

AUGUST 2016

The Sky's the Limit for a Son's Support

By Kevin Burkart

I am Kevin Burkart and I skydive for Parkinson's disease (PD). I've completed four skydiving fundraising events totaling 502 jumps, raising over \$390,000 to increase awareness for PD. I was motivated when my father, Gary, was diagnosed with Parkinson's in 1999, and have tried to play an inspiring role in the Parkinson's community ever since.

My dad was gearing up to retire when he noticed an uncontrollable tremor in his hand during meetings. Shortly after, he was diagnosed with PD. After hearing the news, our entire family set out to learn about the disease. It was a devastating blow to my dad and his wife, Monica. There was an emotional reaction, visceral almost. I knew it was going to be a tragic situation and that we now had a real challenge ahead of us.

I had started skydiving around the time my father was diagnosed. By 2008, I became a professional skydiver and skydiving instructor, and I participated in competitions. I thought, "What if I attempt to do 100 skydives in one day to

raise awareness and funds for Parkinson's?" I confirmed with the Federal Aviation Administration that 2,000 feet was the minimum altitude for skydiving. Mathematically, I knew 100 jumps in a day was possible.

In 2008, I successfully carried out "100 Perfect Jumps for Parkinson's Disease." I jumped 100 times in 24 hours and raised \$48,000. I then felt that I could do more, which led to my second fundraiser, "200 Perfect Jumps for Parkinson's Disease," in 2010. I was able to raise an additional \$78,000 for the fight against Parkinson's.

I was planning my third fundraiser, "300 Perfect Jumps for Parkinson's Disease," when a life-changing snowmobile accident left me with broken bones, shattered vertebrae and severe nerve damage to my left arm. I now have no mobility in my left arm – but my father taught me to be a fighter.

In 2013, I re-branded and successfully completed 151 "Imperfect Jumps for Parkinson's Disease." Since I only had use of one



Kevin and his dad

arm, my asymmetrical flying made my jumps "imperfect." Although it was the toughest thing I've ever had to go through, I devised a way to skydive using one arm, and in the process, set a new world record for one-armed skydives in one day, while raising more than \$135,000. However, I still believe a life with Parkinson's for both my dad and Monica, his amazing wife and caregiver, is more difficult than skydiving with one arm.

I still felt like I had more to do – there are more people to help and there's more money to raise. After all, my dad is still fighting Parkinson's. On June 15, 2016, I completed my last fundraising

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A Last Visit...and a Gift

By Hope Juber

In September of 2011, I took my 93-year-old mother, Mildred, cross-country to visit her sister Natalie, who was 85 and had lived with PD for decades.

Aunt Natalie, who lived in Massachusetts, was an inquisitive, academic person, a psychotherapist and lover of the arts. Married twice, she was forceful, with a sly sense of humor. And she had an exotic beauty. When I was a little girl, my aunt seemed to me like a movie star.

Though they were very close, the sisters often butted heads. My mother, who lived in California, was an amazing, funny, remarkable woman. But Aunt Natalie found her a bit bossy. They lived on opposite coasts for a reason!

I would often hear about my aunt's PD through Mom's phone conversations with her. Whatever the complications and obstacles PD brought, she always tried to find ways to have as independent and normal a life as possible. But over time, the disease took its toll. Sometimes she'd suddenly cut a phone call short. And she occasionally became depressed, which was so unlike her. My aunt became increasingly dependent on others, which was difficult for this

highly independent woman. But she'd still sing me silly songs on the phone.

When Aunt Natalie was in her 70s, she moved to an assisted-living facility. In the following years, she suffered more with Parkinson's and grew weaker. However, she still zipped around on her little scooter. My mother was not doing well either. From sheer determination and stubbornness, Mom knew she needed to see her sister, so she called me and said, "I want to see my sister – will you take me?" We all knew it would be the last visit.

Mom and I stayed with Aunt Natalie for a week, sharing a big bed in a guest room in the facility. Natalie had a full circle of friends; they adored her and she adored them. The sisters looked through photo albums, recounting memories only sisters can know. They laughed about their dad, a really stubborn man. Their long friction was gone. They knew this was time to cherish; time to focus on their relationship with each other as sisters. The entire visit, there was this unspoken lovely sad tie. When my mother and her baby sister said goodbye, their hug never ended...



