Most of us know little about the dangers faced by people with Parkinson's disease during a hospital stay. But research shows that three out of four people with Parkinson's don't get their medication on time in the hospital. What's more, a recent study by NPF discovered that the vast majority of hospital staff don't know which drugs are unsafe for Parkinson's patients.

That's why NPF is launching a new awareness campaign called Aware in Care. This national initiative aims to make sure every person with Parkinson's gets the very best care possible during a hospital visit. This is important because people with Parkinson's are admitted to the hospital more frequently than their peers, have longer stays and experience more complications.

The Aware in Care kit is the centerpiece of this campaign. Each kit includes useful tools and information on how to prepare for a hospital stay—whether it's a planned visit or an emergency. This kit is free of charge and available to everyone with Parkinson's. Read on to learn more about the “10-Step Hospital Action Plan” included in the kit.

…continued on page 2
Generous support for Aware in Care has been provided by lead sponsor the Edmond J. Safra Philanthropic Foundation; the Eleanor M. and Herbert D. Katz Family Foundation; Novartis Pharmaceuticals Corporation; UCB; TEVA CNS; Abbott; and people like you.

Letter from the President

I’m often asked why it is that Parkinson’s lacks the broad awareness of many other diseases. After all, it’s now the 14th leading cause of death in the country.

The primary reason for this, in my view, is that the burden of having a progressive disorder for both the patient and care partner, particularly later in life, makes sustaining a highly organized volunteer leadership difficult. And without a group of strong local organizations all pulling together in the same direction, under a national umbrella, overall awareness suffers.

NPF has set about to change this. This year, we’re organizing on a community level, building visibility and funding through our Moving Day walks—all 15 of them! With Katie Couric as honorary national chair, these walking events promise to raise much needed awareness on a local level as never before. But along with grand gestures, awareness is also created in small things.

Nationally, during the month of April, you can also help us move Parkinson’s to center stage by wearing a Parkinson’s awareness limited edition bracelet featuring the message, “Move To Beat Parkinson’s.” The wristband is free in April when you make a $25 donation to NPF. It highlights the benefit of movement in combating Parkinson’s.

We believe that the time is now for Parkinson’s to come into the light...to increase awareness, to develop more support services, better treatments and meaningful research that moves our community forward.

Thanks for your support,

Joyce Oberdorf
President and CEO

P.S. Check out other ways to get involved on page 8!
Karen Anderson
An Advocate for the Parkinson’s Community

Six years ago, Karen Anderson’s husband, Roger, went into the hospital to undergo surgery for a herniated disc. This should have been a fairly straightforward procedure except for one thing, he had Parkinson’s disease. Like any spouse, she was nervous about the operation but assumed that her husband was in good hands.

Karen was not prepared for what was to come. After explaining Roger’s medication schedule to the medical team, she was astonished to find out how unaware they were about this part of his care. With each shift change, she had to go over his medication schedule with every new doctor and nurse. And when Karen wasn’t by her husband’s side, he didn’t get his medication on time. He was even given a drug not meant for Parkinson’s patients.

As time went on, the situation got worse—Roger suffered hallucinations and couldn’t communicate with the doctor. “It was a horrible nightmare that I could not wake up from,” recalls Karen of that alarming experience. “Here I was, the distraught spouse trying to fight for my husband’s life—and I had to constantly find ways to care for him.”

Therefore, if you ask Karen how she became an advocate for people with Parkinson’s, she’ll tell you she didn’t have a choice. She’s been on this road for more than twenty years with her husband, who was diagnosed with Parkinson’s at the age of 47. As a full-time caregiver, she’s advocated for her husband every step of the journey. Looking forward, she plans to make sure every person with Parkinson’s has an advocate for good care when they need it the most—in the hospital.

Last year, Roger had to go back in the hospital for surgery but this time Karen was proactive. She consulted with his surgeon beforehand and made copies of his medication schedule for everyone on staff.

“The Aware in Care kit is a life-saver; as a person with Parkinson’s or a caregiver, you have a role to play in advocating for your own quality care. Make sure you carry your medication list with you and be aware of the medications you take and what happens if you don’t take them,” stress both Karen and Roger.

