

PARKINSON

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First Connect *My Page* for the Newly Diagnosed

Getting a Parkinson's diagnosis is hard enough.

Trying to understand all the ways you need to manage your condition to stay healthy is sometimes harder. This is why the National Parkinson Foundation (NPF) recently launched First Connect *My Page*, a web-based educational series that gives the newly diagnosed the knowledge and tools they need to successfully navigate this unfamiliar and difficult territory.



“*People often feel unmoored—like they are adrift at sea—when they receive a Parkinson's diagnosis. This tool will help them navigate this uncharted territory because it is based on the experiences of people who have been there before, said Joyce Oberdorf, NPF's President and CEO.*”

Most physicians, especially if they are not trained in movement disorders, don't know how to deliver a Parkinson's diagnosis and often leave their patients feeling lost and alone.

Subscribers to First Connect *My Page* get tailored content delivered directly to their e-mail inbox. All of the articles are written by people who know the landscape firsthand; having actually tackled the challenges of living with Parkinson's for many years, the writers offer practical advice based upon personal experience. Those

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**NOVEMBER
IS NATIONAL
FAMILY
CAREGIVERS
MONTH**



**A Caregiver Who
Makes Every
Moment Count**

“There are moments which mark your life. Moments when you realize nothing will ever be the same and time is suddenly divided into two parts: before this and after this.”

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Moving Day®

“NPF's national signature event, Moving Day, a walk for Parkinson's, continues to grow and is now in twenty markets across the United States.”

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practical things range from how to overcome anxiety and deal with intimacy issues to how to travel with Parkinson's and manage medications. The aim is to help the recently diagnosed minimize the life-changing effects of Parkinson's on their own lives.

According to Jackie Hunt Christensen, a feature writer for First Connect My Page and a Parkinson's advocate, this is a much-needed service. "I believe that people who are newly diagnosed need information on how to live well with Parkinson's. Hearing from others with Parkinson's can make it much easier for everyone involved to come to terms with the disease," she said.



Subscribers can also access video segments and other content through First Connect My Page, all of which helps those facing a Parkinson's diagnosis get a handle on specific aspects of living with this disease early on, for example, understanding new ways to interact with loved ones and doctors, learning about procedures, getting help for depression and more.

Parkinson's disease requires a lot of education and action. For this reason, NPF continues to invest in developing the right tools—including the *Parkinson's Toolkit* app for health care professionals, the *Parkinson's Central* app for patients and caregivers, and now First Connect My Page—that bring people better and faster access to Parkinson's-specific health information. All these tools build upon our goal to take our power to communicate to the next level of impact.

"I have dealt with a lot of situations that could have been avoided or minimized if only I'd had access to something like First Connect My Page. If I can help even one other person

First Connect My Page

with Parkinson's avoid unnecessary bad experiences, I will feel that my own journey with Parkinson's has been worthwhile," Christensen said.

In today's social online world, First Connect My Page is yet another option that allows those facing a Parkinson's diagnosis to join a supportive community where they can share and solve problems together. NPF has also created a free "Newly Diagnosed Forum" in addition to the "Caregivers Forum" and "Young Onset Forum" as another opportunity to connect with others (Parkinson.org/forums).

First Connect My Page is made possible by the generous support of Medtronic Philanthropy and thousands of people with Parkinson's and their families.

How does it work?

SIGN UP
IN 3 EASY
STEPS

1

Call our Helpline 1.800.4PD.INFO
or visit parkinson.org/mypage.



2

Provide your current email address.



3

Learn more, Be empowered,
Stay Connected! You are now
a part of our online community.



To sign up for First Connect My Page,
visit www.parkinson.org/mypage
or call NPF's Helpline at
1-800-4PD-INFO (473-4636).

♥ Rosie Roessler, a Caregiver Who Makes Every Moment Count



The Roessler family.

