Join NPF’s National Campaign to Beat Parkinson’s Disease

The National Parkinson Foundation (NPF) has always believed that the impact of Parkinson’s care should be measured in the real proving ground: daily life. That’s why NPF recently launched an exciting new campaign, *Whatever It Takes to Beat Parkinson’s*, to empower people to take control of their Parkinson’s disease and their health care.

“Every person with Parkinson’s should know that they can help fight the impact of the disease,” stated Joyce Oberdorf, NPF’s President and CEO.

“It is never too late to see improvements in their daily life. This campaign brings to light the many ways that anyone can take action, and arms them with the resources they need to live their best life with Parkinson’s. It speaks to the core of our mission to improve care, and improve lives.”

Right now in America as many as one million men and women are living with this illness. And, every year some 60,000 more join their ranks. Though there is no known cure for Parkinson’s disease, mounting scientific evidence shows that there is much we can do to start to beat it. That’s why when we designed the symbol for the campaign—a graphic mosaic of NPF’s blue “P” ribbon for Parkinson’s—we created 118 icons that symbolize proven actions people can take to improve their health and quality of life.

...continued on page 2
Join NPF’s National Campaign to Beat Parkinson’s Disease ... continued from cover

United in this symbol, these icons show the variety of potential strategies that individuals can use to fight Parkinson’s.

Starting in April and throughout 2013, NPF will collaborate with our chapters across the country to raise awareness through educational programs and other outreach efforts. In addition, an interactive web page profiling the new symbol and the goals of the campaign will allow users to draw motivation and inspiration from other people.

No matter where you are in your fight against Parkinson’s disease, get ready to be inspired. We’re committed to helping everyone facing this diagnosis—especially those who are in the dark about this illness—take better care of themselves and have a healthier future.

Learn more at www.parkinson.org/whateverittakes.

WHATEVER IT TAKES MERCHANDISE

To show your support and make the cause your own, visit our new online store which showcases Whatever It Takes to Beat Parkinson’s branded items available for purchase such as t-shirts, hats, tote bags, buttons and mugs.

To place an order, visit www.parkinson.org/store.

Letter from the President

Throughout the year, as I travel and meet so many people and families affected by Parkinson’s, I am amazed at the passion and commitment to “beating” the disease. Ralph won’t miss Tai Chi and pilates. Martin flings himself into yoga dance. Amy turns out her whole family for a walk, and Mavis won’t stop spreading the word.

I won’t kid you, Parkinson’s is debilitating. And my heart aches as I see the physical toll that it can take. But so many everyday heroes look at each day as an opportunity to take control and fight back.

To honor that spirit, we created the Whatever It Takes to Beat Parkinson’s campaign to highlight the many ways you can take charge of your own health.

Throughout the month of April, NPF is offering a limited-edition, blue awareness bracelet with the message Whatever It Takes to Beat Parkinson’s. The bracelet, free with a donation of $25 or more, will help create awareness of Parkinson’s and can serve as a daily reminder to feed the fighting spirit within.

I hope you’ll join this campaign, and like everyone at NPF, be committed to doing “whatever it takes.”

Thanks for your support,

Joyce Oberdorf
President and CEO

P.S. If you are on Twitter, tell us how you are beating Parkinson’s by using the hashtag #BeatParkinsons (@parkinsondotorg).
Detecting Early Cognitive Changes in Parkinson's

From attention difficulties to forgetfulness to a feeling of being easily overwhelmed, cognitive change is a particularly distressing symptom of Parkinson's disease. Early signs of cognitive change predict a different course of the disease and higher caregiver stress, and today's care offers few options to alter the prognosis.

Antonio Strafella, MD, PhD, FRCPC, a senior scientist in the Division of Brain Imaging and Behaviour Systems-Neuroscience at the Toronto Western Research Institute, University Health Network and Research Imaging Centre at the Centre of Addiction and Mental Health, is working to change that. With funding from the National Parkinson Foundation (NPF), Dr. Strafella is using a high-tech imaging technique called positron emission tomography (PET) to identify biomarkers for early cognitive change in Parkinson's disease. PET scans allow scientists to see inside the brain and measure brain responses at the cellular level. Establishing such imaging biomarkers may provide doctors with a better understanding of the mechanisms affecting cognition to help recognize and prevent cognitive change with new treatments.