Karen and Roger Anderson are both active members of the NPF Chapter, Parkinson’s Resources of Oregon.

5 REASONS TO BECOME AWARE IN CARE

1) 3 out of 4 people with Parkinson’s disease don’t get their medication on time in the hospital.

2) Only 25% of neurologists surveyed say they are confident that they would be contacted if their patients were admitted to the hospital.

3) 70% of neurologists report that their patients do not get the medications they need when hospitalized.

4) People with Parkinson’s are hospitalized 50% more than their peers without the condition.

5) People with Parkinson’s suffer avoidable complications at a higher rate than people without Parkinson’s, resulting in longer hospital stays and a higher risk of mortality.

Call 1-800-4PD-INFO (473-4636) or visit www.awareincare.org to order a free Aware in Care kit.
Imported Insights into Hospitalization and Emergency Room Visits in Parkinson's Disease

Patients with Parkinson's disease (PD) are 50 percent more likely to visit an emergency room (ER) or be hospitalized than those without the disease. The increased risk is attributed to injuries from falls, problems related to Parkinson’s and other medical reasons (such as heart attack, pneumonia and urinary tract infection). Once admitted to the hospital, these patients have a higher risk of complications, which contributes to longer stays and a greater chance of being discharged to a nursing home. Collectively, these issues reduce a patient’s quality of life and increase costs of care.

Researchers at the University of Florida, an NPF Center of Excellence, recently examined which risk factors lead to ER or hospital visits in patients with PD. For the study, they analyzed data on nearly 3,000 Parkinson's patients from more than a dozen NPF Centers of Excellence. These Centers participate in NPF’s Quality Improvement Initiative (QII), which has data on 5,000 patients with PD, making it the largest clinical study of PD. They found that one-third of these patients had visited the hospital or ER at least once prior to their enrollment in the registry. These visits were associated with several factors, including a longer duration of PD (about 10 years), having multiple medical problems, taking multiple medications, a slower walking time and higher caregiver burden.

Researchers also examined data on patients who had been hospitalized for the first time after being enrolled in the registry. Of 503 patients who were not hospitalized in their first year, 117, or 23 percent, had reported a new ER or hospital visit during the second year. These new visits were also associated with a longer duration of PD, multiple medical problems, and a lower quality of life.

This NPF-QII study highlights several important issues: 1. Hospital and ER visits are surprisingly common for Parkinson's patients, 2. Patients who have had PD for 10 years or more have an increased risk of hospitalization and ER visits, 3. The wellbeing of both the patient and caregiver is very important, therefore better preventive care could lessen the chance of ER visits and admissions.

Future research looking into how to better prevent or modify these risk factors will likely reduce ER and hospital visits, as well as improve the quality of life of the patient being treated for PD and their spouse or caregiver.

Selected reference:
A. Hassan; S. Wu; P. Schmidt; I. Malaty; M. Okun, on behalf of the NPF QII Investigators. Emergency Room Visits and Hospitalization in Parkinson’s disease: A NPF Quality Improvement Initiative (NPF-QII) Study. Center for Movement Disorders & Neurorestoration, and Department of Biostatistics, University of Florida, Gainesville, Florida; National Parkinson Foundation, Miami, Florida.

Author: Anhar Hassan, MD, Post-Doctoral Fellow, University of Florida, Center for Movement Disorders & Neurorestoration, NPF Center of Excellence

Here’s what you can do to become Aware in Care:

- Make sure all of your medical problems are well-managed.
- Review and optimize your medications at each doctor’s visit.
- Inform your neurologist if you’ve been to the ER or hospital since your last visit.
- Notify your neurologist when you’re admitted to the hospital. He or she may be able to help coordinate your Parkinson's care with the hospital staff.
- For caregivers: Let your doctor know if you’re feeling stressed or unable to cope. Support groups, counselors and social workers can help.