Rosie Roessler of Lauderhill, Florida, knows something about making every moment count. “There are moments which mark your life. Moments when you realize nothing will ever be the same and time is suddenly divided into two parts: before this and after this,” said the 30-year-old mother of three.

That moment happened two and a half years ago when Rosie’s 41-year-old husband was diagnosed with young-onset Parkinson’s disease. Now with all the demands on Rosie’s time and emotions—juggling a full-time job, her husband’s needs, and multiple kids—every day is a struggle. With such a stuffed schedule, she admits that it is not possible to feel happy and positive all the time.

“There is a positive, because life has become better than before. My husband and I are even closer. Now the best part of my day is coming home to him. Parkinson’s has given us something that I believe we would never have had without it: simple unconditional love, she said.”

“I love my husband, but I hate Parkinson’s. The feelings of helplessness are overwhelming, and nothing is worse than watching him suffer while knowing I can’t fix it,” Rosie said. But, she adds that her desire to raise Parkinson’s awareness is a continual source of motivation.

“It’s 100 percent normal to feel like you just can’t take it anymore, especially after you go for days being a single mother and a caregiver to your husband because there has been a recent medication change that is taking everything out of him,” Rosie said. Instead, she has learned to look at life from a different perspective. These days, she says she lives by the motto, not every day is perfect, but there are perfect moments in every day.

So instead of facing reality, Rosie is now creating reality, moment by moment. “I know that we have an uphill climb fighting this battle, but when I feel like I can’t make it through the day, I break it down hour by hour, and when even that is too much, minute by minute. The great thing about life is we all get a do-over—every morning. And that’s really kind of amazing,” she said.



“It was good to read the experience of someone else and know I am not alone with these frustrations. It’s an emotional roller coaster watching my husband struggle.”

~ Julie

ROSIE’S TIPS FOR LIVING IN THE MOMENT

- ✓ **Know that you are unique.** Never compare your experience as a caregiver to someone else’s. This gives you the choice of how you want to live.
- ✓ **Slow down.** Focus on the present moment and the simple things in everyday life that bring you joy. Pay attention to feelings that come up and, without guilt, acknowledge them.
- ✓ **Be thankful.** Appreciate the fact that you actually have the health and strength to care for your loved one. Take stock of how your relationship with your loved one may have deepened.

To find an NPF Chapter with a Caregiver Support Group near you, please visit www.parkinson.org/search or call NPF’s Helpline 1-800-4PD-INFO (473-4636).

Aware in Care: Eliminating Disparities in Parkinson's Care

In working to meet the challenges of the underserved, the National Parkinson Foundation (NPF) is bringing *Aware in Care's* lifesaving messages to underserved communities by providing thousands of free hospitalization kits in low health literacy English and Spanish versions.

"The unfortunate reality in our country is that many people remain isolated and unable to access services in the healthcare system at large," said Joyce Oberdorf, NPF's President and CEO. "NPF is working to ensure that everyone—regardless of who they are, where they live, what language they speak or how much money they have—receives much-needed Parkinson's resources."



With more frequent hospital visits and a high sensitivity to the timing and dosing of Parkinson's medications, people with Parkinson's face great risks in the hospital. In 2012, NPF responded to the needs of the Parkinson's community by launching the *Aware in Care* program. Since then, NPF has distributed more than 25,000 *Aware in Care* hospitalization kits across the United States and launched a national awareness campaign encouraging patients and caregivers to, "Get the Kit. Know the Facts. Be *Aware in Care*."

"We know that three out of four individuals with Parkinson's do not get their medications as prescribed during hospitalization, which can lead to prolonged stays and complications," said Becky Dunlop, RN, a Nurse Coordinator for the Johns Hopkins Parkinson's Disease and Movement Disorders Center. "We also know that the health care delivered to non-English speaking individuals is dissimilar from care delivered to those who speak English, leading to disparate outcomes. Now, *Aware in Care* is taking the lead to address these well known challenges."