"A lack of information of these symptoms has limited the development of optimal treatments to alleviate these non-motor aspects of Parkinson's disease," Dr. Strafella said. "By identifying the neurobiological changes associated with early cognitive changes, we will be able to set the path for early treatments that could have a significant impact on the quality of life and day-to-day activities of patients."

After studying nine Parkinson's patients with signs of cognitive change, five Parkinson's patients with normal cognition, and nine normal controls, Dr. Strafella's team identified a weaker signal coming from dopamine cells in regions of the brain associated with executive function in the patients experiencing cognitive change. In fact, he found that even among patients with Parkinson's disease, the patients with cognitive change had measurable differences in their scans from the patients who didn't in the part of the brain called the putamen. The putamen is very close to the substantia nigra, which is where Parkinson's disease affects motion. The study participants were all similar in age, education and Parkinson's disease severity, and so Dr. Strafella believes that these differences represent differences in how the disease is progressing.

This study gives hope that further research on imaging biomarkers will provide a better understanding of the parts of the brain affected by this disease and yield promising new ways to treat the dysfunction as well as therapeutic approaches to help prepare people to cope with cognitive changes. Importantly, it has been thought that nearly everyone who develops Parkinson's disease would experience some cognitive decline, but Dr. Strafella's scans indicated a difference between Parkinson's patients with cognitive change and those without. This difference offers more than an indication of where cognitive change occurs: it offers insight into the areas where new treatments will have to target to help provide relief.

New findings from this study are expected at the 17th International Congress of Parkinson's Disease and Movement Disorders in Sydney, Australia in June.

Dr. Strafella's research is funded through NPF's grant program. NPF has funded more than $172 million in research and support services. These studies support NPF's commitment to serving people with Parkinson's disease, their families and communities, and health care professionals worldwide.

To learn more about NPF’s research, visit www.parkinson.org/research.
A man with Parkinson’s is driving home from a friend’s house one afternoon when his car veers off the road and hits a tree. Moments later he is surrounded by first responders. At the site of the accident, he is unable to maintain his balance or follow orders. Because the police are unable to recognize his Parkinson’s symptoms and his special medical needs, they think he has taken drugs. He is handcuffed. Unfortunately, this scenario and many other potentially life-threatening mix-ups occur every day in the Parkinson’s community.

At the National Parkinson Foundation (NPF), we are committed to help you stay healthy and safe. Our new Aware in Care Parkinson’s ID bracelet is a simple and effective way to communicate your special medical needs in any emergency situation. The 100 percent stainless steel bracelet signals that the individual wearing it is a person with Parkinson’s disease. The NPF Helpline phone number, 1-800-4PD-INFO (473-4636), is engraved on the back of the bracelet. This ID bracelet is being offered free of charge to all people with Parkinson’s.

Mark Comes, RPh, who writes NPF’s “Ask the Pharmacist” forum, is a pharmacist, a national public speaker and a person living with Parkinson’s disease. He offers the following suggestions for staying safe.

- **Cover all your bases.** “I wear a bracelet, and have an ID on my key chain, one in my wallet, and one in both car glove boxes,” Comes said. “And, I carry a wallet card that reads, ‘I am not intoxicated, I have Parkinson’s Disease.’ The card lists my meds, my doctor’s name and phone number, my wife’s name and phone number, and a friend’s name and phone number.” (Both the Parkinson’s ID bracelet and a medical alert card for your wallet are also included in the Aware in Care kit.)

- **Put a friend on ICE.** It’s an acronym that stands for “In Case of Emergency.” Simply add the contact name ICE along with the phone number of the person you would like authorities to call in an emergency to your cell phone. “Anyone and everyone should do this, because all police, fire, and ambulance workers are aware of this and look for it on cell phones,” Comes said. “Of course, please let that person know you are using them as your ICE.”

Made possible through the generous support of the Edmond J. Safra Philanthropic Foundation.

To order the new Parkinson’s ID bracelet, visit [www.parkinson.org/store](http://www.parkinson.org/store) or contact the NPF Helpline at 1-800-4PD-INFO (473-4636).

For more information about Aware in Care, visit [www.awareincare.org](http://www.awareincare.org).
Many people with Parkinson's prefer the convenience of seeing their local doctor, rather than traveling to see a Parkinson’s-expert neurologist. Most neurologists who specialize in Parkinson's, called movement disorders neurologists, work at busy academic medical centers, sometimes with cramped parking and long walks to the clinic. Still, many people wonder whether they would do better if they went to an expert neurologist. I think they would, and I’ll tell you why.

