Pedaling for Parkinson’s: East 2 West
By Adam Levine

When Peter Genova and I came up with the idea to do a cross-country bike ride this summer, we had no idea how incredible the experience would be, and how many lives we would touch along the way. The trip seemed like the perfect adventure to undertake before entering the so-called “real world.” We also decided it could be truly impactful if we rode across country for a worthy cause.

My grandfather, Robert Schaefer, suffered from Parkinson’s disease for most of my life. I witnessed firsthand just how great a toll it can take. It was because of my grandfather that we linked up with the National Parkinson Foundation (NPF) through Team Hope™, to help raise money for people and families who have felt the terrible effects of this disease.

In order to raise money for NPF and our travel expenses, we created a website complete with pictures and a mission statement. With the support of friends, family and people we met on our cross-country journey, we raised more than $8,000!

We understood we were working for a cause greater than our own pain and that idea inspired us during every hardship and with every push of the pedal.

This experience was unlike any other and the memories will last a lifetime. What surprised us most was how incredibly generous and kind people were. Many times during our journey, we stopped for food or water, and workers gladly donated a lunch or an energy drink to help us keep trucking along in the summer’s heat. Even during lunch breaks, people approached us, having seen our matching Team Hope™ jerseys, to ask us why we were riding. That was the greatest pleasure for us – spreading the word about NPF and Parkinson’s disease, and watching people’s faces fill with joy as they saw two young men riding to make a difference in the world.

Sometimes it was difficult riding through the Appalachians, Great Plains, Rockies, and Arizona desert. But through it all, we knew our hard work was dedicated to something bigger than ourselves. It was in those humbling moments that we realized that, as much as we wanted to quit cycling, we couldn’t, because those suffering from Parkinson’s don’t get any breaks either.

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Greetings from Paul Blom, NPF’s Interim CEO

As some of you may already know, Joyce Oberdorf, NPF’s president and CEO of more than seven years, has stepped down. I am honored to have been asked to serve as interim CEO. I want to thank Joyce for her leadership that fundamentally changed the organization, vigorously moving NPF forward in so many ways, and improving the lives of countless people and their families.

Under Joyce’s watch, our Center of Excellence network has been refined to a coveted peer-reviewed program. Pete Schmidt, Senior Vice President, Chief Mission Officer, conceived of and launched the Parkinson’s Outcomes Project, and NPF has built this investigation involving more than 8,000 patients into a clinical study like no other, with ongoing impact on people’s care and lives. We secured a prestigious PCORI grant for telemedicine and funded cutting-edge research. NPF originated the idea and launched Moving Day®, which has not only raised a great deal of funds but has allowed us to make amazing connections and forge communities across the US.

I know that Joyce is particularly proud – and rightly so – of our Aware in Care work, which has transformed the hospital experience for Parkinson’s patients. She also led NPF to establish simply the best helpline in the field, staffed by the most knowledgeable and caring people. And Joyce was instrumental in forming relationships with new and substantial donors, such as the Edmond J. Safra Philanthropic Foundation, and the family-oriented Katz Foundation.

Now you are probably wondering, Who is this Paul Blom? I grew up in Wisconsin and live in Minneapolis, Minnesota. Until recently, my husband and I had two acres in a rural town outside Minneapolis with a huge garden. That garden inspired my tradition of canning a jar of rhubarb jam for each of my elderly Right at Home clients — 500 jars! — that we hand-deliver during the holidays.

I was elected to NPF’s national Board of Directors in November, 2014, as an ex-officio member. For 10 years, I served as President of the NPF Minnesota Board of Directors, and I am the current Chair of NPF’s Chapter Advisory Council. In this role, I travel the country to share NPF’s vision for serving the Parkinson’s community, while helping to strengthen the NPF Chapter Network.

During my tenure as Board Chair of NPF Minnesota, the chapter’s budget went from under $30,000 to nearly $750,000. We received significant major gifts, sponsorships and planned gifts. And we added a People with Parkinson’s Advisory Board and a Clinical Advisory Board. I have also served as a member of the Community Advisory Board for Struthers Parkinson’s Center, an NPF Center of Excellence. My husband, Bob White, and I are the owners of the Right at Home franchise in Bloomington, MN, which we started.

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More Evidence Links Exercise with Living Well
By Peter Schmidt, PhD, Senior Vice President, Chief Mission Officer

Exercise has long been recognized as a powerful tool to fight Parkinson’s – so long, in fact, that in 1957, the National Parkinson Foundation was founded by a woman who moved to Miami so her husband could play golf year-round. That was the leading treatment for Parkinson’s disease at the time.

In June of 2014, research from NPF’s Parkinson’s Outcomes Project scientifically demonstrated a new aspect of the power of exercise. We were able to show evidence that exercise may really be what we have long hoped for: a treatment that slows Parkinson’s disease.