Natalie and Mildred

My mother passed in April of 2015. Aunt Natalie passed in December of that year. My mom and dad (a comedy writer, who created "Gilligan's Island" and "The Brady Bunch") loved and supported many causes. My mother's estate designated a large amount to charity, so my three brothers and I chose organizations within her areas of interest to receive donations. Because of the relationship between the sisters, we researched Parkinson's groups. We were impressed by how the National Parkinson Foundation (NPF) uses nearly all the money they receive to help people with the disease. We also liked the fact that NPF is dedicated to helping people today. For these reasons, we awarded NPF a gift of \$30,000 from my mother's estate, in memory of her beloved sister, Natalie.

If you are leaving an estate and something is important to you, I encourage you to designate part of your estate ahead of time, so that cause doesn't get disregarded. People who come after you will respect your choice, and the cause will become important to them.

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When Simple Care is Enough – and When It Isn't

By Peter Schmidt, PhD, Senior Vice President, NPF Chief Mission Officer

This June, NPF participated in the 20th International Parkinson and Movement Disorder Society's annual conference. Over 5,000 physicians, scientists, and other professionals focused on helping people with Parkinson's live better lives, came together to discuss the latest research. There were lots of new findings in the basic sciences, ideas that we hope will someday change the course of the disease. On the clinical side of the conference, in which NPF participants presented promising ways to improve the lives of people with Parkinson's now, there were two themes: Sometimes Parkinson's is complex and sometimes it is easy.

NPF Center of Excellence director Bastiaan Bloem, MD, PhD, gave a talk about managing problems with walking. After discussing how certain drugs can disturb gait, he shared a secret: Many of the great outcomes he achieves with patients are due to using a simple medication strategy, not a complex one. Of course, because Professor Bloem's center participates in the *Parkinson's Outcomes Project*, we knew he uses a simple strategy. In fact, we knew he tries to keep his patients on nothing more complex than levodopa alone – in various forms – for as long as he can. Professor Bloem presented research that he and I conducted together, showing that across 20 NPF Centers of Excellence, the centers that took

a simpler approach to medication had patients who fell less often. Patients seem to benefit from simpler medications. We are not quite ready to turn this into a clinical guideline, but we are working on it.

Separately, NPF researchers have been looking at patients who experience one of the most worrisome aspects of Parkinson's – psychosis. A powerful aspect of the *Parkinson's Outcomes Project* is



Peter Schmidt, PhD

our ability to turn back the clock, that is, to look at what *preceded* the onset of complex symptoms. Almost 300 patients in the study were first treated for psychosis in their third year of participation. We are able to look at how they were doing in the first year, well before they were treated for psychosis.

It turns out that these patients experience complex symptoms that require complex care for years before developing psychosis. Ideally, at the earliest signs, typically when patients start experiencing hallucinations, a complex process is put in place that involves reducing medications – often taking patients completely off some “helper” medications like Comtan – and increasing team care, integrating a social worker and a psychiatrist for counseling, and also increasing the use of physical therapy to keep patients active.

We hope to use Professor Bloem's insight – that the best care

delivered by experts to manage routine patients can be simple – to inform a model that can be delivered by doctors outside university medical centers. In doing so, NPF would create a model of Parkinson's care that can help patients get better care close to home. However, we recognize that our review of psychosis treatment shows that managing psychosis is even more complex than we thought.

In the last issue of the *Voice* newsletter, I wrote about how we hope we can create a “paint by numbers” manual for teaching community-level providers to deliver the art of care as practiced by experts. One of the hardest components of such a care recipe is educating physicians on how to identify signals that the patient should be referred to a specialist. We now see that these early signs need to trigger a complex care paradigm where patients receive the expert guidance of an experienced movement disorders neurologist.

Often, when people think of science, they think of microscopes and petri dishes. NPF is leading the way in using science to investigate the very best ways to make life better for people living with Parkinson's. Sometimes this means a new drug – NPF has been involved in major breakthroughs since the 1970s – but sometimes this means doing the right things with the tools we have. Understanding the best use of the current tools is called the *science of performance*, and in this area, NPF and our Centers of Excellence are taking the lead.

“I Can Be a Voice for People with Parkinson’s”

By Clarissa Martinez-Rubio, NPF’s New Director of Research & Centers Programs

Growing up in San Juan, Puerto Rico, I was always curious about science. I wanted to learn how a complex system like the human body could function as an entire structure. As an undergraduate at the University of Puerto Rico, Rio Piedras Campus, I majored in Biology.