Movement disorders neurologists are trained to prevent, recognize and treat the problems you face at each stage of the disease. A lot of the drugs you take for Parkinson’s act to replace or enhance a chemical called dopamine, but the ways they act and interact can make getting the perfect combination difficult. When we see a new patient who has been cared for by a non-specialist we frequently need to optimize their medications. We aim to better manage their mobility, and we always address other aspects of Parkinson’s disease that go beyond tremor and slowness including the “non-motor” symptoms and the side effects of medications.

Recently, a team led by Allison Willis, MD, scientifically studied every person covered by Medicare diagnosed with Parkinson’s in 2002, and followed those people for four years. She found that many of these people were never seen by a neurologist, and many more were only seen by a neurologist once—just 40 percent of the patients got regular care from a neurologist. She studied various ways that a person with Parkinson’s might be affected by their care, such as hospitalizations for complications of over-medication, injuries from falls, and moving to a nursing home because of inability to live independently, and she found that patients treated by a neurologist did better in every measure. In fact, patients who went to a neurologist frequently (three to four times a year) did better than patients who saw a neurologist less often (once a year or less).

The bottom line is that patients who see a neurologist experience better outcomes—specialists improve many critical aspects of care, from mobility to a longer life. Recent research from NPF’s Parkinson’s Outcomes Project is beginning to reveal for the first time what expert neurologists do: we consider a range of treatment options and tailor them to fit the needs of our patients.

Sometimes you just can’t get to a neurologist, or a movement disorders specialist. The good news is that telemedicine—the use of video conferencing to connect with and evaluate patients—will likely make virtual neurologist visits a possibility in the near future. To locate a neurologist in your area, call NPF’s Helpline 1-800-4PD-INFO (473-4636) or e-mail helpline@parkinson.org.

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/whatsshot.
Top Questions and Answers from NPF’s “Ask the Doctor” Forum

April is National Parkinson’s Disease Awareness Month. In this issue, we focus on commonly asked questions about Parkinson’s disease from NPF’s “Ask the Doctor” web forum. We encourage all patients, caregivers and friends of the Parkinson’s community to start a dialogue with us and take advantage of this free online resource at www.parkinson.org/forums.

Q I recently read that the benefits of exercise are significant for people with Parkinson’s disease, but I’m afraid of falling. What do you recommend?

A Fear of falling is a major problem for many people with Parkinson’s disease. It often causes them to limit their activities, which can make them feel isolated and depressed. In fact, recent research found that fear of falling is one of the three main reasons people living with this disease don’t exercise. The others are lack of time and low expectations of benefit. If you’re worried about falling, ask your doctor to refer you to a physical therapist who has worked with people with Parkinson’s. The physical therapist can develop a safe home-based or gym-based program that focuses on improving balance, flexibility and fall prevention. Getting 30 to 60 minutes of exercise a day most days of the week is enough to benefit. If you don’t have a block of time to devote to exercise, split your program into smaller increments. Another way to overcome your fear is to participate in a Parkinson’s exercise class offered at your local NPF Chapter. There, you will be surrounded by supportive people. Remember, studies have shown that exercise helps in controlling the symptoms of Parkinson’s and may even slow its progression. The message is: “it’s worth the effort to get moving.”

Q I will be undergoing surgery soon. Is there anything I can do to make sure my symptoms are well-controlled during my hospital stay?

A There are several things you can do to prepare for a safe hospitalization, but it will require some legwork. A new study concluded that for best symptom management in people with Parkinson’s, surgery should be scheduled as early in the day as possible (8 a.m. to 9 a.m. is the optimal time); doses should be administered as close as possible to the patient’s medication schedule pre- and postoperatively, and restarted immediately postoperatively; and, nurses should be educated about the special medication needs of people with Parkinson’s, including the cardinal rule of on time, every time.

Here’s what you can do:

➡️ First, arm yourself with information by ordering an NPF Aware in Care kit. The free kit, which includes a guide called the “Hospital Action Plan,” was developed to educate people with Parkinson’s and their medical team about appropriate Parkinson’s care during hospitalization. Next, schedule a meeting with your surgeon to review your Parkinson’s symptoms, medications and time of surgery. Finally, once you’re admitted, you should discuss your symptoms and medication schedule with everyone on your health care team. Importantly, talk to your anesthesiologist about keeping sedation as light as possible and avoiding...
any potential drug interactions, particularly with MAO-B inhibitors (selegiline, rasagiline). Soon after your operation, ask the doctor who is treating you to recommend physical, occupational or speech therapy. The therapist will assess your condition and develop an individual treatment plan to manage your condition.