As a key part of my work for NPF, I have led the Parkinson’s Outcomes Project since 2009. It is the largest clinical study ever conducted of Parkinson’s patients in order to understand what the medical community can do today to get the best results for people, and to help them live the best life with Parkinson’s. The study includes an annual comprehensive evaluation of more than 8,000 people with respect to their Parkinson’s, including their symptoms, how Parkinson’s is affecting their lives, and how it affects caregivers. As part of the evaluation, we look at how much each person exercises.

In 2014, working with Parkinson’s Outcomes Project data, a neurologist named Anhar Hassan, MD, won an MDS Award from the Movement Disorders Society for the best research of the year. Dr. Hassan studied people who have been living exceptionally well with Parkinson’s for over 20 years – some, as long as 50 years. Those she studied are living at home, continue to engage in activities they enjoy, and many find their lives only minimally affected by Parkinson’s.

Dr. Hassan found that many of these patients were active on a regular basis. It looked as if their commitment to exercise was an important factor in their well-being despite Parkinson’s.

This year, working with Miriam Rafferty, who has a doctorate in physical therapy and is completing a PhD in neuroscience, our Parkinson’s Outcomes Project team studied the difference in symptom progression between people who start exercising soon after a Parkinson’s diagnosis versus those who start exercising later. This approach paralleled what is called a “delayed start” trial. The goal of a delayed start trial is to see if a treatment affects only symptoms or if it can change the course of a disease. For example, if you are sensitive to bright light, sunglasses will affect this symptom, but if you take off the sunglasses, you will still be sensitive. Most Parkinson’s medications are like this: while you are taking them, you feel better, but stop taking them and slowness, tremor, and stiffness will return. If a treatment changes the course of a disease, then people who get that treatment earlier will benefit more than people who start later, because the ones who start earlier will have slowed the impact of their disease for a longer time.

Dr. Rafferty and the NPF research team showed that people who started exercising earlier did better than people who started later. The results also suggested that if a person delays starting exercise, they may not be able to get all the benefit they would derive from starting now. The type of exercise seemed not to matter, just that the person did it at least 2.5 hours a week – for example, for five 30-minute sessions. When we made these findings public in June, the medical community was very enthusiastic. Now that physicians can point to scientific evidence of the positive impact of exercise on Parkinson’s, they hope to be more effective in getting their patients moving.

There are lots of ways exercise might slow Parkinson’s symptom progression. Some good research has shown that exercise does rejuvenate the brain. In addition, we believe that good symptom control also helps slow the impact of the disease: if you have a cut and wear a bandage, it doesn’t change how your cut heals. However, it does protect you from infection or re-

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Taking Control of My Life
By Jerry Yarov, Chair Elect, National Parkinson Foundation Central & Southeast Ohio, Co-Chair Moving Day®

I was diagnosed with Parkinson’s disease (PD) about 10 years ago. As is the case with many people, the news that I had an incurable degenerative brain disease was not easy to take. At the age of 56, I really didn’t know how it would affect my life. My first challenge was to find the right medicine combination to control my symptoms, which took more than two years. But I still needed something more, because I was always tired and had trouble just trying to get through the day doing normal things.

My daughter, Liza, researched PD and found information about the importance of exercise. That’s when I found out about David Zid and his OhioHealth Delay the Disease exercise program, offered for free through the NPF Central & Southeast Ohio Chapter. The classes really seemed to help delay my disease progression, and while I can’t do everything I used to do, my life is relatively normal and I’m still independent, which is of the utmost importance to me.

After benefiting from these wonderful classes, I wanted to do more for PD, so I volunteered to be a board member of the NPF Central & Southeast Ohio Chapter. My first assignment was to chair a new fundraising walk event called Moving Day®. This was a great fit for me since it focuses on raising funds to improve the quality of care for people with PD, while raising awareness of the importance of movement and exercise.

Our first Moving Day® event in 2012 was very successful – raising more than $57,000. It was a wonderful day, during which I met other PD patients and their families. Words can’t express how I felt at seeing my wife Debby, my daughter Liza and my granddaughters Jadyn and Elliot, along with many friends, walking together on my team, Jerry’s Movers. It was a day I will never forget!

Since becoming involved with NPF and Moving Day®, I’ve had the opportunity to meet some incredible people in the local Parkinson’s community. I hope that, together, we can continue raising funds and awareness so people not only know the importance of exercise but also have access to classes and programs to keep them moving.

While we can’t reverse or stop the disease, exercise gives us more power over our symptoms and quality of life. In a world where so many things are beyond our control, I can’t imagine letting a few hours of exercise stand in the way of future mobility and good health.

