I ran 40 miles on my 40th birthday to raise money and awareness for Parkinson’s. My incentive was a natural result of my great love and devotion for my dad, Guy, who was diagnosed with Parkinson’s disease three years ago.

From 6 a.m. until 2 p.m., I ran eight five-mile segments. The day was one of celebration, as many friends and family members turned out to share in parts of my run. The atmosphere was one of unity and friendship as my mom, Cathy, brother, Matt, my sister, Megan and my dad, Guy, did everything to support all the runners and me with food and drinks. There were smiles all around for a community event that took a year of planning and much physical effort.

As you can imagine, success in such an endeavor encompasses multiple goals. These included raising public awareness, raising a sizeable amount of money, creating a fun-filled activity and having an important specific purpose, all realized within the running community umbrella. Last, but certainly not least, was the goal of running 40 miles – not an easy task for most. As measured by all of these parameters, the day’s event surpassed all my goals. Hard work behind the scenes helped to raise $6,600.00 for NPF’s Team Hope for Parkinson’s. My family was outstanding and embraced all the participants. The running community shared their effort and their love of running, especially for a good cause.

My husband, Erik, and I appreciate the fact that our exercise routines provide an invaluable lesson to our children and those living with Parkinson’s: One exercises to both feel good and to be healthy in mind and body. We want our children to get the message to strive for balance and to see exercise as a healthy way to cope with stressors and better our health.

While I don multiple hats – spouse, parent, work peer, athlete – I work to maintain emotional balance. A loving, nurturing family such as mine, gives me the courage to dream and then we can all blossom. Thanks go to my family, friends and strangers who pursue their goals and generously give of their effort to build up the community in various ways.

I was brought up in Park Rapids, in central Minnesota — the North Star state and the Land of a Thousand Lakes. While I live in Florida, train in Florida and ran the event in Florida, I will forever be a Minnesota girl, not to mention a “dad’s girl”— and I did this for him.
We already know that high-quality care substantially increases a person’s ability to live well with Parkinson’s disease. Now, research conducted by the National Parkinson Foundation demonstrates the overwhelming value of one particular component of that care – regular visits to a neurologist.

The findings are specific: In order to receive significant medical benefits, a person with Parkinson’s needs to see a neurologist at least annually. What’s more, patients who saw a neurologist regularly – between one and four visits a year – enjoyed more than double the benefit of those who saw a neurologist occasionally.

What are these striking benefits? Our data show that a person with Parkinson’s who sees a neurologist annually or more frequently is less likely to wind up in a nursing home; less likely to fall, thus suffering fewer hip fractures requiring hospitalization; and less likely to suffer a deteriorated condition in a hospital as a result of complications of Parkinson’s. Hospitalization can cause grave medical problems for a person with Parkinson’s disease.

When any person is hospitalized, the typical protocol is to first, withdraw all medications; and second, for the physician managing their care to administer medications from the hospital’s pharmacy. Despite the increasing positive impact of the National Parkinson Foundation’s (NPF) Aware in Care kits, this hospital protocol results in about two-thirds of hospitalized people with Parkinson’s receiving incorrect medication for the disease, or none at all. To make matters worse, the effects of the altered medication regimen on the patient often go unrecognized by hospital providers.

These unintentional changes in medication can put a hospitalized patient at great risk for serious complications of their Parkinson’s disease. A patient can develop severe constipation – very serious in an older person. In addition, an improperly medicated Parkinson's patient can become disoriented or confused, which is typically handled in a hospital setting with additional complex medications. Unless the doctor really knows Parkinson’s, the drugs commonly used in this situation can worsen Parkinson’s, causing major medical problems. Finally, it is imperative that a person with Parkinson’s disease either exercise or be mobilized regularly, or they risk permanently losing movement function. This activity often does not occur in a hospital.

Research has shown that about one in five patients with Parkinson’s admitted to the hospital for any reason experiences worsening of their Parkinson’s disease, and that half of these people never recover to their prior status.

(continued pg 6)
New Parkinson’s Book to Help Patients and Caregivers
By Michael S. Okun, MD, National Medical Director

I have just released a new book on Parkinson’s disease that aims to help patients and caregivers around the world manage symptoms more effectively and live better lives. I also wrote this book because many of the valuable resources for patients with Parkinson’s disease are only available in English. To help correct that gap, my new book, Parkinson’s Treatment: 10 Secrets to a Happier Life, is translated into more than 20 languages. My book's single aim is to offer people with Parkinson’s specific ways to improve their quality of life. Even the most educated patients, who have access to everything, are often not aware of very simple strategies that could help them live significantly better with Parkinson’s. My new book shares these strategies across a wide range of areas, including medications, depression, hospitalization, exercise and more.

