Shoe Lovers Care
By Katie Back

My name is Katie. I am a shoe lover, wife, manager, mother to a sweet English bulldog, sister, and the daughter of an amazing woman recently diagnosed with Parkinson’s. Two years ago my mother, Rosanne, found out she had early-onset Parkinson’s disease, but kept it quiet from myself and my five siblings for almost a year. When she finally broke the news to us, we all rallied together to brainstorm ways to help.

Last September, we participated in Moving Day® Pittsburgh, dressed as superheroes for our hero, our mother. My sister, Mary, organized our team and together we raised $1,600 – not a bad start for our first event! Moving Day® was a blast from start to finish. Coming up with team shirts, starting off the day with mimosas, watching my three-year-old nephew do aerobics, walking together, and a picnic in the park afterwards, all helped us really embrace mom’s disease and realize we can make a difference.

A week after Moving Day®, the company I work for, Designer Shoe Warehouse (DSW), announced it was time to award their Shoe Lovers Care Challenge. Twice a year, DSW asks their associates to nominate an organization they are passionate about, then they narrow it down to eight organizations to compete for a $75,000 donation. I nominated the National Parkinson Foundation for my mother. Fast forward to a month later, I received a phone call from corporate headquarters letting me know I was chosen as one of the eight finalists! Once voting began, we had 12 days to get as much support as we could through every form of communication possible.

Mass emails were sent out to companies and groups we were involved with. Numerous social media posts went out several times a day, and I even learned how to hashtag! One of the countless benefits of coming from a big family is being able to get in touch with a lot of people very quickly. For 12 days, we did nothing but talk about voting. It was amazing to see how many people with no connection to Parkinson’s quickly started backing our cause. Once voting ended, it was such a close race between NPF and another organization, so I had no idea who won. The next day, I received the call that we had won and that I would be going to Miami with the CEO of DSW to donate a check for $75,000 to the National Parkinson Foundation. Words cannot express what I felt at that moment.

Who knew one small gesture of nominating an organization for my mom could turn into a significant donation that can help her and millions of others living with Parkinson’s disease!

Katie Back with her mother, Rosanne

(continued pg 5)
A New Direction for Stem Cells
By Peter Schmidt, PhD, Vice President, Research and Professional Programs, Chief Information Officer

There’s been a change in the way Parkinson’s researchers are viewing stem cells recently, and NPF is at the heart of it. Edward Fon, MD, an NPF-funded scientist at McGill University in Montreal, Canada, is looking at ways that we can use cells from real patients to understand how effective a drug will be in treating their Parkinson’s.

The story starts with a protein. This protein is called alpha synuclein, and it plays a role in helping people think. Proteins are often called the building blocks of cells, but a better way to think about them is that they are like slinkies – very long strings that coil up and move around in a particular way. Like slinkies, proteins that have been around for a while can get tangled-up or bent in the wrong way so that they don’t work. Normally, the body has ways to prevent this by disposing of old proteins as waste.

However, if for some reason, old alpha synuclein proteins remain inside cells, scientists believe they will cause Parkinson’s disease. We already know at least a dozen scenarios in which this can happen. In addition, the more we study this phenomenon, the more scenarios emerge that lead to Parkinson’s. We identified most of these scenarios by finding a particular gene that seems to put people at greater risk of Parkinson’s. One of the first such genes discovered had the code for alpha synuclein.

Here’s where stem cells come in. Over the past decade, scientists have figured out how to create brain cells from stem cells derived from biopsied tissue, often from skin. These brain cells can be cultivated in a lab incubator to grow and proliferate. If a genetic defect has led to Parkinson’s in the person who donated the tissue, that defect will probably also appear in the incubated cells as they grow. Scientists have recently learned many new things about Parkinson’s disease by growing cells that have a gene that causes Parkinson’s.

Dr. Fon is taking it another step. He is making stem cells from tissue that he collected from Parkinson’s patients and turning these into brain cells. In addition to examining how these cells behave in fairly normal conditions, Dr. Fon is testing how they react to different stresses in the environment – thereby creating what scientists call a “model” of Parkinson’s disease. Using this model, scientists could test new drugs to understand exactly how they affect cells, and not just any cells, but cells from people whose Parkinson’s has been studied for progression rate and response to medications, among other factors. Someday, before giving medications to a person with Parkinson’s, doctors might test drugs against a model like this, one made from that individual’s unique cells. Some current treatments are tailored to aspects of your individual biology and we expect future breakthrough treatments will be, too. Medications that target specific mechanisms can better control symptoms and minimize side effects.

Other scientists, who also are making brain cells from stem (continued pg 4)
Paddling for Parkinson’s
By Crystal Ybanez

Discovering that someone you love has a degenerative disorder with no cure is a bit like being in an earthquake. Your world turns upside-down. You panic. You don’t know how to do anything except hold on until the Earth stops moving. Even breathing seems like effort. But eventually the world stands still again and you have to decide what to do in the aftermath. For my family, it was important to not only clean up our own pieces from the impact, but to help others as well.