The new low health literacy English and Spanish versions of the kit are being distributed in targeted geographic regions in partnership with five NPF Centers of Excellence (Baltimore, Houston, Philadelphia, Phoenix, and Washington, D.C.). Over our history of six decades, NPF has maintained a steady commitment to eliminating Parkinson's-related disparities in health care.

"If every individual living with Parkinson's uses this kit, we have the potential to educate at least one million health care providers, because the kit educates by doing the talking. Ultimately, this achievement will improve care for all people living with Parkinson's and go a long way in the elimination of health care disparities for everyone," Dunlop said.

The new kit is a self-advocacy tool that includes a guide to prepare the Parkinson's patient for a planned or an emergency hospital visit, a medical alert card, and a medication form to fill out and share with hospital staff.

This initiative was made possible by the generous support of Medtronic Philanthropy. *Aware in Care* is also supported by the generous contributions of its lead sponsor, the Edmond J. Safra Philanthropic Foundation and the Eleanor M. and Herbert D. Katz Family Foundation.



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FREE WEBINARS**

November 7th

*Caring for
the Caregiver*

December 5th

*Parkinson's Treatment:
10 Secrets to a Happier Life*

www.parkinson.org/webinars

**For more information about
Aware in Care or to order a free kit,
visit www.awareincare.org
or call NPF's Helpline
1-800-4PD-INFO (473-4636).**

What's Hot in Parkinson's Disease?

Recognizing and Treating Caregiver Strain

Helen Keller's caregiver, Anne Sullivan, once said, "I cannot explain it, but when difficulties arise, I am not perplexed or doubtful. I know how to meet them." As a neurologist, I see a lot of Parkinson's patients, and I know that one of the keys to success is a fully engaged caregiver.

Findings from a new study from the National Parkinson Foundation (NPF) paint a picture of just how important the caregiver really is. NPF's Parkinson's Outcomes Project has assembled the largest group of Parkinson's disease patients being studied over time in a clinical setting. We have been using a measure called the multidimensional caregiver strain index (CSI) to collect data on caregiver strain. This scale reflects how spouses and caregivers feel about caring for their family members and loved ones.

To understand how vital the caregiver is to the person with Parkinson's as well as the dramatic impact caregiving has on a person thrust into this role, we looked at data in caregiving situations where the caregiver changed from spouse to another family member. We wanted to know how hard caregiving is on those thrust into this role.

As expected, we found that caregiver strain was higher for new caregivers. In addition, when a patient's caregiver changed from his or her spouse to another family member, the CSI increased 20 points from a year earlier when the spouse was the caregiver. When the spouse remained the caregiver, the increase was just five points. On this 72 point scale, where zero means you have little or no stress and 72 means you are experiencing a great deal of strain, this 15 point difference is 20 percent from no impact at all to intolerable strain, and is quite serious.

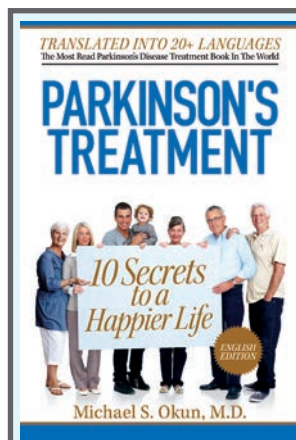
The study also showed other notable results. When a patient's caregiver went from spouse to another family member, the patient suffered worse health. They got sicker, reported worse health and experienced slower mobility. Not only do experienced caregivers have well developed coping skills, they also provide better care and help maintain the health of their loved ones.

Also using data from the Parkinson's Outcomes Project, Tanya Simuni, MD, a movement disorders specialist at the NPF Center of Excellence at Northwestern University, examined the impact of caregiver strain on patients. In this study, she found a correlation between the self-reported health of patients, and caregiver strain: the better the patient's health, the lower the strain. This is important because our research indicates that it is more the patient's perception of their own health than the clinical measurement of the impact of the disease that determines strain.

