

www.startribune.com/opinion/commentary/22122349.html

Watch where you're beaming that signal

By JACKIE HUNT CHRISTENSEN

June 29, 2008

In January 2006, I had my "battery-operated brain," also known as BOB, installed. What I mean is that I underwent two surgeries to have lead wires with electrodes implanted deep into my brain, which were then hooked up to neurotransmitter "pacemakers" in my chest. Medtronic pioneered this deep brain stimulation technology, which controls most of my physical symptoms of Parkinson's disease (PD) for most of each day. This technology has stopped the dyskinesia -- the involuntary writhing movements caused by Parkinson's medication that caused me to "swang" my body along like one of the Festrunk brothers (the "wild and crazy guys" from "Saturday Night Live"). Now I can do *almost* everything I could do before PD if I give myself enough time and revise my standards slightly. At least that's what I thought until I began learning about ways in which our ever-changing world of technology can affect my system.

You see, the neurotransmitters in deep brain stimulation systems produce electrical pulses in the brain similar to those made by a cardiac pacemaker. Although those pulses are delivered at different settings in each organ, their basic function is the same: to keep that particular organ operating as normally as possible. And you would probably think that as long as these pieces of electronic hardware and software are under unbroken skin and tissue, the systems are safe from harm. But you would be wrong.

When BOB was first turned on in February 2006, my programmer began a process of setting the voltage of each transmitter to its optimum setting for my body. (This process varies for everyone. Mine took six visits, about a month apart). She listed items and situations to avoid: large magnets, commonly found in refrigerator doors, grocery-store freezer doors and stereo speakers; metal detectors used in airport security; antitheft systems in stores; MRIs -- basically all large sources of electromagnetic interference (EMI).

Each time I see her, the list of potential problem products or situations grows: invisible dog fencing, home gaming systems with wireless controllers (Wii, Xbox 360, PS3), and cell phones in breast pockets.

It seems that every day, there is a new wireless product: light switches, pest-control systems -- you name it. And now the corollary products to *block* wireless signals are beginning to emerge, such as a Japanese device whose makers claim it can block cell-phone signals within 100 feet. If it can do that to a cell phone, what can it do to BOB and me?

The latest threat to make headlines: RFID (radio frequency identification) tags that hospitals use to keep track of their medical equipment! So now I am potentially at risk if I go to the very institution whose practitioners pledge to "first, do no harm."

Last October, I began having dyskinesia on my left side. I hadn't changed my medication. I couldn't figure out what might be causing it. Many phone calls, several hundred dollars in plane fare to see my neurosurgeon in Cleveland, numerous X-rays and a long session with a programmer revealed that *something* had caused the neurostimulator on my right side, which controls the left side of my body, to be reset to factory settings. The left neurostimulator had maintained its programmed settings. My neurosurgeon said he knew of only two ways this could have happened: equipment failure (which seemed unlikely, because the device was reprogrammed and, within an hour, I felt fine) or exposure to a large source of electromagnetic interference. But I always go out of my way to avoid known sources of EMI. So what could it have been?

I now find myself cringing whenever I hear of a new wireless widget, as I wonder what its implications will be for BOB and me, and for those with cardiac pacemakers or defibrillators, which could also be affected. Some of us seem to be more sensitive to sources of EMI than others. We are the proverbial canaries in the coal mine.

This canary is not going to go quietly, nor simply begin building a nest of tinfoil to block the electromagnetic interference. No, I plan to sing -- and to call on Congress to force the Federal Communications Commission to implement Public Law 97-259. This law, enacted in 1982, gave the FCC the power to regulate the makers of consumer products that can generate EMI. The FCC abdicated that power, instead allowing the electronics industry and others to come up with standards and voluntary compliance plans that we've seen fail in so many other areas.

I urge all of the other canaries out there, such as pacemaker patients Dick Cheney and Sen. George Voinovich, and employees at medical-device manufacturers Medtronic, Guidant, St. Jude Medical and others, to join in my song.

Jackie Hunt Christensen, Minneapolis, is a Parkinson's disease and environmental health activist.

© 2008 Star Tribune. All rights reserved.