Over the last decade, I have written a blog forum for the National Parkinson Foundation, and have answered questions from around the world in the famed “NPF Ask the Doctor.” When I announced the book on the forum, I received this reply from Rebecca from Paradise, California. “I just wanted to say thank you for writing the book. My father was diagnosed two weeks ago and I bought your book and three others for my mother. She called me up today and said your book was the best; she said she got so much more out of your book than the others. Then I said, ‘You know, Mom... Dr. Okun is who Dad has an appointment with early next year.’ She was over-the-top thrilled. She felt you explained everything so well and she got a great deal of comfort and most of all she got HOPE from your book; I could hear it in her voice. This alone is healing, so thank you!” Rebecca continued, “Also, I want to say thank you for being such an amazing support to PD patients and their families in the National Parkinson Foundation online ‘Ask the Doc’ forum. As someone new to PD, it can be overwhelming, and being able to read your past and present posts is a true gift. You know, people in teeny-tiny towns (probably big cities too) just don’t have an opportunity to find someone so knowledgeable. I just can’t imagine there not being a ‘you’ in the world! Seriously I wonder if you really know how much help you are providing!”

Patricia from Newport, RI, writes, “Dr. Okun, enjoyed reading your book... thanks for taking the time to write it. I have passed it on to the people in my PD movement class.”

Renee from Glendale, AZ, says, “I just read your book and wanted to tell you it is fantastic, it really lifted my spirits. I am new to this and pretty nervous about the future. I am 52 years old with a lot of dreams not fulfilled. Your book inspires hope.”

I was completely humbled by Rebecca’s comments and praise and thank Rebecca. I truly enjoy working with NPF to help people lead better lives with PD.

Visit www.parkinson.org/10secrets for more information on where to purchase Parkinson’s Treatment: 10 Secrets to a Happier Life. You can also find Dr. Okun’s online forums and blog posts at www.parkinson.org/forums.
Staff Profile:  
Fernando Cubillos, MD,  
Director of Research Programs

Swept up in a flurry of activity at his desk, Fernando Cubillos, MD, brushes visitors aside. “It’s Wednesday, I have to get ready for the steering committee call,” Fernando tells a colleague. After a successful early career as a physician in Colombia, Dr. Cubillos – Fernando to his colleagues – has shifted to research. Upon coming to the United States, he took a job at the University of Miami, leading research operations in pulmonary and critical care. Fernando found the work very rewarding.

The Cystic Fibrosis Foundation launched a national quality improvement program in the 1990s across specialty centers, and Fernando helped the University of Miami join the effort. He now uses that experience to help lead the National Parkinson Foundation’s initiative to improve the quality of Parkinson’s care through its Parkinson’s Outcomes Project, the largest study of Parkinson’s disease ever conducted. Fernando is on the steering committee.

In his leadership capacity, Fernando has raised the quality of the Parkinson’s Outcomes Project’s research operations to be on par with a multimillion dollar drug trial. “The kinds of things we’re looking at, including the patient impact of medication use, surgery, and exercise, deserve to be done at this level,” Fernando says. “When Robin Williams died, I understood what he had gone through because I’ve seen how the lives of the thousands of depressed patients in our study are affected. When I was practicing medicine, I helped people one at a time. My goal is to use research to help a hundred thousand people – or more.”

Run to Beat Parkinson’s!

On January 25, 2015, you can race with TEAM HOPE in the Miami Marathon and Half Marathon to support the brave people who battle Parkinson’s every day. You will make the personal achievement of running a long-distance race even more memorable by helping NPF improve care and change lives for people with Parkinson’s.

Team Hope participants who commit to $750 in FUNdraising, will receive:

- Guaranteed race entry
- Team Hope running apparel
- Recovery booth at finish line
- Fundraising support

Join today! Contact Sara Teeter at teamhope@parkinson.org or 305-537-9951 or visit www.parkinson.org/marathon for more information.

Want to participate in an endurance event for Team Hope but not in Miami? Contact Sara Teeter and she can help you get started!

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Moving Day® Teams Do Whatever It Takes to Beat Parkinson’s®

By Joel Goldstein

The Goldstein/Goodman Team is excited to be part of the inaugural year of Moving Day® Boston. We hope to make it a wildly successful event. My brother was recently diagnosed with Parkinson’s disease (PD) and this has brought into sharp focus and priority the challenges faced by people with the disease and the fact that we need to do more to support people living with it. Given the size of the population impacted by Parkinson’s disease in the greater New England area, as well as the excellence of the medical centers and biotech and pharmaceutical research companies located here, we feel uniquely situated to increase the awareness of PD and of the need for services to help patients, families and caregivers.

