out to the lobby and checked my cell phone for messages from my friend to see why he was late. Not a word.

So, I left and went back to work at a radio station in West Bend, Wisconsin where I worked part-time in the early 90s. I had the overnight shift, and they had done some sort of restructuring to the studio. The microphone, tape players, turntables and all that were gone. There was easy-listening music playing, and there was a list of the songs being played taped to the front of a machine. But there was no way for a live announcer to interact with the music. All I could do was sit there.

Then, in the early morning, staff started to arrive. I tried telling the General Manager that there would soon be dead air because the last few songs on the list were playing and I had no idea where to find another tape -- or whatever it was -- that was playing. He ignored me.

The station engineer showed up, only he was another friend of mine from my XM days. I told him the same thing, and he went into his desk drawer and pulled out a bunch of charts and schematics so he could figure out what to do.

The last song finished, followed by dead air. "There's your dead air," I announced to no one in particular. I went outside to my car to drive home.

That's when a border collie nudged my bed and started whining because it was nearly 6 am and she hadn't been in the yard since 1.

Once again, reality intrudes.

5. SUMMING IT UP

As I sit down to finish this project, the date is March 9, 2010. My website is doing well – generally a couple hundred hits a day. A modest start.

In my search for Parkinson's disease-related news yesterday, I saw an interesting article in the Vanderbilt University Medical Center's newsletter – "The Reporter."

They're making plans to expand the DBS clinical trial beyond the original 30 patients – taking it to a bigger, multi-center trial involving hundreds of patients.

(Dr. David) Charles and his co-investigator, Pete Konrad, M.D., Ph.D., associate professor of Neurosurgery, are embarking on a two-year planning period to prepare for a large-scale study with representatives from Cleveland Clinic, Ohio State University, University of Cincinnati, Rush University, Emory University, University of California-San Francisco, University of Michigan, Stanford University and University of Florida. The Department of Neurology has pledged $100,000 to the planning effort, and the researchers have submitted a grant application for additional funding from Medtronic, the manufacturer. "We have been working on this for 10 years, and we need to be planning for the next study right now so we can get started once the pilot is complete," Charles said. "If we find something in the pilot that indicates we shouldn't proceed, we won't, but the likelihood of that is probably low. If we wait, that is just two years longer that patients have to wait for this answer."

That's wonderful news. It says that the preliminary data from the first part of the trial is sufficiently encouraging that

it's worth the time, money and risk to try it on a larger group of people.

I'm proud to have been one of the original 30. And, in the areas where DBS can help a Parky, mine is doing just fine. In the areas where DBS is not particularly helpful…

Well…

Gail is getting used to finishing sentences for me. When I'm calm and relaxed, the words come out pretty smoothly. When I'm stressed, I sound like Porky Pig. It seems like my primary effort these days is keeping my lungs and windpipe clear of phlegm. My chest muscles hurt, and the constant throat-clearing is driving Gail nuts.

Work proceeds apace. There are busy days and there are slow days. When things are slow, I try to work ahead. When things are really slow, I write.

I have no idea how long I have until things progress to the point where I'll have to retire. As I've mentioned, most folks 10 years after being diagnosed don't work anymore. But most folks are diagnosed later than I was. As long as I can still type, I suppose I can still work.

Parkinson's disease is a capricious bitch. It's different for everyone. There's no way to say with any certainty how it will progress. The first seven years were smooth. The last three, especially following the DBS surgery (but not BECAUSE of it) have been rough.

But I'm still here. To quote someone much wiser than I, "I may have Parkinson's, but it doesn't have me."

Thanks for reading this. I hope you'll continue to visit "My Parkinson's Disease Diary" online at http://www.parkinsondiary.com for the latest updates.

Be well. Hug a dog. And enjoy every cheeseburger!