

Wilderness House Literary Review 14/3

Douglas Hawley
Balance

On June 23 2005 a fellow hiker got a request from The Balance Disorders Lab of Oregon Health & Science University (OHSU) to find males from ages 52-73 to join a balance study with the goal of better treatment of Parkinson's disease. At that time I was a male of age 62, and it sounded interesting to me. I had not had much knowledge of Parkinson's, but another fellow hiker had died of it. Another fellow hiker joined the study as well.

How bad is Parkinson's? In American 60,000 are diagnosed a year. Men are 150% as likely as women to get it. More people have it than MS, MD or ALS combined. The annual cost is \$52 billion in the U.S.

The response to my request to volunteer:

The purpose of this research is to determine how deep brain stimulation (DBS) and levodopa influence abnormal patterns of walking and balance movements in patients with Parkinson's disease. You are invited as an age-matched control.

You will be asked to undergo clinical tests of your balance and walking (e.g., standing with your eyes closed, standing on one foot, walking, turning, etc.). You will also be asked to stand on a movable platform. On some trials you will be asked to simply stand quietly or asked to take a step. On some trials, the platform will move and you will be asked to try to keep your balance without stepping. During all these trials, your body movements will be recorded by small movement sensors that will be attached to your body. Small self-adhesive electrodes will be placed on the skin over selected muscles of the leg, thigh, and trunk to record muscle activity as you move.

Some criteria that would make you not eligible for such a study would be past orthopedic surgery (hip, knee, back) or any sensation loss in your feet.

I found out later that Levodopa is synthesized into dopamine in the body and is a common drug for Parkinson's because loss of dopamine neurotransmitter is the cause of Parkinson's disease.

I passed all of the criteria and set up my first appointment for August 22.

The initial study was at the main OHSU facility at "Pill Hill" because of its location on a hill and its medical facility. The proper name is Marquam Hill after some early Oregonian. I have been told that a railroad bought the area before finding that it was a hill, and then donated it knowing that it was not a good place for a railroad line.

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My invitation to a mouth motion study:

Wed 7/27/2005 3:23 PM

You

Dear Mr. Hawley, Thank you for interested (sic) in becoming our control... As you might have heard from xxxx about the DBS study for the Parkinson's patient, we are a part of the study.. We focused on jaw & facial movement... I am working for Dr. xxxx.. This study has been going on for about 8 years or so... We are testing to see whether the Deep Brain Stimulators (DBS) implanted in the Parkinson's patient is helping them or not. In doing so, we need control subjects that age & gender matched with our Parkinson's patient to compare the results... The testing should be done within 1 to 1 1/2 hours.. A small piece of magnetic (sic) is placed on the lower jaw with the head frame around the head to detect (sic) the jaw & facial movement with the electromagnetic field.. We are asking you to perform the basic jaw movements such as open & close your mouth, bite on cotton roll, chew gum, and bite on carrots... These tasks are easy for normal people, but can be very difficult for Parkinson's patients... If you are interested in becoming a control subject, I would like to schedule you for August 3rd or August 10th (after August 22nd is okay, too)... I am looking forward to hear from you.. I can be reached at (xxx) xxx-xxxx..

The session was much as described. The interesting part was the apparatus attached to my face. I asked for and got a picture of me during the study. I looked like Hannibal "The Cannibal" Lecter when he was imprisoned.

There was another study on "Pill Hill" which tested reaction time with something like a simple computer game on a computer screen. Both hands were tested and unsurprisingly my non-dominant hand (left) was slower to react. Everything else was at the balance lab.

The balance studies were much as indicated:

They pulled the rug out from under me (actually moving a steel plate without warning). I had a harness on, but didn't need it. I found that my reaction was to step forward with my dominant right leg and go into a semi-kneeling position. That was completely involuntary; there was no time to think.

I failed miserably at walking in a straight line while blindfolded.

I was fairly good at walking in a circle and ending where I started while blindfolded.

While walking I counted backwards by threes from a number announced as I started. Example - Researcher 88 go. Me 85, 82, 79, This was to test multi-tasking which they said was more difficult for a Parkinson's brain.

Another test of multi-tasking was starting walking and saying names of either males or females in alphabetic order. Example Abe, Bob, Carl,

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Staring at a wall or a picture showed in one case that I could fall asleep standing up. Their electronics confirmed my impression. I later used that skill in the fiction "Court" about someone listening to a really boring speech.

Besides the electrodes, light reflectors were attached. They could be used for motion capture like films to aid motion analysis.

I had to skip one session because of a very painful foot. Another time I kept quiet and suffered though the session. In 2014 after my part was concluded, I had serious foot and knee problems for months, which were helped by what I call bracelets around my knee. None of my foot or knee problems were caused by the study.

Age, height and weight were used to match me with me with a person with Parkinson's. I believe that my experience with yoga and as a hiker and a park steward probably made me better than average with balance. Those activities require a lot of experience balancing and falling.

Occasionally there were interns who helped and learned. They were from different countries, but all were young and attractive. The Italian was complimentary about my muscle tone and conductivity. I would have been more pleased if it had been a she rather than a he, but still good.

A part of the study took place outside of the lab. For several months my wife and I kept a falls diary. It was for detailing all of my falls and near falls for the time that it was maintained. At first I was very careful not to fall, but I was told to behave normally. With my park stewardship and hiking, I was frequently on vine covered hillsides which could be wet and slippery. As a result, I fell a lot. I inferred that they were looking for falls around the house, so results surprised them. Every time that I reported my many falls, they would ask what drugs I was taking. My most extreme report was on a hot day when I was dehydrated. The terrain was treacherous and I had a very painful foot. I had three falls in half an hour. My reports would have more extreme if I had reported "near falls".

There was a get together which included both controls and Parkinson's people. I made the insensitive mistake of introducing myself to a victim of the disease as a "normal" rather than a control subject. The investigators summarized the results of the study. It showed that, despite many benefits of DBS for signs and symptoms of Parkinson's disease, jaw movements and balance are not improved, and may worsen after surgery.

I missed out on a potential brain study because of scheduling and equipment problems. When I was available, the equipment wasn't and when the equipment worked, I wasn't available.

At the end of the study we were treated to review of the results.

After my participation in 2012, I ran into a few people who had Parkinson's. One was in my high school class. He had stem cell treatment, but died about a year ago. The husband of someone in the same class had DBS. Because he was bald, the implant on his head was easily visible. Both a grade school crush of mine and a neighbor attended specialized Parkinson's classes at our gym recently.

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I've done several volunteer things – flower basket hanging, China Camp docent on the San Francisco Bay, wheelchair jockey / unpaid escort / pusher at a local hospital and the aforementioned park stewardship. The balance study was the most entertaining – I never knew what would happen when I showed up – and the best potential for helping mankind.

This website has information on the Balance Disorders Laboratory <https://www.ohsu.edu/xd/education/schools/school-of-medicine/departments/clinical-departments/neurology/research/horak-lab-balance/> in case you want to volunteer to be a subject in a future study.

After all these years my remembrance is a bit fuzzy, but I have consulted all of my correspondence with OHSU and talked to my live in editor.

Since I wrote this I have OHSU has solicited me to have my head examined in another study. This study asks the question “Do social contacts, particularly conversations help the brain”. I'm probably qualified for this study because I don't have many close contacts, avoid long conversations, hate phones, and never text. The study involves lots of phone or video conversations, so maybe I'll get a better brain. We will see.