

On My Feet Again

JENNIFER FRENCH



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*For my husband, Tim, who is
My biggest critic,
My toughest therapist,
My loudest voice of reason, and
My dearest friend
With love*

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Foreword

by P. Hunter Peckham

I first met Jen French early on during her participation as a research subject—really a test pilot—in our research program. I was the Director of the Functional Electrical Stimulation Center where the research was being conducted and I was told that I should meet her because we had a common interest in sailing. Nothing brings people together like a common love—and for us it was sailing. So it was that I met one of the strongest and most courageous people that I have had the privilege to be around and to work with.

People who choose to participate in human research truly are test pilots. They take upon themselves, possibly for no personal gain, the risks associated with being a pioneer—going where no one or only few have gone before. Although risks versus benefits are carefully evaluated by regulatory bodies before any study can be undertaken—and researchers carefully document those risks and potential benefits—it is still a journey into the unknown for those who decide to participate. In this case, Jen was to become one of the early pioneers evaluating an implanted electrical stimulation device intended to assist her in standing. The possible risks included infection, rejection of the device by the body, and failure to perform the standing function as intended. These test pilots are not frivolous; they are most careful in asking critical questions and evaluating their own personal choices of the potential outcome for them. But they also assess selflessly their contribution to the greater good—to people like them who have sustained similar injuries and may benefit from

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their contribution even if they themselves do not. They give of their time—and of their body—and journey into the unknown for a greater good to society.

Jen's story is remarkable in every respect. After a life-changing snowboarding accident, which instantaneously took her from an avid outdoor sports enthusiast to wheelchair dependency, she fought back to find the resources that would again enable her independence. That is how our paths crossed, as she looked for research that was ready for prime time to assist her in achieving her goals. For Jen, her participation in the research has enabled her to gain significant capacity to stand and walk, even walking down the aisle at her wedding. She has gone on to have an advanced device implanted, providing even greater function. Only she can say how many of her goals have been achieved, but suffice it to say that every test pilot wants to test the limits of how far they can push the envelope. They always strive for a higher goal.

I would not want to sail competitively against Jen. She is meticulous, calculating, and fearless. She understands the rules of the game, and puts together an unbeatable game plan. You want her on your boat—on your team—she is a winner. And this is the best part for me. We *are* on the same team! And the sport is not a sport at all—it is a mission. And that mission is to ensure that people who have sustained spinal cord injury will always have access to this life-altering implantable stimulation technology.

What began as two sailors talking has become a deep relationship of two people with this common goal. For many with spinal cord injury, this technology offers the best near-term solution for restoration of critical body functions, and to fall short of this goal would be to shortchange thousands of people of key benefits for their health and independence.

Our society is indebted to pioneers like Jen who have the courage to live their convictions, to put themselves on the line, and to work tirelessly to provide a better life for an entire class of disabled people. Jen's willingness to "put herself out there," to be the best that she can be, to challenge herself in every di-

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mension—whether it be competitive sailing or advancement of research—is truly an example of the greatest spirit of mankind.

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Acknowledgments

In this book, I've mentioned members of the research team including the surgeons, the engineers, and the therapists. The small team that interacted with me on a daily basis is key to the value of the research. Dr. Ron Triolo is the principal investigator, lead engineer, and maestro of the research team. At times he would pace the floors and at other times he knew how to step aside and let his talented team do their work. He is the brains behind the system that I enjoy today. In the words of a post-doctoral student of his, "Ron is a god of biomedical engineering."

Along with this close research team, there are engineers, like Mike Miller, Stephanie Nogan Bailey, Dawn Lissy, Tina Vrabec, and Jim Uhlir, who are great troubleshooters and translators of engineering lingo. The administrators who dealt with my needs, like Jeanne Teeter (may she rest in peace), Mary Buckett, Julie Jacono, Laura Polacek, Cathy Naples, and Cheryl Dudek, showed a lot of patience. The doctoral candidates that worked in this project have come and gone over the years, like Sahana, Kofi, and the illustrious Dr. Fisher. The full team of surgeons are some of the most talented in their field with a bedside manner and a sense of humor: Dr. John "Chip" Davis, Dr. James Anderson, Dr. Harry Hoyen, Dr. Gilles Pinault, and Dr. Kutaiba Tabbaa. You have given me the J-Lo butt. The team of nurses: Ruth, Debbie, Mary Beth, Mary Anne, Nancy, and Cathy (who exercised with me) plus Jeanne and Barb gave exceptional care like I've never experienced and would join in sing-alongs from the Muppets and Disney. Because of Barb, I will always know the words to "I Never Go to Work," and will continue to work on my arm wrestling abilities. The therapists in the program prob-

