

# Jim Hill's Journey with Parkinson's

Teri my wife and my daughter Alea observed Parkinson type symptoms in me. Not much arm movement or rhythm when walking, balance a bit off and my morning newspaper didn't want to hold still for me to read. It was time to get answers.

**And so my journey with Parkinson's disease began in 2007.** I was first diagnosed with Parkinsonism but not Parkinson's. I didn't really understand all of this; the true PD flag was raised in 2007. I was started on Requip; it didn't have any effect on me. So I switched to Carbidopa-Levodopa (Sinemet), considered the Gold Standard. The meds helped control the slurred speech, mild tremors and more. I thought it worked pretty well.

Once you've been diagnosed, educating yourself about PD is very important. Prior to the pandemic my wife and I attended numerous meetings, conferences, support and exercise groups. Since the pandemic Zoom classes and webinars are our means of staying in touch with others about PD. **If there were one comment I would make - don't get obsessed with PD and let it become the focal point of your life. Relax and enjoy; take each day as it comes.** It will be a challenge, but try to do it.

**Informing myself - hearing doctors speaking, attending support groups, seminars - helped guide us along the way. Teri was always with me and we would talk about what's next and what options we had.** Together now for 43 years of a wonderful marriage. Along the way I have been treated for these PD symptoms: tremors, freezing, dyskinesia, dystonia, low blood pressure, high blood pressure, constipation, foot drop, restless leg syndrome, fatigue, sleep disorders, acting out dreams, depression, poor balance, falling. Over time my health declined.

I heard about DBS - Deep Brain Stimulation - and listened to top physicians discuss this and some other possible remedies. DBS is a huge decision. I found out I was a good candidate in the initial round, but would have to have more extensive testing before I could be officially certified and accepted.

**I discussed DBS with Teri and other family members before I had the surgery in 2014.** I had no problem with the surgery; it was a 3-step procedure. My daughter Alea shaved my head. And she shaved others in my family.

I was surprised when I saw that my son Justin, Daniel my son-in-law and Andrew my 2-year-old grandson were ALL bald too. This support meant so much to me. My daughter not only shaved heads, she had a tee shirt made for me that said: "Bald and Ballsy." I wore it into the operating room and announced to the surgeon "Go ahead - Make my Day!"



Jim Hill with his DBS tee-shirt

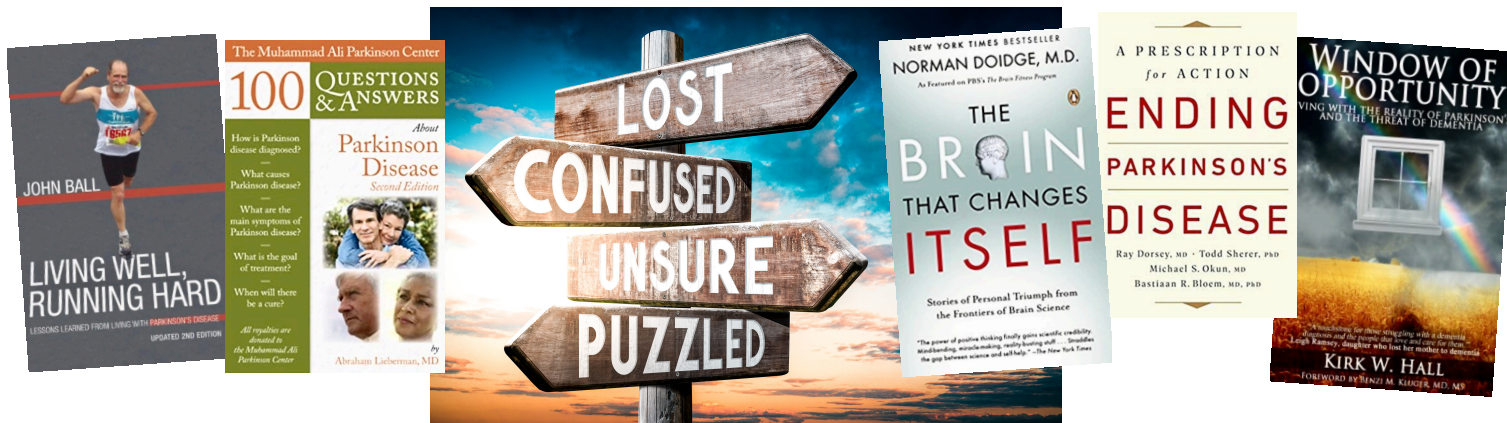
**After the DBS surgery in 2014, my gait and balance improved and I had better voice and movement.** Videos were taken prior to the surgery and again afterward. You could watch me in the before video; I was wobbling and found it hard to speak clearly. After the surgery, my video showed improved walking and that my speech had improved.