My dad was 54 when he received the diagnosis of Parkinson’s disease. I was shocked. My dad was supposed to be invincible. He was the man who picked me up when I fell, dealt with any problems we had as a family, and protected us and kept us safe. He couldn’t have a disease that would eventually render him helpless. It took some time, but after the typical stages of anger and grief, our family was ready to take the next step. My aunt, Ramona Singleterry, suggested we find a support group; however, it turned out there wasn’t a group in our city that catered to newly-diagnosed Parkinson’s patients. So we started our own. For the first few months, there were only a handful of us meeting once a month. Then it slowly began to grow. We steadily brought in new families facing the same confusion and sadness that we too had dealt with. We meet monthly in Corpus Christi. Some meetings include professionals like speech therapists, physical therapists, doctors, and health care providers. Other meetings involve those diagnosed with Parkinson’s and their family members simply talking about their experiences and their needs. We’ve become a family, supporting one another through the painful times.

At the same time we were learning how to host a support group, we decided to start a fundraiser in order to raise money to donate to Parkinson’s disease foundations working to find a cure. We saw an advertisement in a magazine about the “Hook the Cure” Team Hope™ fishing derby in Massachusetts, and fed off that idea. In April 2007, we held a fishing tournament that we called “Catch the Cure.” We raised just over $6,500 that first year! It was inspiring to see so many people willing to come out and help! We held two more fishing tournaments in 2008 and 2009, but our competition was getting fierce as more and more organizations also held fishing tournaments. We needed a new idea.

My aunt, Ramona, lives on an island where she and others paddle their kayaks and stand-up paddleboards (SUPs) daily. She came up with the idea to start “Paddle for Parkinson’s,” a kayak and SUP race and relay! In 2010, we hosted our first “Paddle for Parkinson’s” and raised $6,000! Each year, the number of paddlers grows. Our recent fifth Paddle event (in 2014) attracted more than 200 participants, and raised over $20,000! Since we started in 2007, our group has contributed over $95,000 to Parkinson’s organizations, as well as to reserved funds to help any local patient in need. We have also awarded two scholarships to students in a speech pathology graduate program! Two groups, the Bustamante Legacy and Team Coach K, raise funds on a pledge basis and have been a large part of the relay by paddling for the memory of their loved one and to honor their coach, respectively.

Michael J. Fox once said that “Acceptance doesn’t mean resignation. It means understanding that something is what it is and there’s got to be a way through it.” Our family found acceptance through “Catch the Cure” and “Paddle for Parkinson’s.” My dad is the one who has to battle the disease every day. But we found a way to help him with that battle. We can’t wait for someone else to do something, now that we realize every single one of us is someone.
Rigidity is a key motor symptom of Parkinson's and every new therapy for Parkinson's is tested for its benefit to rigidity. Here is what I recommend:

1. **What can you do today?** Seeing an expert neurologist should offer the possibility of benefits from medication optimization. It is important to consider the possibility of non-neurological causes of rigidity – for example, being sedentary because of Parkinson’s may lead to muscle stiffness in addition to the Parkinson’s rigidity – and a referral to an expert physical therapist can help with that. If, after working with an expert to figure out the best mix of medications for you, you feel that you still need more help, you should be evaluated to see if deep brain stimulation (DBS) might help. DBS is proven to reduce rigidity in appropriate candidates.

2. **Thinking about the future.** The Parkinson’s Outcomes Project is conducting research into motor features of Parkinson’s, such as rigidity (and non-motor features, as well). We are already exploring how insight from the Parkinson’s Outcomes Project will teach us how to better treat rigidity. We have found that several Centers of Excellence manage patients’ motor impairment better than others – both in terms of how motor symptoms are evaluated in the clinic and also how patients tell us that they feel their motor symptoms are progressing. In upcoming research, we will be designing a Parkinson’s exercise program and will be measuring rigidity in the evaluation. All these improvements in knowledge and care practices are likely to produce results that will help people with Parkinson’s live significantly better lives.

3. **New research theories.** The latest work is focusing on a protein called alpha synuclein, and NPF is at the forefront of these investigations. This research grows out of a deeper understanding of how the brain works at a cellular level and is a dividend from the genomics and stem cell revolutions. We are funding the development of two new models for testing drugs -- several of which are currently under development -- that may be able to stop Parkinson’s in its tracks, perhaps even giving us the capacity to stop Parkinson’s in the next generation at its very first signs and symptoms. Soon after NPF chose to target this area for research, the US government’s National Institutes of Health picked it as “the most promising area for new drug development.”