The findings from this study will be presented at the International Congress of Parkinson’s Disease and Movement Disorders in Dublin later this year.
What’s Hot in Parkinson’s Disease?
Medication Tips for Patients with Parkinson’s

Every patient being treated for Parkinson’s disease (PD) should be “Aware in Care,” especially when it comes to two important issues: medication and hospitalization. Here’s a rundown of several more medication-related issues that so many patients care about: pill allergies, pill shortages and pill limits.

First, inactive drug ingredients, especially the synthetic color dyes often used in pill manufacturing, can cause a variety of negative effects. Some patients have reported serious hypersensitivity reactions, including swelling of the face, lips and mouth, as well as rashes, after switching from a blue Sinemet CR 25/100 to a yellow generic formulation. Though rare, the yellow dye present in the generic version of Sinemet (carbidopa/levodopa) can cause these types of adverse reactions. Keep in mind that yellow dye allergies may occur more commonly in patients who are also allergic to aspirin. If you suspect a pill color allergy, contact your doctor. The treatment is simple: switch to a blue pill formulation. Some patients may also benefit from avoiding yellow dye in their diet.

Next, in 2010 and 2011 there was a national shortage of Sinemet. This occurred as the brand transitioned from Merck and Company, Inc. to Mylan Pharmaceuticals, Inc. As a result, patients began taking generic formulations. Complaints ranging from worsening of motor fluctuations to dyskinesia to skin rashes were reported to the NPF Helpline. It’s important to understand that FDA approval of a brand name drug requires demonstration of its quality, efficacy, safety and tolerability in both a healthy population and the PD population. However, approval of its generic equivalent only requires demonstrating that it contains the same active ingredients as the brand and gets into the bloodstream in a similar manner, but not its clinical treatment effect. As far as switching to a generic is concerned, patients should be aware that there may be as much as a 20 percent difference in strength. In some cases the weaker generic version may be the right therapy, especially in patients who experience dyskinesia from tiny medication dosages.

Finally, an important issue that has surfaced recently is the “eight Sinemet limit.” Unfortunately, pharmacies and insurance companies have been citing the language in the original FDA approval of Sinemet as a way to deny prescriptions to patients requesting more than eight tablets a day. To compound the problem, the advent of electronic medical records means that automatic limits are now being set by nationalized computer systems. Once these limits are set in computer systems, they can be difficult to change.

If your insurance carrier or pharmacy blocks your Sinemet prescription based solely on this reason, we suggest that you contact your doctor and send an appeal letter to your insurance company. Beforehand, contact the NPF Helpline at 1-800-4PD-INFO (473-4636).

Selected references:

Read Dr. Okun’s monthly column, “What’s Hot in PD?” online at www.parkinson.org/whatsshot.
April is National Parkinson’s Disease Awareness Month. In this issue, we focus on commonly asked questions about Parkinson’s disease from our “Ask the Doctor” web forum. We encourage all patients, caregivers, and friends of the Parkinson’s disease community to start a dialogue with us and take advantage of this free online resource at http://forum.parkinson.org.

Q How do I know if my Parkinson’s medication intervals are too close?

A One unique aspect of Parkinson’s disease (PD) is that when patients take their medication many of their symptoms may be reduced or even disappear. As the disease progresses, however, many patients experience a condition referred to as “wearing off.” When this occurs, their symptoms (tremor, stiffness, slowness, etc.) return before it is time for their next medication dose. Fortunately, there are many strategies that you and your doctor can employ to treat “wearing off.” The simplest strategy is to take your medications at equally spaced intervals throughout the day, and, if necessary, to move those doses closer together. One common question patients ask is, how close is too close? There actually is no such thing as “too close,” and it is not uncommon for patients to require a dose every one to two hours. We recommend you report changes in your symptoms to your neurologist at each visit so that medications can be adjusted to avoid the “wearing off” phenomenon.

Q As my disease progresses how do I know if I need more Parkinson’s medication or less?

