Our Clinical Study Experience with Parkinson’s Disease

By Leslie Peters

A clinical study gave my husband a new purpose in life.

My husband, Steve, and I have lived in Colorado Springs for two years. Before that, we lived outside Denver, where he was an executive in the treasury department of a financial services company and I was the insurance pre-authorization coordinator for a large cardiology practice. We have two children: Noah and Amanda.

In 2006, when Steve was 43, he started dropping pens, hitting the wrong keys on the keyboard, and spilling drinks. Then he started having problems walking. Steve had always been active in the community and loved the outdoors, but he became self-conscious and couldn’t move around well, so it really interfered with his life. Mine, too. We both felt isolated.

It was not until 2013 that a movement disorder physician diagnosed the cause as young onset Parkinson’s disease. If no shaking is 100%, he was at 25%. Parkinson’s is also often associated with cognitive, GI and other problems, so it’s quite a burden. Fortunately, my hours were flexible, and I could work at home three days a week.

Medications didn’t help much, so in April 2015, Steve enrolled in a clinical study of Boston Scientific’s new deep brain stimulator, which has eight electrodes instead of four, so it can work on both sides of the body. Steve wanted a cure, of course, but he also wanted to do something useful. He couldn’t work, and his hands shook so badly; he couldn’t even pay the bills at home. The study gave him the chance to do something useful.

Steve experienced a “honeymoon” effect after the surgery before the device was turned on — apparently, that’s common. But after it was turned on, the difference was night and day. He was back to 100%. We really saw the difference when, at one point, he accidently turned the device off, and we saw how far the disease had progressed.

Steve hasn’t been able to go back to work because of cognitive problems, but he’s found a new purpose in life: running a support group for the Parkinson’s Foundation. He can do that fine — he’s good at it. Our son, Noah, is doing some fundraising work and has joined us on Capitol Hill to meet with legislators and their staffs to discuss policy issues.

Clinical researchers should really spend time with people who have the disease they are trying to treat and their care partners. We can learn a lot from each other, as individuals, and there is no substitute for that person-to-person connection. The Parkinson’s Foundation brings researchers, physicians and patients together, and the result has been amazing. Their website is parkinson.org.

The Foundation is a great source of support and information for patients and also care partners, which is what I’m called now. I feel honored to serve on the Parkinson
Foundation’s People with Parkinson's Advisory Council. Next spring, I might speak at their care partners summit. Caring for someone with a disease like Parkinson’s can be overwhelming, so care partners should take it one day at a time and ask for help when they need it. Everyone is so focused on the patient, they might not notice if the care partner is struggling.