This new evidence has really shed light on how I look at the concerned spouse who accompanies my patients to their visits with me. Caregivers are an integral part of care, and we have found that a happy, knowledgeable caregiver is not only better able to cope with the stress of caregiving, but also an equally important member of the Parkinson's care team. With this new research, we have learned that recognizing and treating caregiver strain is critical.

Author: Michael S. Okun, MD, NPF National Medical Director

Read Dr. Okun's monthly column, "What's Hot in PD?" online at www.parkinson.org/whatshot.



**Parkinson's Treatment:
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**by Dr. Michael S. Okun,
NPF's National Medical Director**

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Top Questions and Answers from NPF's "Ask the Doctor" Forum

November is National Family Caregivers Month. Many experts agree that the most important factor for living successfully with Parkinson's disease is having an empathetic and supportive spouse or caregiver. In this issue, we will focus on commonly asked questions about caregiving from our "Ask the Doctor" forum. NPF also offers a "Caregiving" forum which is open for discussion. We encourage everyone to visit www.parkinson.org/forums to take advantage of this informative and free resource.

Q My mother-in-law has already had two minor accidents while driving that she excuses as "just being careless." I don't want her to hurt herself or anyone else. When should we take the car keys away?

A You are right to be concerned about your mother-in-law's safety, and also the safety of others. Even in the early stages of Parkinson's disease, a person's ability to drive safely may be impaired due to many factors including balance, perception, mental clarity, tremor, reaction time, and many other disease-related features. If you notice that your mother-in-law may be putting herself or others in harm's way, ask her to have her driving skills assessed by a Driving Rehabilitation Specialist (DRS). To find a DRS, inquire at hospitals, rehabilitations facilities or driving schools. No one likes to think about giving up driving, but it is something she might have to consider. You can help to make her transition easier by assisting with alternative forms of transportation.

Here are some tips:

- ➔ Contact your local community center to see if they provide transportation services.
- ➔ Check with your local city/town government to find out if there are special shuttle services for people with disabilities.
- ➔ Call your local public transportation office to find out about bus passes for the elderly and people with disabilities.



AUTHORS:

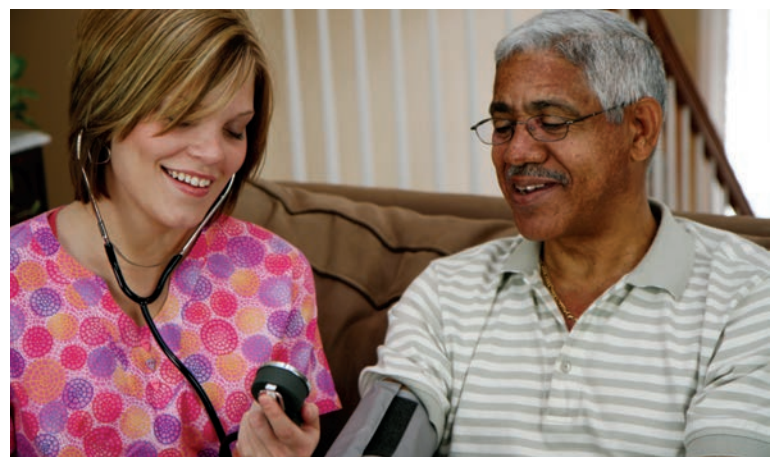
Left: Michael S. Okun, MD
Center: Kelly D. Foote, MD
Right: Ramon L. Rodriguez, MD

➔ If your mother belongs to a religious organization, call to find out if they have a transportation committee of volunteers who drive community members to different destinations.

➔ Ask if family members or friends can help out.

Q My father lives with me. His Parkinson's symptoms are getting worse and he is having a hard time remembering everything. How do you know when it's time to hire outside help?