A Although this seems like a simple question, the answer is not clear-cut. PD symptoms can be quite unique in each patient, and, in fact, no two patients are alike. In many cases, the dose of Parkinson’s medication will increase over time, while the intervals between doses will shorten. However, there are subsets of patients who require a different approach. In PD patients with longer disease durations (more than five years), it is not uncommon for them to require a decrease in their dose of medication, accompanied by an increase in frequency. The complexity of PD medication management underscores the critical need for patients to visit a neurologist regularly, so that appropriate adjustments can be made. Receiving timely medication doses and interval adjustments can have a meaningful and immediate impact on your quality of life.

Q Are we closer to a blood test for Parkinson’s disease?

A A recent pilot study investigated a protein called phosphorylated alpha-synuclein as a potential biomarker for early detection of PD. Though the study was too small to be conclusive, it did bring attention to the fact that a PD blood test could be on the horizon. Currently, many groups around the world are working to develop tests that will measure levels of proteins in the bloodstream and other markers that indicate PD risk. In the near future, it is likely that highly accurate, specific tests will determine whether a person is at risk of developing PD. At that time, close communication between a patient and his or her doctor will be critical in deciding which test, or which battery of tests, would be appropriate to check.
Should I do tai chi, resistance training or stretching to help manage my Parkinson’s disease?

A recent study adds to a rapidly growing body of research supporting the benefits of exercise and other physical activities for the management of PD. Researchers at Oregon Research Institute in Eugene assigned 195 PD patients to one of three exercise groups: tai chi, resistance training or stretching. The patients completed hour-long exercise sessions twice a week for 24 weeks. The study showed that those in the tai chi group performed better than those in the stretching and resistance groups on balance measures. In addition, tai chi was shown to have a lower incidence of falls compared to stretching (New England Journal of Medicine, February 2012). Keep in mind that there are four components of fitness: aerobic endurance, strength, balance and flexibility. Tai chi uses slow, controlled movements to help enhance balance, posture and walking stride. Resistance training, which focuses on building strength, has positive effects that are different from tai chi. Similarly, daily stretching is critical for maintaining flexibility. Therefore, these findings should not be interpreted to mean that resistance training or stretching should not be pursued. The bottom line? Many different types of exercise can be beneficial. You should develop an exercise program tailored to meet your individual health needs.

Tips for Daily Living

You’ve heard that regular exercise will help control the symptoms of PD. But where should you begin? The key is to develop a personal plan tailored to your needs and lifestyle. For best results, your fitness program should include three essential components: stretching, aerobic activity and resistance (weight training). Here’s what to do:

✔ Design a plan. Ask your doctor to refer you to a physical therapist or an exercise physiologist to develop a plan comprised of practices that are most appropriate for your health needs and goals.

✔ Pick the right time. Choose an optimal time to exercise, when your medicines are working well and you feel rested.

✔ Change your venue. Changing where you exercise is a great way to stay motivated. Join a community center or gym that offers classes such as yoga, tai chi or swimming. Plus, being with people who are supportive can lessen the impact of stress.

✔ Team up. You will find the most benefit if you exercise on a regular basis. A friend or spouse can provide ongoing encouragement and help you stick to your goals.

✔ Call NPF’s national Helpline. If you have questions or need more information on exercise and PD, call 1-800-4PD-INFO (473-4636).
Ways to Get Involved with NPF

PARKINSON’S AWARENESS MONTH: GIVE HOPE YEAR-ROUND

Get Involved with the Community—Team Hope

NPF’s Team Hope is a community fundraising program that anyone can take part in! Choose an event or create one and help raise awareness of Parkinson’s in your hometown. It can be a team event or a personal quest—pick your passion, whatever it may be: singing, hiking, paintball, golfing or kayaking, to name a few. Visit NPF’s Web site to watch an inspirational video about how others have helped spread our message of hope! We will help you with tips and resources to make your event a success. What are you waiting for? Create a Team Hope annual tradition today.

www.parkinson.org/teamhope

Celebrate Movement—Moving Day

We’re changing the way the world views Parkinson’s. In cities across the United States, Moving Day is your chance to speak up about PD and inspire others to take action. It is a movement for change—towards more awareness, more funding and more understanding of a disease that affects so many of our family and friends. We use movement as a symbol of hope and progress because of its essential role in treating Parkinson’s. Every move you make and every penny you raise will help us fund local services through our chapters and bring us closer to beating Parkinson’s! Assemble a team of walkers and shout with us, “People Who Move Change the World!”