I earned a PhD in Anatomy and Neurobiology from the University of Puerto Rico, Medical Science Campus. During my doctoral research, I used a simple invertebrate model to study neuronal (brain cell) connections and networks to understand how a behavior can be achieved and modified by pharmacological agents and electrical stimulation. This work triggered my interest in deep brain stimulation (DBS) surgery.

During my postdoctoral training, I studied DBS as a research tool and medical treatment at the Massachusetts General Hospital (MGH) of Harvard Medical School, training in neuromodulation, learning and memory, and DBS. Deep brain stimulation is an amazing tool in the treatment of diseases that produce brain changes. Interestingly, we don’t fully understand how it works.

While at MGH, I performed the intraoperative physiology during DBS surgeries. Intraoperative physiology is the physiological mapping of the brain’s trajectory towards the chosen target for the placement of stimulating leads. To my surprise, I also ended up being the support system for the patients, who are usually awake

during this procedure. For them, this is a moment filled with anxiety, fear, hope, and expectation. During four to five hours of surgery, I held their hands, dried tears, engaged in conversation – anything that would make them feel better and help them get through the surgery. Afterwards, patients always thanked me. The truth is that I owed them thanks. This experience changed me, making me a more grateful and compassionate person. The patients taught me to never take things for granted, especially the little things in life, like writing my name or getting dressed.

Working with the DBS team at MGH made me realize the value of giving back to the community through research, outreach, and education. Before applying for this position at the National Parkinson Foundation (NPF), I researched the Foundation and was amazed by its mission. Reading NPF’s mission statement made me realize that there are others with a similar mindset: people with empathy, who desire to make a change in the lives of people affected by Parkinson’s. In my new role at NPF, I wake up happy every day and my sole goal at the Foundation is to help others.

The Foundation has had a Centers of Excellence program for over 20 years. Our centers are recognized for their expertise in Parkinson’s

disease and their high-quality patient care. Centers are expected to train other health care providers, deliver support and education to Parkinson’s patients, caregivers and the community, and conduct cutting-edge research. Currently, our network includes 26 domestic and 15 international centers.



Clarissa Martinez-Rubio, PhD

My mission as the director of this program is to share the centers’ successful practices and programs, and to continue reaching our underserved communities. I am very excited to have the opportunity to work with

all stakeholders and experts in the Parkinson’s disease field: health care providers, researchers, and the people living with Parkinson’s every day.

NPF is special. The NPF family comes together every day with a focus on people with Parkinson’s. Our daily schedules are wrapped around a single question: *How can we make life better for people living with the disease today?* I have never been part of such an extraordinary team.

As far as I know, no one in my family has been diagnosed with Parkinson’s. But that doesn’t mean the disease is not personal to me. The patients that I had the privilege of meeting during DBS surgeries have made my job personal. They mean a lot to me and now I am trying to do more for them. I can be a voice for them and advocate for their needs.

Building Bridges of Understanding Through Moving Day®

By Matt Haltom

I live in Lantana, Texas, a suburb of Dallas. A lawyer by profession, I am Senior VP, General Counsel for Sally Beauty Holdings, Inc., an international retailer of specialty beauty supplies in North America, South America and Europe. My wife, Ruth, and I have two young children – a seven-year-old son and a five-year-old daughter.

In 2005, I suffered a major concussion. Over the next few years, I experienced a number of neurological symptoms, including migraines. But my tests, including an MRI, were clean. No one added everything up. It was over seven years before I was officially diagnosed with Parkinson's by a movement disorder specialist. He looked at the entire puzzle and told me I'd had obvious signs and symptoms of Parkinson's for some time. I was 40 years old.

My first thought was about my children. I didn't want them to have to take care of me when they were still young. This still scares me the most. My attitude is that I must do everything possible to be able to take care of them as long as I can.

How am I doing today – at age 45 and several years after my diagnosis? That depends on what day you ask me. Most days, I'm focused on my work and my children, and being the best general

counsel I can be. Other days, my symptoms are more pronounced, things are more difficult, I'm more frustrated, and I take more breaks. I've been a workaholic all my life, so taking breaks isn't natural. Some days, I take my medication and don't even think about my Parkinson's; on those days, people are shocked when I mention it. Other days, I have to use the handicapped parking and have trouble getting out of my car.