A The first step is to determine the level of stress and anxiety you and your family may be experiencing in caring for your father. Do you feel overwhelmed by your caretaking duties? If so, it may be time to look for outside help. Remember, it is never too early to think about hiring a home health aide or someone to help with activities of daily living. That may mean finding someone to help you for a couple of hours a day or even a week. Or, it may mean asking friends and family members to pitch in. Your goal should be to organize the duties of caretaking, prepare for potential disability and engage in daily activities that relieve stress. You want to avoid caregiver strain, a common condition experienced by people who care



for loved ones with a chronic illness. To get the support you need, we recommend consulting with a licensed clinical social worker. He or she can help sort out the optimal solution for you and your family.

Q Most people think Parkinson's disease is all physical, but I have noticed significant changes in my husband's personality. He has frequent mood swings and cognitive issues. These behaviors are very stressful to live with. Anything I can do?

A It is true that each person will respond differently to a Parkinson's diagnosis and to treatments, and changes in personality and mood may manifest over time. Some of these changes may be disease related and some may be medication related. The first step is to see a movement disorders specialist or a neurologist experienced in Parkinson's disease so that adjustments to and optimization of his medications can be made. Since he may be depressed, anxious or have another treatable non-motor feature of his disease, you might want to consider consulting with a counseling psychologist. It is also vitally important to your own health and well-being that you seek support and counseling in order to deal with the demands and chronic stress of being a caregiver. There are resources available that can help make both of your lives better, and a short consultation with a licensed clinical social worker is a good place to start.

Q My mom recently found out that she has Parkinson's. My siblings say she should make out an advance directive. Does she really need it?


A An important reason for your mom to make her wishes known in advance of death is to minimize the burden you and your family will face in the future. Though Parkinson's disease usually does not directly cause death, it is still important for patients to make an advance directive. Advance directives carefully detail for physicians and your family all medical issues and instructions your loved one wants implemented just in case she becomes unable to make a decision. You simply designate a health care proxy (sometimes called a power of attorney for health care) who will make the important medical decisions on her behalf. The best time to create the advance directive is sooner rather than later, when your mom is healthy and able to make rational decisions.


The information published in this "Ask the Doctor" Forum is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise. Accordingly, please consult your own professional for all advice concerning medical, legal, or other matters published in connection with this Forum. NPF assumes no liability of any kind for the content of any information transmitted to or received by any individual or entity in connection with their use of the "Ask the Doctor" Forum on the NPF Web site, and NPF does not endorse or recommend any such information.


Caregiver Tips for Daily Living





Did you know? 39% of U.S. adults provide care for a loved one, up from 30% in 2010, and many navigate health care with the help of technology, according to the latest Pew Research. So if you are a caregiver, you are far from alone. Here are some tips to help make your job easier:

 **Take "me" time.** You need to take care of your physical and mental health. That means getting plenty of sleep, eating healthy, exercising and socializing with friends.

 **Embrace technology.** From health apps and health tracking tools to medication reminders and assistive devices, you can make your day-to-day routine easier by exploring technology options beyond the Internet.

 **Make small changes.** Things as simple as using satin sheets on the bed to facilitate turning and special kitchen utensils such as easy-to-hold angled utensils and high scoop plates can also help make your days go more smoothly.

 **Get the help you need.** Family, friends and neighbors can all be a source of ongoing support. But if they can only help out in a pinch, consider hiring a cleaning service or home health aide.

 **Call NPF's Helpline.** If you have questions or need to find an NPF Chapter or support group, call 1-800-4PD-INFO (473-4636) for more information.

Moving Day® Expands Into New Markets

The National Parkinson Foundation's national signature event, *Moving Day*, a walk for Parkinson's, continues to grow and is now in twenty markets across the United States. This year, NPF introduced three new walk locations: Atlanta (November 9th), Honolulu (November 16th) and the Research Triangle in North Carolina (November 2nd). In 2014, *Moving Day* will be heading to Orlando.