www.npfmovingday.org

EDUCATE YOURSELF AND CONNECT WITH OTHERS—CONFERENCES AND RETREATS

Living Well with Parkinson’s Disease: A Wellness Retreat for People Living with PD and Their Care Partners (June 4-8, 2012)

Together with leading Parkinson’s specialists, learn how to integrate exercise, nutrition and personal insight into your care to fight Parkinson’s. Join us for this 5-day program for people with Parkinson’s and their care partners. Workshops range from the latest research to lifestyle changes, and take place in a small group setting of 60 people. The program includes daily yoga classes at the beautiful and peaceful Kripalu Center for Yoga and Health in Massachusetts.

www.parkinson.org/retreat

Young Onset Parkinson Conference (June 15-16, 2012)

NPF hosts a series of conferences for people diagnosed with Young-onset Parkinson’s disease. Join us in person or on the web to learn about topics such as medical advances, exercise programs, and how Parkinson’s affects relationships. Many people come to make new connections and keep up with old ones. The conference in June will be held in Orange County, CA.

www.parkinson.org/yopc

Visit NPF’s Booth at the Parkinson’s Unity Walk on April 28, 2012 in Central Park, NYC, or visit NPF’s Facebook page to view photos from the event, www.facebook.com/parkinsonsotorg.
For husband and wife Gary and Janet Altman, the first-ever Moving Day, Walk for Parkinson’s held in Pittsburgh in October 2011 was a long-awaited opportunity to raise awareness.

“I watched my mother battle Parkinson’s but didn’t fully understand her struggle until I was diagnosed myself,” said Gary Altman, who has lived with the disease for more than a decade. “Moving Day was our chance to speak out about the impact Parkinson’s has on people like me, but also on families and communities.”

The Altman’s journey with Parkinson’s was one of many highlighted through NPF’s Moving Day, which brought together more than 300 participants from around the Pittsburgh area. A partnership between NPF and its local chapter, NPF Western Pennsylvania, the event raised more than $100,000. The money will help fund research and programs, while contributing to local services and support for people living with Parkinson’s and their families.

“The resources, support and camaraderie that the Chapter provides really makes life easier,” said Altman. “Moving Day allowed us to contribute to their hard work and also help fight Parkinson’s in a big way.”

Despite cold rain on event day, the crowd’s energy was apparent to everyone involved. Participants sported balloon hats and joined in for yoga and Pilates demonstrations in the featured “Movement Pavilion.” They chanted “People Who Move Change the World!” showing support for the Moving Day message, which highlights the importance of movement.

Chapter representatives were encouraged by the enthusiasm shown by active members like the Altmans, as well as the many new connections they made. “There were a lot of people that got to know us through promotion surrounding Moving Day—so it really helped us get the word out and let people know we are here to help,” said Barbara Farrell, the chapter’s executive director.

Building on this momentum, the Chapter is expanding to a new facility that will host regular exercise programs, support groups, and other services directly on site. They are also preparing for their next Moving Day, coming up on Sept. 29th. Pittsburgh is one of 15 cities hosting a Moving Day in 2012.

“The walk is helping NPF and its chapters stand out as a cohesive group throughout the country,” Farrell said. “By increasing our visibility we are building a strong following for the ongoing work that is really making a difference in people’s lives.”

To learn more about Moving Day and how you, your family and friends can get involved, please visit www.npfmovingday.org.

2012 SCHEDULED MOVING DAY EVENTS

- Cedartown, GA  4/21/12
- Twin Cities, MN  5/12/12
- Kansas City  6/16/12
- Rochester, NY  9/16/12
- Buffalo, NY  9/16/12
- Pittsburgh  9/29/12
- Tallahassee, FL  9/29/12
- Columbus, OH  9/30/12
- Sioux Falls, SD  10/6/12
- Miami  10/7/12
- Orange County, CA  10/13/12
- Chicago  10/14/12
- Augusta, GA  10/20/12
- Boca Raton, FL  10/21/12
- Rome, GA  10/27/12
When most people talk about raising awareness, events like 5K walks or golf tournaments often pop up. But that expression has taken on a whole new meaning for Kevin Burkart, of Prior Lake, Minnesota, who will take on the challenge to skydive 300 times in one day on June 19 to increase Parkinson’s awareness.