My partner, Reed Goodman, and I are fortunate to have many former colleagues from Fidelity Investments, Digital Equipment Corporation and other places we’ve worked or consulted to who have been incredibly generous in their support of our team, making donations, joining the team or agreeing to walk with us. My brother, Walter, who was diagnosed with PD last year and his wife, Toni, are part of our team and part of the planning committee helping to establish Moving Day® in Boston. My brother spent many years as a development professional and his wife is a physician, so they are both great resources for NPF. In addition to working on the event itself, I am co-chair of the corporate sponsorship team, which is having great success this first year in attracting amazing companies to sponsor the walk. Our non-work friends, family and neighbors have all been supportive and one personal friend, newscaster Randy Price of WCVB Boston, has agreed to help on the day of Moving Day® Boston and to help publicize the event in the weeks leading up to the walk. We’re also working with our local health club, the senior center and other organizations to get the word out and raise funds.

Thanks to the support of family, friends and former colleagues, we’ve actually blown past our original goal for our team of $5,000, have exceeded our increased goal of $10,000 and hope to hit a milestone of $15,000 by Moving Day® Boston. Wish us luck!

For more on this great team and other teams like it, visit www.npfmovingday.org.

Calendar of Events

October

5 Miami, FL: Moving Day. Bayfront Park
8 Free Webinar: Managing Cognitive and Behavioral Changes in Parkinson’s
11 Boston, MA: Moving Day. Artesani Park
11 Philadelphia, PA: Moving Day. A Walk to Stamp Out Parkinson’s MLK/West River Drive
19 Chicago, IL: Moving Day. Lincoln Park, Grove 2
19 Stockbridge, MA: Kripalu Wellness Retreat. Kripalu Center for Yoga and Health, Stockbridge, MA
25 Los Angeles, CA: Moving Day. The Autry at Griffith
25 Honolulu, HI: Moving Day. Honolulu Hale Civic Grounds

November

1 NC Triangle: Moving Day.
1 Atlanta, GA: Moving Day. Centennial Olympic Park
8 Augusta, GA: Moving Day. Wilson Family Y Track
13 Free Webinar: Practical Pointers: Caring for Someone with Parkinson’s
15 Phoenix, AZ: Moving Day. Wesley Bolin Memorial Park
16 Boca Raton, FL: Moving Day. FAU Stadium
20 Boca Raton, FL: Fashion Under the Stars

January 2015

25 Miami, FL: Marathon and Half-Marathon. Bayfront Park
On the flip side, our new research shows that when a person with Parkinson’s receives regular care by a neurologist, their risk of hip fracture, nursing home placement and Parkinson’s-related deterioration in health decreases by about 20 percent. Even more stunning, some statistics suggest that the benefit to a person with Parkinson’s of seeing a neurologist specializing in movement disorders – specialists with the deepest knowledge of Parkinson’s disease – is double that of seeing a regular neurologist.

Regular care by a neurologist results in better medication, better recognition and treatment of the complex non-motor symptoms of Parkinson’s, and in care that treats the whole patient. New research suggests that developing a good working relationship with a neurologist, in particular, a movement disorders specialist, prepares a person with Parkinson’s for what is coming up and ensures that they are ready. That readiness makes them safer in a very concrete sense.

Now consider the fact that 32 percent of people with Parkinson’s never see a neurologist. And another 39 percent of patients see a neurologist just a few times over the course of their disease. Clearly, we need to turn these statistics around. That happens when people with Parkinson’s and those who care for them, understand what constitutes the very best care. And that’s where the NPF’s Centers of Excellence come in.

Only NPF’s Centers of Excellence bring together clinicians, evaluated for their expertise in patient-centered Parkinson’s care, in a proactive network. NPF’s Parkinson’s Outcomes Project, a long-term research study launched in 2009 at our Centers of Excellence, is collecting data, piece by piece, to reveal the nature of the most effective care for people with Parkinson’s. We’ve learned that the best care is team care, including a neurologist – or even better, a neurologist who is a movement disorders specialist – a psychiatrist who can monitor anti-depressive use and possibly offer counseling, often a social worker who provides counseling, and physical and occupational therapists.

We have the knowledge today to significantly improve the health and daily lives of Parkinson’s patients. It’s time to harness that knowledge for every person with Parkinson’s.