NOVEMBER 9, 2013
ATLANTA, GA



Moving Day Atlanta coordinator and "Atlanta All Stars" team captain, Annie Long, got involved with the walk after her mother was diagnosed with Parkinson's disease earlier this year. "I'm uncertain about what the future holds for my mom, but I refuse to just sit back and wait," Annie declared. "This event is all about raising awareness and funding to improve the quality of care for people living with Parkinson's disease. For my mom, this care will be more and more important as the years pass."



Annie Long and her mother, Allyson Weathers.

Moving Day Atlanta is NPF's fourth location in Georgia with walks in Augusta, hosted by the NPF Central Savannah River Area Chapter, Cedartown and Rome hosted by the NPF Georgia Chapter. The fundraising goal for *Moving Day* Atlanta 2013 is \$100,000 and more than forty teams are registered! The event will take place on the Georgia Tech Campus with both a one-mile and 5K walk option. The event also features a Movement Pavilion (Zumba, Pilates, Tai Chi and Tango), Kid Zone (Bounce house, face painting) and a massage area.



Allen and Jan Rabinowitz.

Allen and Jan Rabinowitz, of Sandy Springs, GA, will be at the first-ever *Moving Day* in Atlanta along with Annie. Allen was diagnosed with Parkinson's at the age of 48 and is now retired. His wife and care partner, Jan, helped found the Well Spouse Association—a community group that offers support for those taking care of their spouses—and she is the team captain of "Well Spouse Support."

"Moving Day is our day to show the world that people with Parkinson's are not much different from anyone else, Allen said."

Annie, who is now carrying her first child, wants to ensure that her Mom's quality of life is the best it can be so that she can be an active grandmother. "That is why I got started with this effort and why I will continue to move so that people, like my mom, have access to excellent care and support."

Moving Day is made possible through the generous support of our national partners: UCB, Medtronic and Right at Home. *Moving Day* Atlanta local sponsors include: UCB, US WorldMeds, Georgia Institute of Technology, PT Solutions, Smith & Howard, TGS Media, Big Peach Running Co., and Everything Is A Party, LLC.

Moving Day Atlanta, Saturday, November 9th, 2013 is free and open to the public. To register, visit www.MovingDayAtlanta.org, or call 404-400-2705.

To find other Moving Day walk locations, visit www.NpfMovingDay.org.

Stand With Us

Dear friends of NPF,

I am contemplating the future of the National Parkinson Foundation (NPF) and its many projects and programs: the launch of First Connect My Page, our newly released *Parkinson's Central* app, the celebrated success of our grassroots programs like *Moving Day*, the national helpline and our *Aware and Care* outreach to the underserved. My excitement continues to grow as I think about how your support has played a major role in the success of these programs.



I think about the very first planning meeting over 50 years ago when a small group of determined family members got together and set in place the beginning of what has become NPF. We are now about to enter a new year that is filled with great hope and aspirations of increasing our assistance and programs to families and individuals dealing with the issues and impact of Parkinson's on their everyday lives.

This is why I have such high hopes and aspirations for the work of NPF, and why I have joined the team as Vice President of Constituent Relations. Clearly there will be challenges as we move forward, but the bedrock of NPF has proven to be strong and stable. For this reason, I truly believe we are up to the challenges before us whatever they may be.

I think our accomplishments speak loudly. We are fostering a more financially-secure, technologically-informed and results-motivated organization which, in turn, will help our constituents and families who rely on NPF to live more satisfying and rewarding lives. We here at NPF are grateful for the support that you have shown us in the past and are asking you to **stand with us** as we continue working to achieve our goals.

Sincerely,

Darcy Taylor
Vice President of Constituent Relations

TEAM HOPE NATIONAL PARKINSON FOUNDATION



Have Fun. Give Hope. Beat Parkinson's!