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ably had the hardest job: dealing with me on every visit. They are talented and truly led the research team to customize a great system. Carol Bieri (may she rest in peace) and Lori Rohde were my cat-loving friends who could always fill the time with another cat story. To Lisa Lombardo, I hope you are impressed.

These are only a few of the research team who touched me. In reality, there is an army of people working on developing this device from the Cleveland FES Center and the Advanced Platforms Technology Center.

There are also the hidden heroes. I've been fortunate to have an incredible support network. My husband, Tim, has sacrificed so much to help me from surgery recovery to functional use. He has become harder on me than the therapist, but I love it. My in-laws, Betty and Joe, are loyal cat-sitters and help with the cleaning while I'm away. My sister Chris and her family have hosted me in their home for the many visits to Cleveland with countless meals and scheduling arrangements. My father, in the early days, would drive and sometimes just accompany me to the lab. His inquisitiveness always kept the conversation flowing. My previous employer, PC Connection, was supportive of me participating in the research and was flexible with my rehabilitation and work schedules.

This book wouldn't be complete without recognizing my Mom. What a trooper; meeting me at the airport in wee-hours of the morning, driving me between hospitals and laboratories, waiting while I have secret squirrel meetings and tests, and pitching in when the research team needs a hand. And the cookies! The research team will forever be spoiled by my mom's cookies. Over the course of time, she has become a member of the research team. She is a true hidden hero.

The research projects that I was able to participate in would not have been possible without the support of the funding agencies that believed in the concept and allowed the research team to make it a reality. The Rehabilitation Research and Development Service of the U.S. Department of Veteran Affairs has been a long time supporter of this research. Yes, these projects are partially funded by the VA. Although I am not a veteran, being

Acknowledgments

a participant in a VA sponsored program is one way that I can give back to our wounded warriors living with spinal cord injuries. One day, they will benefit from the discoveries and assistive technologies resulting from this research. Support for the development and implementation of my systems were also provided by the Office of Orphan Product Development (OOPD) of the U.S. Food and Drug Administration (FDA), the National Institute of Biomedical Imaging and Bioengineering (NIBIB) of the National Institutes of Health (NIH), the Clinical and Translational Science Collaborative (CTSC) at Case Western Reserve University and the Cleveland Clinic Foundation funded by the National Center for Research Resources (NCRR), a component of the National Institutes of Health and NIH roadmap for Medical Research. Generous institutional support was provided by Case Western Reserve University, MetroHealth Medical Center, and the Louis Stokes Cleveland Department of Veterans Affairs Medical Center. Additional support was provided by the Neural Prosthesis Program of the National Institutes of Neurological Diseases and Stroke (NINDS) of the NIH.

This book is an acknowledgment of the commitment that these funding agencies have made to advance the science and clinical translation of lower extremity neuroprostheses for standing, walking, and seated function after spinal cord injuries. The contents of this book are solely the responsibility of the author and do not represent the official views of any of these agencies.

There is another team of people who believed in me and the need to improve access to neurotechnology. Neurotech Network was founded in 2005 as a nonprofit organization to improve education and increase access to neurotechnology for persons with impairments. Jim Cavuoto is my encouragement to keep the organization moving forward even in the toughest times. Jack Gardner and Mary Buckett gave me invaluable advice. Hunter Peckham is my kick in the pants motivator and sailing friend. Without their support and guidance, Neurotech Network would never exist.