Speaking with patients and families in order to incorporate their priorities into our research strategy is so helpful. Parkinson’s can be a devastating disease, but with today’s increasingly personally-tailored treatments and potentially game-changing therapies in the pipeline, the future is looking brighter than it ever has.
NPF Becomes a Member of CHC

We are pleased to announce that NPF is now a member of Community Health Charities. Community Health Charities offers a diverse group of respected health charities to employers, so the coordinators of their employee-giving programs can be confident they are connecting employees to credible and trusted health charities. Before an organization becomes a member of Community Health Charities, it is subjected to a rigorous screening to make sure people’s contributions will have an impact. NPF recently passed that screening!

This new partnership provides NPF with access to more than 1,500 workplace giving campaigns, including all private sector campaigns, and the ability to participate in the 2015 fall Combined Federal Campaign.

Through these workplace giving programs, NPF can continue to fund important research projects to beat Parkinson’s.

If your company has a workplace giving program, please select the National Parkinson Foundation as your charity (CFC Code: 11098). If you’d like further information, please contact your human resources department or Kathy Tamargo at KTamargo@parkinson.org.

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NPF Legacy Society

Legacy Society members are a select group of donors who have recognized NPF in their wills, trusts, estates and other planned gifts.

Their generosity and forethought will help thousands of people with Parkinson’s live better lives in the years to come.

As an NPF Legacy Society member, you will have the satisfaction of knowing that you are continuing our tradition—helping to ensure the future strength of NPF through your generous support.

We recognize and thank members by listing your name in NPF’s Annual Report. If you have already named NPF as the beneficiary of a planned gift, we welcome you as an NPF Legacy Society member.

If you would like more information about how you can become a member, please visit www.parkinson.org/plannedgiving.

You can also contact Darcy Taylor, Vice President of Constituent Relations, at dtaylor@parkinson.org or 305-537-9904.

Shoe Lovers Care cont. from pg 1

This experience has been life-changing! My mother always taught us the power of giving. No matter how small something may seem, it could make a huge difference. Who knew one small gesture of nominating an organization for my mom could turn into a significant donation that can help her and millions of others living with Parkinson’s disease! I will be forever grateful to DSW for funding such a great program like Shoe Lovers Care, to the National Parkinson Foundation for the difference they are making in people’s lives every day, and to all the people who supported me by voting and spreading awareness of Parkinson’s disease.
Fashion Under the Stars Raises Over $80,000

The National Parkinson Foundation (NPF) and the South Palm Beach County chapter organized an elegant evening of food, fashion and fun. The event was held on Thursday, November 20th, at the Boca Raton residence of Robert and Robin Muir, and more than 150 supporters attended. The event raised over $80,000 through ticket sales, a raffle, and a live auction. A special guest, famed comedian Lonnie Shorr, served as “Auctioneer.”

The evening began with a cocktail reception followed by a superb dinner underscored by music performed by an acclaimed string quartet of graduate students from Lynn University. Following dinner, guests enjoyed a fashion show where models “rocked the runway” with fashions from Chukkers and Guy La Ferrera. Both stores are located in Boca Raton, FL.

“We couldn’t have been more pleased with this stellar evening and the amount of support it generated,” noted Gail Milhous. “Everyone here tonight is dedicated to doing whatever we can to raise funds for research, resources and support for people living with Parkinson’s and their families. The evening would not have been the resounding success that it was without the help of all the committee members.” They included Vicki Accardi, Bonnie Austin, Mike and Arlette Baker, Gerald and Pam Coffey, Leslie and Esther Evans, Paul and Mary Ann Milhous, Robert and Robin Muir, Phyllis Riesner and Patricia Travis.

Come join one of our Moving Day® walks this spring! Register today at www.NPFMovingDay.org.

- **March 14**: Moving Day Orlando
- **April 11**: Moving Day Tampa
- **April 12**: Moving Day Tucson
- **April 19**: Moving Day San Francisco
- **April 25**: Moving Day Silicon Valley
- **May 2**: Moving Day Twin Cities
- **May 16**: Moving Day Tallahassee
- **June 7**: Moving Day Washington, DC
- **June 13**: Moving Day Kansas City

Come join one of our Team Hope™ endurance events this year. Contact Sara Teeter at TeamHope@Parkinson.org or 305-537-9951.

- **April 12**: Hapalu Hawai’i’s Half Marathon
- **October 25**: Marine Corps Marathon, Washington, D.C.
- **November 1**: TCS New York City Marathon

“A Helpline specialist took the time to explain everything to me and help me understand my doctor’s instructions. It turned out my medication wasn’t going to affect me negatively at all. I was relieved to have a clear answer right away.”

NPF Helpline Caller, Karl Kovacs

The National Parkinson Foundation Helpline
1-800-4PD-INFO
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Help is just a phone call away.

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