Team Hope allows community heroes to help NPF in its mission to provide quality care for those living with Parkinson's disease. Our dedicated Team Hope members take the lead in creating unique ways to build awareness and raise funds for research. Successful Team Hope events take place around the country—from golf tournaments and wine tastings to marathons and dances. The possibilities are endless and we will be there to help you every step of the way. Sign up today to turn your passion into action!

For more information on how you can give hope, please visit
www.parkinson.org/teamhope
or email teamhope@parkinson.org.



IRA Charitable Rollover: What You Need to Know

Please consider making a gift to NPF now or prior to the end of the year. An IRA Charitable Rollover is just one way that you can positively impact those living with Parkinson's.

The Pension Protection Act of 2006 (PPA) permitted individuals to roll over up to \$100,000 from an individual retirement account (IRA) directly to a qualifying charity without recognizing the assets transferred to the qualifying charity as income. While this initial provision expired on December 31, 2007, it has been extended several times. On January 2, 2013, President Obama signed the American Taxpayer Relief Act of 2012 (H.R. 8) into law, extending the provision until **December 31, 2013**. Note that the new law simply extends the charitable rollover and, other than some modifications regarding timing for 2012 distributions, did not make substantive changes to the operations of the provision.



For information about or assistance with making a gift to NPF, please visit www.parkinson.org/plannedgiving.

Contact Darcy Taylor at dtaylor@parkinson.org.

NPF does not provide legal tax advice; we strongly recommend that you consult with a tax advisor when considering making a charitable contribution or a creating charitable giving plan.



Run to Beat Parkinson's!

On February 2, 2014 you can race with **TEAM HOPE** 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 \$1,000 in fundraising, will receive:

- Guaranteed race entry
- Team Hope running apparel
- Inspiration Kickoff Dinner
- Fundraising support



For more information please contact Sara Teeter at steeter@parkinson.org.



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A team of Parkinson's specialists answer medical questions about Parkinson's disease.

ASK THE SPEECH CLINICIAN:

A team of experts answers questions regarding speech and swallowing.

ASK THE PHARMACIST:

Mark Comes, RPh, fields questions about medication management.

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Ramon L. Rodriguez, MD contesta preguntas con respecto a la enfermedad de Parkinson y materias relacionadas.

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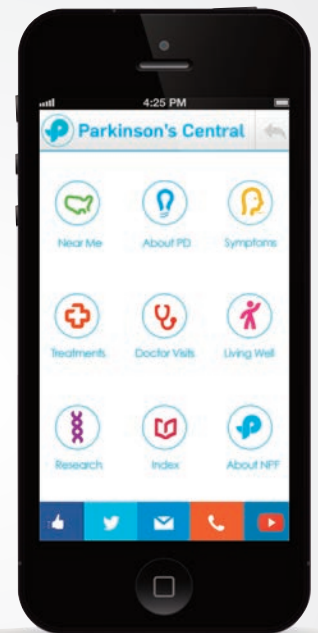
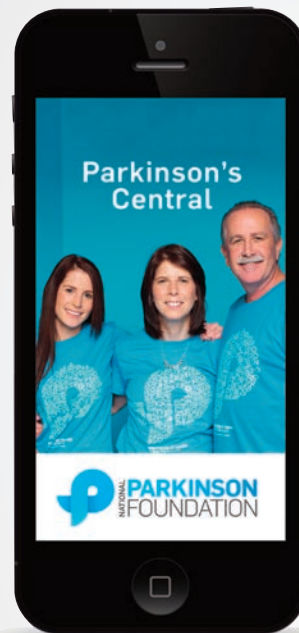
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Headquarters 200 SE 1st Street, Suite 800
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President & CEO Joyce A. Oberdorf

Chairman Bernard J. Fogel, MD

**National
Medical Director** Michael S. Okun, MD

Editor Leilani Pearl

Writer Paula Rasich

Design Jennifer L. Bonnet

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