Finally, this book can't be closed without thanking all the readers and followers of this journey. The messages of encour-

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agement, gracious cheers and heart-felt notes have helped me along the way. I hope this has helped to build an understanding of the human experience and the required commitments of clinical trials. I am not the only one to participate in the exciting world of scientific development, nor will I be the last. This is one small contribution to the evolution of technology and the progress to improve life for people living with spinal cord injury.

Thank you for getting me back on my feet again.

Chapter 1: Life Before Injury

Stepping out onto the front porch of our historic New England colonial home, you could hear the frozen snow crackle under my feet as I descended down the steps to the street. It was a classic mid-winter morning in New Hampshire.

The Last Morning Run

I was out for my pre-dawn run. In fact, at that time of year, the entire morning routine is before sunrise. The air is frigid. Despite my neck warmer, I could see every breath in the air. My breath was comfortingly warm.

I flipped on my Sony Walkman and started the morning ritual run through the neighborhood. On this run I would be accompanied by the 80's tune, "Everybody Wants to Rule the World," by Tears for Fears. Running and music are my formula of clearing your mind and preparing for the hectic day ahead. Up the steep hill to the top of the neighborhood I go and the thighs are starting to burn. I barely notice since my mind has now wandered onto other things.

The year was 1998. The dotcom bubble had not yet burst the U.S. economy. I was happy with my decision to move a few years earlier, switching careers from finance to technology. It was almost like moving from the old-boys club to the latest fashion scene. Frustrated with the pace of the finance business at the time, joining a dotcom was like reconnecting with my peers. Dotcoms were abundant and workaholics were pushing to be the first at what was coming next. We were all striving to be innovators on the latest Internet frontier. I was in my mid-twenties,

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and joining the company PC Connection was the move I would make and the buzz that would motivate me.

Living in Manchester, New Hampshire, my live-in boyfriend at the time, Tim, and I rented the bottom half of a classic colonial. It had plenty of room for two people and was in a good location on the north side of the city. We weren't ready to commit to owning a home. Hell, we weren't ready to commit to each other!

Tim and I met while I was still in college. We both worked for the same company at the Norwood Airport in Massachusetts. After surviving two years of living away from each other, we figured our relationship would survive. We found our home in upper New England and pursued our careers. We lived by the motto "Work hard, play hard." We barely saw each other during the work week. On weekends, it was up early to enjoy the outdoor activity of choice for the season. During winter, it was snowboarding or snow shoeing and the ideal playground was in our backyard within the White and Green Mountains of New Hampshire and Vermont.

Life was good. Life was vibrant. Nothing could go wrong.

Slippery Slope

PC Connection, the small company that I had joined a few years earlier, went public in March 1998. Leading up to that event, it was a circus. Working weekends and late nights was the norm to get this feat accomplished. Now that the event was behind us and the NASDAQ was the exchange to watch, it was time to take some time off.

For several years, we had a tradition of joining a group of friends at a ski resort. We would rent a slope-side house that slept a dozen people but stuff an extra half dozen in too. It was a weekend of skiing/snowboarding all day and playing poker and drinking beer all night. Over the course of the weekend, we would finish a keg, or two and smoke way too many cigarettes.

We typically took this weekend in March during the height of spring ski season. The days were longer and the crowds at the resorts were not as bad. This year, Tim and I were in charge of getting the kegs. Being the beer snobs and being in southern

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New England, we decided to swing by the Long Trail brewery to get our choice beer. Sure, it was a little pricey, but I had dotcom stock inching its way up in value. We would take off work on Friday to arrive at the mountain late morning. Move in and get at least a half day of boarding in.

As planned, we had a great half day to finish it off with a beer in the lodge before heading back to the slope side house. Tapping the Long Trail kegs, the beer began to flow for the weekend. Soon the never-ending poker game commenced. For this Friday—Friday, March 13th—there was a full moon.

It was a perfect opportunity for our traditional “midnight run.” For the run, the most sober of the group would take the



Me and my snowboard

pickup truck to the base of the mountain while a group of daredevils would suit-up, grab our boards or skis, and head for the slopes. This time, Tim was encouraging me not to go.

“Come on. You’ve done this before. I have a bad feeling about this,” he prodded.