Over the years I have had some periodic adjustments of the DBS control unit to adjust to PD that keeps progressing too. Some tune-ups have been better than others. **In 2016 I had my best ever tune-up; I could talk clearly. My walking and talking were much improved. I felt normal again.**

**In 2017 I experienced a problem with feeling an electrical impulse, like a tenz unit, behind my right ear.** It took a year to get x-rays, MRIs and other imaging and to get someone to solve the problem. Finally as 2017 ended my DBS controller was replaced and I haven't had any problems since. **In June 2020 I had a heart attack and a pulmonary embolism that December.** Each time within 2 or 3 days after I was home from the hospital I was outside exercising on my bike. In time I returned to exercising 2 or 3 times a day.

When you think you may want to consider DBS go to a presentation or webinar with your caregiver or spouse. Check out the main companies making DBS units. Check statistical figures. Do you have to recharge the battery? How often? For how long? This is a huge decision so make sure you have asked all your questions and are comfortable with the answers.

Jim Hill's story continues on page 6



## These books are recommended by our members

### **Brain Fables: The Hidden History of Neurodegenerative Diseases and a Blueprint to Conquer Them**

by Alberto Espay & Benjamin Stecher  
*Focuses on how each person lives and ages as advancements in medicine seek to achieve personalized treatments to meet individual needs.*  
 Cambridge University Press, 2020  
 Recommended by Tim Sheehan

### **Ending Parkinson's Disease: A Prescription for Action**

by Ray Dorsey, MD, Todd Sherer, MD, Michael S. Okun, MD, & Bastiaan R. Bloem, MD  
*Cites recent statistics and research. Advocates making cure for PD a united effort.*  
 PublicAffairs, 2020  
 Recommended by Donna Rosenheck

### **My Degeneration: A Journey Through Parkinson's**

by Peter Dunlap-Shohl  
*A cartoonist, the author demonstrates a powerful purpose for graphic comics*  
 Penn State University Press, 2015  
 Recommended by Robyn Perlow

### **Bottle of Lies: The Inside Story of Generic Drug Boom**

by Katherine Eban  
*Written by an investigative journalist. Jim Histan says, "Anyone taking generic medications should become informed how these drugs affect, or do not affect, patients."*  
 ECCO PRESS, 2019  
 Recommended by Jim Histan

### **The Brain's Way of Healing: Remarkable Discoveries and Recoveries from the Frontiers of Neuroplasticity**

by Norman Doidge, MD  
*"Graphic personal stories that demonstrate that we truly do not know the limits of what is possible in rehabilitation."*  
 Penguin Books, 2015  
 Recommended by Glenn Kuhel

### **The Brain That Changes Itself: Stories of Personal Triumph from the Frontiers of Brain Science**

by Norman Doidge, MD  
*Neuroplasticity: the ability of the brain to form and reorganize synaptic connections, especially in response to learning or experience or following injury. Doidge provides unique perspectives to explore this concept.*  
 Viking, 2007  
 Recommended by Jeri Altstadter

### **Living Well, Running Hard: Lessons Learned from Living with Parkinson's Disease**

by John Ball  
*Diagnosed with PD before he turned forty, this memoir is John's story of how he's lived with Parkinson's disease. Spoiler alert: he decides to take up running with a marathon as his goal.*  
 iUniverse, 2007  
 Recommended by Donna Rosenheck

All of the books by Michael J. Fox (born 1961 in Edmonton, Canada) were recommended by many in Tremble Clefs, including John Sylvester, Carol King, Phil Segadelli and Kirk Hall. All are available in print editions, on Kindle & audio. Mr. Fox has written four autobiographical books detailing what it is like to live with Parkinson's disease. They are listed below.

### **Lucky Man: A Memoir**

by Michael J. Fox  
 Hyperion, 2002

### **Always Looking Up: The Adventures of an Incurable Optimist**

by Michael J. Fox  
 Hyperion, 2008

### **A Funny Thing Happened on the Way to the Future: Twists and Turns and Lessons Learned**

by Michael J. Fox  
 Hachette Books, 2010

### **No Time Like the Future: An Optimist Considers Mortality**

by Michael J. Fox  
 Flatiron Books, 2020