Q I am considering Deep Brain Stimulation (DBS) surgery, but have no idea what to expect. Are there any side effects I should know about?

A Deep brain stimulation (or DBS) is a surgical procedure used to treat the disabling symptoms of Parkinson's disease. DBS uses a surgically implanted, battery operated medical device to deliver electrical stimulation to an area of the brain that controls movement, blocking the abnormal nerve signals that cause tremor and other motor symptoms. Though DBS in well-selected patients typically results in dramatic improvements in symptoms—particularly in tremor, on-off fluctuations and dyskinesia—adverse effects do occur, even in patients with successful outcomes. For example, many patients complain of speech and voice issues (slurred speech and softening of voice). The most common cognitive side effect of DBS is a deficit in verbal fluency, meaning a patient’s ability to get words out of his or her mouth declines. Voice changes seem to be more apparent when surgery is done on both sides of the brain. Some patients also complain of gait and balance issues, and occasionally experience confusion or memory problems. In addition, mood changes, suicidal tendencies, psychiatric disorders, and impulse control disorders have the potential to worsen after DBS. Therefore, it’s extremely important to address and stabilize these conditions before surgery. Even with these issues, the majority of patients who undergo DBS experience a substantial improvement in their quality of life.

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.
On a typical windy morning in Chicago last October, more than 1,200 walkers and runners gathered at Lincoln Park to participate in the inaugural Moving Day® Chicago, a walk/run for Parkinson’s. The Northwestern University Parkinson’s Disease and Movement Disorders Center, the only NPF Center of Excellence in Illinois, was the beneficiary of this first-of-its-kind fundraiser in Chicago. The event raised more than $235,000 to help people with Parkinson’s.

Andrew Albert, a Chicago resident and NPF Board member who is living with Parkinson’s stated,

“Moving Day will bring attention to the critical needs of the Parkinson’s community by inspiring our neighbors to become a part of the movement to help improve the lives of those with Parkinson’s and those affected by the disease.”

Andrew’s daughter, Amy Rantala, served as the 2012 Moving Day Chicago Chair and as the Team Captain for “Andy’s Gang.” Their team alone raised more than $26,000 toward the event goal.

“We heard from those whose loved ones are afflicted with Parkinson’s tell us that Moving Day gave them an opportunity to finally channel their concern and put their energy to good use,” said Sara O’Hare, the Moving Day Chicago coordinator. “The success of the inaugural Moving Day in Chicago shows how strong the Parkinson’s community is here and we look forward to our next walk on October 20, 2013.”

The majority of funds raised will help establish an NPF chapter in Chicago and contribute to Parkinson’s support groups and classes at Northwestern’s NPF Center of Excellence and the greater Chicago metro area.

To learn more about Moving Day, visit www.npfmovingday.org.

Check out the NPF Spring Event calendar on page 10 to find a walk near you.
NPF Helpline: Karl Kovacs Gives Thanks

As important as it is to rely on doctors and support of family and friends, when it comes to Parkinson’s disease, and its erratic course, sometimes you have to reach out to others to meet your needs. That’s just what Karl Kovacs did. Recently, the Indianapolis resident was worried about the potential side effects of a new medication he was prescribed.

“I have some very good doctors, but they stay very busy. If I need to talk to a nurse, I might have to wait two or three days,” said Karl, who was diagnosed with Parkinson’s in 2008. After learning about NPF’s free Helpline, he picked up the phone.

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

With Parkinson’s disease, it can be a tough job staying well. Like so many people who live with this disease, Karl has lots of good friends, and a trusted health care team in place, but he also must face his share of daily struggles—alone. That’s where NPF’s toll-free Helpline comes in. Three years ago, the foundation launched this free resource, and, in this time, the average number of calls has gone from hundreds to thousands per month.

The hallmark of the NPF Helpline is its support function. It’s a fact that people who are better informed tend to cope better with stressful situations and make better decisions. That’s why the Helpline is staffed with highly trained Information Specialists—registered nurses (RNs) and social workers—who provide personalized support to callers from all over the country. People living with Parkinson’s, caregivers and family members can get answers to a wide range of questions, from medications to clinical trials to hospitalization issues, all from the comfort of their home.