Being persistent, I pushed back. “This is the perfect time with a full moon. Come on, don’t be chicken. It’ll be fun.”

And back and forth we went, as I pulled on my snowboarding gear. Finally realizing that he wasn’t going to stop me, Tim suited up and joined me on the slope.

Just as expected, the

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full moon was high in the sky. The moonlight made the ski slopes glow in the darkness of the forest. Sitting in the middle of the slope and strapping on our snowboards, I had to sit back and enjoy the view. It was one of those images; the ones that a camera can never catch but will be etched in your mind forever.

“Okay, let’s go!”

The group headed down the mountain. I held back, wanting to get my space among the group—and also to enjoy the serenity. The ride was icy and it became harder and harder to dig in the edge of my board. Nearing the bottom, I took a break and sat down with my board and feet in front of me. Fighting the slippery ice was getting too hard, so I decided to work the edges to get the powdery snow. Something didn’t feel right, but I didn’t know what it was. I took a look up at the moon, got up and proceeded on the final stretch to the bottom.

Working the edges for powder seemed to work and I began to relax. But along with that relaxation came carelessness. I hit a patch of ice and slid off the trail. Unable to stop, I careened down a 40-foot embankment. At first it was just snow, but then came the army of trees. My body bounced off one, then another. It was happening in slow motion, but in a flash it was over. Lying helpless in the snow, I looked up to the moon in the sky.

“Help.”

That was the last thing I remembered.

Down at the base of the mountain, the gang gathered up. Tim was already down there and was impatiently waiting for me. After a while, his irritability changed to dire concern. He headed back up the trail on foot. Far enough away from the rattle of the others, he heard a weak cry. Looking over the side of the trail, he spotted me face down in the snow off the side of the embankment. Sliding down the snow until he reached me, he knew something was really wrong. Tim’s instinct kicked in and he offered verbal comfort to me but didn’t touch me.

Feeling the urgency to get help as quickly as possible, Tim started crawling back up the embankment. The same slippery slope that landed me in the trees was now preventing Tim from getting back to the trail. Crawling and digging in his boots, he

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finally made it back to the trail. Sprinting down the mountain, he went to the lodge searching for a telephone. There was no one outside but some people inside the lodge.

Seeing a mad man banging on the window, the lodge cleaning crew were not about to open the door. When Tim lifted a trash can threatening to break the window, the crew decided to slip the key into the lock and open the door. “Call 911, there’s been a terrible accident,” he yelled.

This being a ski resort, the snow groomers were the first to the scene. Trained on rescue techniques, they knew how to handle the situation. Once the emergency team arrived, it took two snowmobiles and six rescue workers to get me out of the tree-infested embankment and down to the base of the mountain.

They say I was awake and communicating during the entire ordeal. But I can only remember a few vignettes of that night after my cry for help. The first was on a stretcher in the back of an ambulance. I held up my hands out from under a silver thermal blanket to look at them. My entire body was shivering. Apparently, my body temperature had dropped to the upper 80s—a situation I would later see as a benefit.

The next episode was in the emergency room. Someone was taking a stapler to my head. While ping-ponging through the trees, I picked up a gaping wound down the back of my head, just along the part of my pigtails. Evidently, staples were the tool of choice to close up the bleeding gash. I then went black.

Awakened again in the emergency room, I noticed I now had a Frankenstein-like helmet on my head and weights on my limbs. The pulling was unbelievably painful. The process of screwing the helmet onto my head reminded me of torture from the Middle Ages. Back to black.

My final emergency room memorable moment was when I awoke lying on my back in a white room. I had tubes everywhere and my eyes were wandering. To my right, I saw Tim. “I’m gonna get sick,” I said. To ease the pain, the medical staff gave me morphine, a painkiller that does not agree with me. Tim looked around. “I’m gonna get sick,” I reiterated.

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Tim pressed the call button but no response. He stepped out to find a staff member. “She’s getting sick. Now!”

I don’t remember anything else from that evening. I’m told I was awake and communicating. I tend to think that my mind blocked out the rest and I don’t care to find out the other details. The damage was done.