After I was diagnosed, I looked for everything that could help. Some friends are active in the National Parkinson Foundation (NPF), and I saw that NPF does a great job helping people cope with the disease. Moving Day®, a walk for Parkinson's, struck me as a way to get the people in my life aware and involved. Co-workers and friends are constantly asking me, "How can I help you?" While there's not a lot they can do to improve my day-to-day situation, they can help the Parkinson's community by learning about the disease and possibly taking action. There's a lot of curiosity about Parkinson's – over lunches and dinners, people ask questions. Co-workers see me working long hours and wonder how that's possible when the day before, they had to help me to my car. With brain diseases, it's hard to find a way to ask questions without

appearing insensitive. No one wants to say, "How's your brain doing?" Moving Day® gives people an avenue for asking questions.



Matt Haltom, Esq.

I'm the captain of a registered Dallas/Fort Worth team, and this fall – November 5, 2016 – 30 to 40 folks will do a charity walk with me. I'm glad I've found a way that people can meaningfully support me, and also become more aware. This gives all those people who tell me they appreciate what I'm going through, some way to contribute. Just showing up that day – *giving a day of their lives* – means a lot to me. It's a heck of a contribution.

Through my participation in NPF's Moving Day® Dallas/Fort Worth, I hope to open a bridge between people, and whether this leads to greater awareness of the disease or to support for NPF, I aim to give people in my life a way to help. I'm grateful to NPF for giving us this bridge. We need it.

To participate in a Moving Day® event near you, check www.Parkinson.org/MovingDay for upcoming locations and dates.

NOVEMBER 30



The National Parkinson Foundation (NPF) will host our annual "Wines on the Bay" event featuring an online auction in November. Wherever you are, you can participate by making bids on items from your smart phone or computer! Auction items will include exclusive wines, tours and tastings, vacations, weeklong rentals from private homes, and

private dinners. All proceeds benefit the National Parkinson Foundation.

www.winesonthebay.org/auction

To register for remote bidding or to learn more about the event, please email Sara Teeter at rsvp@parkinson.org or call 305-537-9951.

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event, "300 Imperfect Jumps for Parkinson's Disease." I couldn't have asked for a better turnout and media exposure.

Even though weather got in the way of my goal that day, I still completed 101 skydives and raised over \$130,000 for the National Parkinson Foundation (NPF) and our local NPF Minnesota Chapter. My dad and I wanted to create more awareness and raise more funds for Parkinson's than traditional events would allow. We accomplished this in spades with "300 Imperfect Jumps" – some say it was the most covered Parkinson's event ever. You bet we reached a new audience!

I chose NPF and NPF Minnesota as the beneficiaries of these events

because I believe they have the strongest mission and evidence-based research to help improve the lives of people living with PD today. They have truly been a partner in my family's journey.

I always say skydiving is just the gimmick – the real fight is Parkinson's. I've witnessed firsthand the thousands of people who were typically not involved in PD fundraising, yet who supported my jumps and thus the Parkinson's community.

My father and I have been active in the Parkinson's community for 17 years. I look at it as both a blessing and a curse. The blessing lies in the resources you gain access to, the people you meet in support

groups and the ability to serve the community. The curse is that you see every stage of the disease.

I've been so impressed with my father's journey. Caring for my father is both intimate and special. I've often wondered how his wife, Monica, does it full-time! It is an honor and privilege to be able to care for him.

I am Kevin Burkart and I skydive for Parkinson's disease. One son. One father. One day. One arm.



Kevin making a landing.

NPF Endurance Events

OCTOBER 2016

- 9 Bank of America Chicago Marathon
- 16 IRONMAN® 70.3® Arizona
- 30 Marine Corps Marathon

NOVEMBER 2016

- 6 TCS New York City Marathon

FEBRUARY 2017

- 5 Humana Rock 'n' Roll New Orleans Marathon

APRIL 2017

- 30 Big Sur International Marathon

For more information, visit www.parkinson.org/endurance for the list of events and details on each.

THANK YOU!

YOU Made Our 2016 Match Campaign a Success...and Changed the Future!

When we told you that your donation by July 31st would be doubled by a loyal supporter, you responded generously. The success of our 2016 matching campaign means NPF can speed up research aimed at making life significantly better today for people with Parkinson's.

Our researchers are making progress in many promising areas. Thanks to you and thousands of supporters who joined forces with NPF when it mattered most, we can now expect faster progress toward breakthrough therapies and treatments.

From your partners at NPF and on behalf of the entire Parkinson's community – a big and grateful thank you!



www.WPC2016.org