

My Parkinson's Story
by Greg O'Keefe

I used to play pool and ping pong, and adult-league soccer and softball. When my skills started to decline, I chalked it up to old age (I was approaching 40) and moved on. By my early 40s I was playing lots of World of Warcraft (WoW) and getting out of shape. I started running and exercising so that I would be around longer for my kids, be able to do more with them, and set a good example for them to follow. By January 2013 my training runs were up to 14 miles, so I signed up for my first half marathon. That Spring I completed the Red Rock Canyon half marathon in 2 hrs 30 min. I ran less over that summer, but when I heard about the Rock'n'Roll marathon I decided to give it a shot. I registered, and I raised the intensity of my training starting the first week of August.

Before the end of the month I was experiencing occasional cramps (while running) in my right foot. I was determined to go the distance, so I kept on running and tried a variety of work-arounds. I experimented with different strides and cadences, high-stepping, side-to-side stepping, and changes to electrolytes before and during my run. Nothing helped reliably, but I learned that I could always make the cramp go away by walking for 5 to 15 sec.

My final long training run was around 21 miles, right at the end of October. I did not intend to stop training, but I got sick. I had a sinus infection and wanted to be healthy by the day of the race, so I stopped running.

On race day I was well-rested, but I was out of shape, and I was still on antibiotics. I ran anyway, and the problem with my foot was worse than ever. I did not want to stop and stretch during the race, so I implemented a different work-around. I ran normally on my left foot, and I hopped on my right foot. It worked pretty well. My pace was fast (for me)—I ran about seven miles in the first hour. However, all that hopping made my knee sore, and after an hour the pain was so bad that I walked the rest of the way, settling for a half instead of a full marathon.

With no more pressure to meet a deadline, I took a break from training and started thinking more about what to do next. What was wrong with me? What kind of doctor should I see? Physical therapist? Chiropractor? I decided to go to an orthopedic surgeon foot and ankle specialist, and I learned that there was nothing structurally wrong with my right foot. In the doctor's opinion, that left only two possibilities: electrolytes or a neurological issue. I had several years of electrolytes numbers to eliminate that as a possible cause. That was Spring 2014, but for a variety of reasons it was two more years before I finally saw a neurologist. During that time I experienced a continual degradation of balance and coordination, primarily on my right side. Not only was I no longer running, but I stopped playing WoW and other computer games when I could no longer control the mouse.

During a series of appointments the neurologist watched me walk, took a handwriting sample, tested my forearms for nerve damage, and sent me for an MRI to check for ALS. All tests were negative, so the last one was a DAT scan to check for Parkinson's. It was positive. I wanted a second opinion, so I made an appointment to see a movement disorder specialist (MDS) at Lou Ruvo Center for Brain Health. No tests were necessary—he took one look at me and knew right away that I had Parkinson's Disease.

While it was a relief to finally know the cause of my problems, the diagnosis was somewhat surreal. It took some time to accept it as the new normal. I read a lot to learn more about the disease and had

plenty of time to rethink things like my poor performance in sports and games. Could that be related to my diagnosis? Maybe. It is impossible to say exactly when the disease started.

I was so impressed by the people at Lou Ruvo that I decided to stop seeing the other neurologist. There were two things I could do to help manage my symptoms. I started exercising more (although the intensity was too low in the beginning), and I volunteered for a clinical trial. My reading led me to discover Rock Steady Boxing (RSB), but my initial impression was that it was not for me. A year later the MDS at Lou Ruvo recommended it, so I tried it out. Surprise—I loved it! I am now in my third year post-diagnosis and my second year of RSB. I have pushed myself hard at the gym, and I am now able to split my time between RSB and regular classes. I've started running again, albeit with frequent stops to stretch out the cramps in my right foot.

What does the future hold? I don't know, but I do know that I need more exercise, more sleep, and less stress. Maybe a better diet, too.

To keep myself motivated, I've borrowed a saying from the Navy SEALs: "The only easy day was yesterday." I don't go to the gym to take it easy!

And here is something that I came up with:

Exercise is dopamine. Dopamine is movement. Movement is life!