Please don’t wait. Start moving today – and encourage those you love to get moving for better health. And what better way to do so than to register for an upcoming Moving Day® event!

Greetings from Paul Blom cont. from pg 2

14 years ago. I am proud to say that we secured our franchise’s national sponsorship of Moving Day®, I serve as Vice-Chair of Training to Serve, a Minnesota nonprofit that trains senior service providers in the unique needs and barriers of the aging LGBT community. I also serve on the board of Avenues for Homeless Youth, the Twin Cities Gay Men’s Chorus, and as Treasurer of the Minneapolis Area Senior Workers Association.

I want you to know that NPF is in a good, sound financial position. My plan as interim CEO is to work closely with everyone in this wonderful organization to fulfill our mission and vision, always extending NPF’s reach and our impact on people’s lives. I look forward to working with the incredibly talented and passionate staff of NPF, to supporting the tireless work of our national Board of Directors, and to being a resource in furthering our work serving the entire Parkinson’s community. Last but not at all least, I look forward to meeting as many of you, our devoted friends and supporters, as possible.
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We understood we were working for a cause greater than our own pain and that idea inspired us during every hardship and with every push of the pedal. At times, the mental endurance required for an endeavor like this began to waver, but was always refreshed by a kind smile from a stranger and at the end of the day when our tent went up. Every challenge was met with sweat and determination until we finally touched down at East Beach in Santa Barbara, California, after riding 3,200 miles from Washington, D.C., and promptly sprinted into the Pacific Ocean.

The trip taught us so much about ourselves and the world. The big lesson was how powerfully two people can affect others. Ending the trip has been bittersweet for us. On the one hand, we are excited to not wake up and cycle all day, but on the other, we are saddened our journey has come to an end. We would like to thank everyone who supported us. Without these people, we would not have been so motivated to complete our trip. To all those who suffer from Parkinson’s disease, we would like to conclude by saying that riding for you has been our greatest honor, and that we hope our journey has brought you joy knowing that we did it for you. Thank you!

More Evidence Links Exercise with Living Well cont. from pg 3

injuring the cut, and that can make you heal faster. Good symptom control in Parkinson’s makes people safer from falls, while helping them take care of their health in other ways - all of which adds up to enhanced lives with Parkinson’s.

The people profiled by Dr. Hassan, who have had great quality of life with Parkinson’s for decades, have probably figured this out. Based on Dr. Rafferty’s findings, it’s clear that regular exercise will play a key role in reproducing these people’s success with others who have Parkinson’s. Duplicating that success could mean a significant advance in symptom reduction and improved quality of life for everyone with Parkinson’s.

Ways to Give: Combined Federal Campaign and Community Health Charities

Workplace giving is a popular method used by many donors. The largest workplace giving campaign is the Federal Giving Campaign (CFC), which is open to federal employees. The CFC was created to provide all federal employees with the chance to enhance the quality of life for others. Through this very successful annual workplace giving campaign, the CFC raises millions of dollars throughout the country and overseas for non-profit organizations like the National Parkinson Foundation (NPF).

The campaign season runs from September 1 through December 15, during which time people can pledge to support NPF through payroll deductions. The code for the National Parkinson Foundation in the Combined Federal Campaign is 11098.

If you are not a federal employee, the Community Health Charities (CHC) can facilitate your support of NPF through workplace giving. CHC improves the lives of people affected by a disability or chronic disease by uniting caring donors in the workplace with the nation’s most trusted health charities. These partnerships between worthy member charities and corporate partners give employees the opportunity to support the health causes that impact their family and their community.

During giving season at your job, look for Community Health Charities in the charity listings to find the National Parkinson Foundation. If you do not see CHC or National Parkinson Foundation, there may be a space to write in a charity. In that case, please be sure to include our address: 200 SE 1st St, Miami, FL 33131, to ensure that the donation is sent to the correct place.
NPF Legacy Society

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 Amy Gray, Senior Vice President of Constituent and Community Relations, at agray@parkinson.org or 305-537-9906.

Have you always wanted to run in one of the most memorable races in the country? Now you can! Sign up to run with Team Hope and receive guaranteed race entry:

· Marine Corps Marathon 10/25/15
· Miami Marathon & Half Marathon 1/24/15
· Big Sur International Marathon 4/24/15

For more information on Run to Beat Parkinson’s, please contact Sara at teamhope@parkinson.org or 305-537-9951.

Fall 2015 Moving Day® Event Schedule

Register your walk team for Moving Day® and help us spread the word about this life-changing event!

Stay tuned for our spring event dates, coming soon! Visit www.npfmovingday.org for a complete list of events.

RUN TO BEAT PARKINSON’S

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.

www.parkinson.org