

Not Ready To Throw In the Towel:

Suzanne F.'s DBS Story

Suzanne Friedman, a 54 year-old Florida native, has run a marathon, traveled around the world, and raised two children with her husband of 25 years, Steve. “We’re [a] very, very active [family]. We just came back from Colorado where we were hiking and white water rafting.”

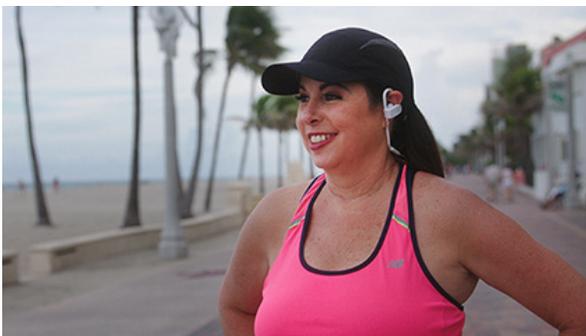
About seven years ago, something started to change for Suzanne. The very first symptom she noticed was when she was walking on the beach in flip-flops. Her shoe kept slipping off and she didn’t understand why. Soon after, she began to notice her left leg shivering a bit while working at her computer in the morning. She asked her husband if he noticed anything strange with her leg. “It was almost like [it was] plugged it into a socket and it was vibrating.” No one else could see it or feel it, but it continued to plague her. Eventually, Steve started to notice that she was dragging her feet, and encouraged her to see her doctor, but Suzanne was resistant—whatever it was, she didn’t want to know.



At her next annual exam with her primary care doctor, she mentioned it, and her doctor told her it was probably a pinched nerve. She went to a neurologist for further evaluation, and it was then that she was diagnosed with Parkinson’s disease—a diagnosis that was soon after confirmed by another specialist.

“I came to terms with the fact that if I wanted to get better, the only way [I felt] I was going to get better was through Deep Brain Stimulation.”

After her diagnosis, she went into an emotional tailspin for about a year. “When you start reading on the computer about what your life’s going to be like, it’s scary.” One of the things the specialist told her is that “if you want to keep moving, you better keep moving.” As a person who was already committed to an active lifestyle, Suzanne re-upped her commitment. From that day forward, she allocated an hour each day to exercise, even joining an intense boxing class designed for people with Parkinson’s disease.



But despite her best efforts, the Parkinson’s disease continued to progress. The medicine began to make her tired and eventually it stopped working consistently—she couldn’t count on it anymore. She would wake up multiple times in the middle of the night needing to use the bathroom, but often wouldn’t be able to get herself in and out of bed. Trips to restaurants, stores, and special events like weddings became unpredictable and anxiety provoking. “Sometimes, I went into the grocery store, I’d fill up [my

cart] and all of a sudden, the medicine would kick off. I'd leave my groceries and go because I just never knew."

When it got to the point where she almost couldn't walk, she decided that she had to find out if there was anything else at all that she could do. Suzanne started doing research online, and when she came across information about deep brain stimulation (DBS), she became hopeful.

The next time she saw her doctor, she asked him about it, but he was against it. Steve remembers her doctor saying "Forget the DBS. There's this new medicine that's coming out. There's an inhaler that's coming out. There's a strip that goes under your tongue, that's coming out. It's all going to be great!" But she tried them and they didn't work, and many had adverse effects on her. Finally, Suzanne said to the doctor, "You know what? I've been waiting for seven years for a medicine to make me feel better and every time they come out, I have other side effects. I'm tired of waiting. I'm watching the years go by, I need to do something now."

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Even though her doctor did not seem to feel comfortable talking to her about DBS, she continued to do research. "Computers are a wonderful thing!" She joined online support groups and reached out directly to nearly twenty people to speak to them about their experiences.

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Her brother is a doctor, and helped her research the best place in the area to get it done, as well as which DBS system would be right for her. After her extensive research, there were three reasons Suzanne ultimately chose a Boston Scientific DBS system.

First, was the size. "I felt very comfortable that it was a very small size and it wouldn't show. I had seen people that had other devices that stuck out of their chest, and mine, I [felt] I could wear a bathing suit with it and nobody would notice."

The second reason was the technology. "Even though it's new to the United States, I found that it had been out in Europe for many years. For me it had the most up-to-date technology, and I thought to myself, 'Why wouldn't you want the latest?'"