In addition, our Information Specialists are bilingual (in Spanish) and provide local referrals from an extensive database of neurologists and therapists as well as information about local NPF chapters and support groups. Recently, NPF launched the “Ask the Helpline” video series. Now, the Parkinson’s community can watch our nurses and social workers share their knowledge about Parkinson’s online. Some of the topics they cover include: caregiving, exercise and the importance of seeing a movement disorders specialist.

“I am thankful everyday that the NPF Helpline is there,” Karl said.

The NPF Helpline is made possible through the generous support of the Medtronic Foundation, the Edmond J. Safra Philanthropic Foundation and the Batchelor Foundation.

Karl Kovacs.

To view the video series, visit www.parkinson.org/helpline.
2013 NPF Spring Event Calendar

APRIL

4/6: NPF’s Parkinson’s Outcomes Project Town Hall Meeting with NPF’s Center of Excellence at Northwestern University, Chicago, IL. Held at Chicago Hilton Downtown.
Register online: www.parkinson.org/townhall

4/12: Free Webinar: “NPF’s Parkinson’s Outcome Project: What factors lead to a better quality of life in Parkinson’s disease?”
Register online: www.parkinson.org/webinars

4/20: Moving Day Cedartown, Georgia—NPF Georgia Chapter hosts their annual walk for Parkinson's.
Register online: www.movingdaycedartown.org

4/27: Visit the NPF Booth at the 19th Parkinson’s Unity Walk, Central Park, NYC.
Register online: www.unitywalk.org

MAY

5/4: Moving Day Twin Cities—NPF Minnesota Chapter hosts their annual walk for Parkinson’s.
Register online: movingdaytwincities.org

5/18: NPF’s Parkinson’s Outcomes Project Town Hall Meeting with NPF’s Center of Excellence at Johns Hopkins University, Baltimore, MD. Held at Sheraton Hotel, Towson, MD.
Register online: www.parkinson.org/townhall

5/18: Moving Day Tallahassee, Florida—NPF North Florida Chapter hosts their annual walk for Parkinson’s.
Register online: www.movingdaytallahassee.org

JUNE

6/4: NPF’s Parkinson’s Outcomes Project Town Hall Meeting with NPF’s Center of Excellence at University of Florida, Gainesville.
Register online: www.parkinson.org/townhall

6/10-6/14: Kripalu Wellness Retreat in Stockbridge, MA at the Kripalu Center for Yoga & Health. This retreat is specifically for people living with Parkinson’s for more than five years.
Learn more: www.parkinson.org/retreat

6/15: Moving Day Kansas City, Kansas—NPF Heartland Chapter hosts their annual walk for Parkinson’s.
Register online: www.movingdaykansascity.org

To find an event near you, visit our online calendar: www.parkinson.org/events.
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 305-243-6554.
JOIN ONE OF OUR FREE ONLINE “ASK THE EXPERT” FORUMS

For detailed, step-by-step instructions for registering and logging into the forums, visit www.parkinson.org/forums.

ASK THE DOCTOR:
A team of Parkinson’s specialists answer medical questions about Parkinson’s disease.

ASK THE PHARMACIST:
Mark Comes, RPh, fields questions about medication management.

ASK THE SPEECH CLINICIAN:
A team of experts answers questions regarding speech and swallowing.

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

Although we attempt to ensure accuracy, the publisher cannot accept responsibility for the correctness of the information supplied herein or for any opinions expressed. Articles received and published may be edited at the editor’s discretion. Information provided in reference to medical diagnosis, treatment, and research reflects the views of the authors and should not be taken as endorsements by the National Parkinson Foundation. In case of medical issues, an individual should always check with his or her personal physician. The National Parkinson Foundation does not advertise, but rather offers information it feels will be helpful to patients, caregivers, and families.

Every effort is made to avoid duplication of mailing labels; however, occasional duplications are inevitable. If you receive an extra copy of the Parkinson Report, please pass it along to a friend or colleague. If you do not wish to receive further issues of the Parkinson Report, please contact us by e-mail or by phone as listed immediately below, and your name and address will be removed from our mailing list.

Comments? Questions? Contact us.
contact@parkinson.org
Toll-free 800-473-4636
In Miami, Florida 305-243-6666
www.parkinson.org

Please recycle this newsletter.