Inspired by his father, Gary, who was diagnosed with Parkinson’s in 1999 at the age of 60, Burkart has learned to stand strong. “My father was diagnosed on the cusp of retirement, so I thought it was a pretty sad story for him,” said the life-long doer, who opened his own marketing agency, StepStoneGroup, 16 years ago, and started competitive skydiving several years later. “But he showed me that regardless of what ailment you’re suffering from, don’t give up.”

Five years ago, Burkart wanted to put his talents to work helping other families facing similar challenges so he became what he calls a “charitable leader.” “Even as the second most common neurodegenerative disease, it’s a very quiet, silent disease,” he said. “So I think it’s up to people like myself to toot the horn and get more discussion going on behalf of this humble demographic.”

So far, Burkart’s attention-grabbing hobby is paying off. In June 2008, he completed 100 skydives in a single day, raising $48,000 for Parkinson’s. Two years later, he returned to the skies to perform 150 skydives, raising over $68,000. Now, in this final tribute, he’s shooting for some ambitious goals: 300 jumps and $100,000.

For Burkart and his crew—10 parachute rig packers, two pilots and a host of volunteers—the event will begin in the early hours of the morning and wrap up some 19 hours later. He’ll use two airplanes. Once in the air, he’ll climb to 2,000 feet in 45 seconds (a typical skydive is from 13,000 feet and takes 15 minutes to ascend to altitude), exit the plane and complete a jump every three minutes.

Above all, Burkart hopes to make each dive a moving tribute.

“I would really like to have every jump dedicated to one person’s story who is struggling with Parkinson’s disease or who has passed away from Parkinson’s disease,” Burkart said.

Throughout the event, a professional announcer will read the dedication for each jump.

Burkart and his team of volunteers are pulling out all the stops. “I’m sure it will go well. I’ve got a great crew, and we know it can be executed safely,” he said. “The people I am surrounded with during this skydiving event—including the skydiving community, the Parkinson’s community, my family and friends and my business associates—are extraordinary people. They’re taking the opportunity to lift up those around them and make their community better.”

Proceeds from this event will benefit the NPF and the NPF Chapter in Minnesota.

To learn more about 300 Perfect Jumps visit www.perfectjumps.com.
To learn more about how you can begin your own NPF community fundraising event, please visit www.parkinson.org/teamhope.
Help NPF Beat Parkinson’s!
Memorial and Honorary Gifts

If you have a family member or friend whose life has been touched by the National Parkinson Foundation, we hope you’ll consider making a gift to us in honor of that person. Providing a gift establishes a living tribute that allows you to:

- Honor a loved one or yourself.
- Support our continuing efforts.
- Receive personal financial benefits from your contribution.
- Give now or later.

Any charitable gift you arrange can be made in honor of someone. Consider these two basic methods of establishing an honorary gift.

1. A gift today—An outright gift can help fund our immediate needs or an upcoming project. The financial benefits include an income tax deduction and possible elimination of capital gains tax.

2. A gift through your will or living trust—You can include a bequest in your will or living trust stating that a specific asset, certain dollar amount or—more commonly—a percentage of your estate will pass to us at your death in honor of your loved one.

No matter which basic method you choose, you have the ability to endow your gift so that it lasts forever. Endowments are structured so that a small portion of your gift, rather than the whole amount, is used each year to fund a particular purpose.

For more information, visit [www.parkinson.org/plannedgiving](http://www.parkinson.org/plannedgiving) or call 1-800-4PD-INFO (473-4636).

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SPECIAL THANKS TO
Tiffany & Co. for their generous donation of the Mystery Blue Box Items.
Southern Wine & Spirits for their generous donation of the evening’s beverages.
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.