And last, there's the battery. "I don't want to go through another surgery until I have to. I know some other devices say they might last five years, but I would rather have a device that lasts at least 15 years."*

Suzanne finally had her Boston Scientific DBS system implanted. On the day that the device was "turned on,"



she brought Steve and her daughter with her. Steve recalls how nervous Suzanne was, worrying that it wasn't going to work. "We were sitting there and her leg is shaking, her foot is shaking. They turned on the device and all of a sudden, the foot stopped. They turned it off and the foot started again. Turned it back on, the foot stopped. My daughter started crying." After the programming, the three of them went out to eat, and Suzanne was walking like her old self again.

"Now there's nothing that she really can't do. She feels whole as a wife and a mother. She [drives], she goes shopping... We just went away and were hiking, and she was way ahead of me. I couldn't keep up with her. I'm very grateful."

For Suzanne, one of the greatest gift DBS has given her is consistency. "Life before DBS was a struggle. I was suffering every day. Now, [my experience has been that] I don't have to worry about whether my medicine works, whether it's not going to work, when I have to eat, when the next medicine's due. I'm sleeping better, not napping every day, being able to stay up late. Everybody keeps telling me that I seem happy and that they see me smiling more. DBS has brought my personality back."

Steve adds, "Now there's nothing that she really can't do," Steve said. "She feels whole as a wife and a mother. She [drives], she goes shopping... We just went away and were hiking, and she was way ahead of me. I couldn't keep up with her. I'm very grateful." On their next trip, the family plans to go skiing.

Suzanne doesn't understand why more doctors don't encourage DBS for their Parkinson's disease patients.



"[What] I have learned is a lot of older people don't know anything about [it]. Their doctors don't even tell them about it."

Suzanne happily talks about her experience. A few weeks ago, a young man in his thirties with Parkinson's disease who's considering DBS called Suzanne. As they were finishing their conversation, Steve said "You know what? Let me get on the phone with this guy." Steve shared the dramatic changes that he'd seen happen for Suzanne with DBS, and "the guy started crying on the phone. He was crying just to know that he [may] be normal again."

Steve added this final note: "For anybody who's thinking about going for DBS, there is hope. I know everybody has that fear factor. When you read about it, it's invasive, but it is so well worth it. There is no reason to give up. There is hope."

*Battery life is dependent on the stimulation settings and conditions.

Results from case studies are not necessarily predictive of results in other case studies. Results in other studies may vary.

Indications for Use: The Vercise™ Deep Brain Stimulation (DBS) System is indicated for use in bilateral stimulation of the subthalamic nucleus (STN) as an adjunctive therapy in reducing some of the symptoms of moderate to advanced levodopa-responsive Parkinson's disease (PD) that are not adequately controlled with medication.

Contraindications: The Vercise DBS System is not recommended for patients who will be exposed to the following procedures: Diathermy as either a treatment for a medical condition or as part of a surgical procedure, Electroconvulsive Therapy (ECT) and Transcranial Magnetic Stimulation (TMS). The safety of these therapies in patients implanted with the Vercise DBS System has not been established. Patients implanted with the Vercise DBS System should not have Magnetic Resonance Imaging (MRI). The Vercise DBS System is not recommended for patients who are unable to operate the system or are poor surgical candidates or who experience unsuccessful test stimulation.

Warnings: Unauthorized modification to the medical devices is prohibited. You should not be exposed to high stimulation levels. High level of stimulation may damage brain tissue. Patients implanted with the Vercise DBS System may be at risk for intracranial hemorrhages (bleeding in the brain) during DBS lead placement. Strong electromagnetic fields, such as power generators, security screeners or theft detections systems, can potentially turn the stimulator off, or cause unpredictable changes in stimulation. The system should not be charged while sleeping. If you notice changes in mood or behavior or have thoughts of suicide contact your physician immediately. Chemical burns may result if the Vercise Stimulator housing is ruptured or pierced. The Deep Brain Stimulation System may interfere with the operation of implanted stimulation devices, such as cardiac pacemakers, implanted cardioverter defibrillators, or medication delivery pumps. Patients should operate motorized vehicles or potentially dangerous machinery with caution. It is unknown if the device may hurt an unborn baby. Your doctor may be able to provide additional information on the Boston Scientific Vercise DBS System. For complete indications for use, contraindications, warnings, precautions, and side effects, call 833-DBSINFO or 833-327-4636.

CAUTION: U.S. Federal law restricts this device to sale by or on the order of a physician

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