Announcing Katie Couric as the Honorary National Chair of Moving Day

Katie Couric has agreed to be the Honorary National Chair of the National Parkinson Foundation’s (NPF) inaugural Moving Day campaign. Moving Day is the first grassroots campaign to spotlight Parkinson’s disease (PD) awareness on a national level. The importance of high-quality care for people with Parkinson’s is near and dear to Couric—her father, John Couric, died recently from complications due to the disease at age 90.

“Parkinson’s is a challenging and often debilitating disease that robs too many people of their ability to lead a full life. I watched in awe as my father bravely battled this disease and know that he greatly benefited from care, which significantly minimized his symptoms by addressing all aspects of his well being,” said Katie Couric, Honorary National Chair of Moving Day.

Every individual coping with this disease should have the same quality care my Dad did, and that’s why the work of the NPF is so critically important. Its three-pronged mission of research, education and outreach will help countless people suffering from Parkinson’s today and will develop better treatments for the scores who will be diagnosed in the future. I am proud to be...
Announcing Katie Couric as the Honorary National Chair of Moving Day

...continued from cover

a part of this mission and in doing so, honor my wonderful father, who was a true profile in courage as he soldiered on every day to remain an active and vibrant part of the family he so loved,” Couric said.

Moving Day is a new campaign created to raise awareness and funds through annual fundraising walks. Each walk will feature a “Movement Pavilion” with stations such as yoga, Pilates, tai chi, dance and much more. Studies show that movement is one of the most beneficial ways to help manage the symptoms of PD, improving flexibility, strength and mobility. Vigorous exercise such as biking and running has been shown to potentially delay progression. NPF is rolling out this fun-filled, family-friendly event to cities across the country, including the three pilot walks held in October: Pittsburgh; Washington, D.C.; and Rome, GA.

“We are delighted that Katie Couric is serving as the Honorary National Chair of Moving Day to raise awareness of Parkinson’s disease, and to highlight NPF’s focus on improving the quality of Parkinson’s care for every person diagnosed with this disease,” said NPF President and CEO Joyce Oberdorf. “With her help, we are better able to reach people of all ages and abilities about the role that movement and exercise plays in managing symptoms and in keeping people with Parkinson’s healthy.”

A long-time advocate for cancer research and other health-related issues, Parkinson’s disease joins the list of causes Couric publicly supports. In 2000, Couric launched the National Colorectal Cancer Research Alliance in association with the Entertainment Industry Foundation and Lilly Tartikoff, to fund new medical research in colorectal cancer. Following Couric’s on-air colonoscopy in 2000, a scientifically documented 20% increase in the number of colonoscopies performed across the country was dubbed “The Couric Effect” by researchers at the University of Michigan. In May 2008, Couric and her network news counterparts participated in Stand Up To Cancer, an unprecedented effort to focus attention on cancer that culminated in a one-hour, primetime program on ABC, CBS and NBC in the fall of 2008.

Moving Day is an exciting new initiative that will educate the public about Parkinson’s both nationally and locally, where NPF chapters are participating in this campaign. All proceeds will go to support local services for people living with the disease and research leading to better treatments.

Moving Day is made possible, in part, through the generous support of national sponsors, including Champion Sponsors: Dick’s Sporting Goods, Medtronic and Right at Home, and Hope Sponsor: Office Depot Foundation.

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Watch Katie Couric’s Moving Day public service announcement and help us spread the word at www.npfmovingday.org.
NPF Releases Free Smartphone App for Clinicians
Parkinson’s Toolkit Now Available In iTunes App Store and Android Market

Over the summer, the National Parkinson Foundation launched the first free smartphone application to help doctors ensure that patients receive the right diagnosis and treatment of Parkinson’s disease. The Parkinson’s Toolkit is a mobile-enhanced website with a companion smartphone app available for download.

“NPF is dedicated to providing clinicians with tools to improve the way they treat Parkinson’s, and there is no better way to do this than with a point-of-care mobile app,” said Joyce Oberdorf, NPF’s President and CEO.

“The cost of misdiagnosis and inappropriate treatment in Parkinson’s, in human suffering alone, is incalculable. We created the Parkinson’s Toolkit to provide a quick and easy reference tool for clinicians to help bridge the knowledge gap where they need it—in the examining room,” Oberdorf said.

With guidance from an interdisciplinary steering committee chaired by Janis Miyasaki, MD, MEd, FRCP, of the Edmond J. Safra Parkinson Program at Toronto Western Hospital, University of Toronto, NPF built the Parkinson’s Toolkit to help clinicians prepare for patient appointments as well as provide them with a quick, accessible reference tool they can use during visits. The Toolkit highlights issues that are often overlooked such as constipation, sleep and the need for melanoma screening. The app also has a feature to help doctors determine whether or not a patient requires a consultation with a specialist. Useful Parkinson’s reference tools and patient resources are included as well.

“The Parkinson’s Toolkit includes more than 100 topics that incorporate evolving best practices in Parkinson’s care,” Dr. Miyasaki said. “With the tap of a finger, clinicians can access first line meds and dosing and better understand complex aspects of care like impulse control disorders as they navigate their daily practice.”

NPF estimates that fifty percent of Parkinson’s patients in the United States are managed by primary care physicians (PCPs); however, most PCPs see only two Parkinson’s patients per year, therefore have little experience with diagnosing and treating the disease.

The Parkinson’s Toolkit is available for download at www.parkinson.org/toolkit and is also available in the iTunes App Store and the Android Market. On the website, clinicians can also sign up to receive e-mail updates from NPF on a regular basis.

NPF gratefully acknowledges the hard work of the steering committee formed by Gordon Hardacre, MD, and PD patient; Janis Miyasaki, MD, movement disorder specialist; John Morgan, MD, movement disorder specialist; Fleur Sack, MD, family physician; and Mickie Welsh, RN, PhD. Financial support for the Parkinson’s Toolkit came from Teva Pharmaceuticals, Ipsen and UCB.

Tell your health care professional to download the Parkinson’s Toolkit app at your next visit!
Learn more at www.parkinson.org/toolkit.
PF is proud to announce funding for three new research projects which support our mission of improving the quality of care in Parkinson’s disease. These studies will focus on three key areas in Parkinson’s research: the prevention of Parkinson’s disease, the development of new information technology, and the integration of care that focuses on patient-centered interests. Studies such as these pave the way for advances in understanding and treatment.

NPF funded the following three studies at Centers of Excellence in Israel, the Netherlands and the United States:

**Can Parkinson’s be Prevented? A Study of Healthy First-Degree Relatives of non-Ashkenazi LRRK2 Carriers with PD:** Anat Mirelman, PhD, and Nir Giladi, MD, Tel Aviv Sourasky Medical Center, Tel Aviv, Israel.

Many people with PD worry that they might have passed on the disease to their children. This study addresses this issue by identifying patients with genetic PD then working to prevent the development of PD in their relatives. Since North Africans have the highest risk anywhere of genetically-associated PD, this study will focus on that population. The researchers hope to delay or even prevent PD by applying the best medical care and latest technology to people who are at risk for developing the disease. Once the risk is known, the hope is to slow the mechanisms that cause PD.

**Smartphones for Ambulatory Monitoring of Gait Disturbance in PD:** Mark Shapiro, PhD, Northwestern University, Chicago, Illinois.

Every day, many of us carry around a sensitive instrument for measuring motion: our smartphone. Dr. Shapiro is writing a smartphone “app” that will measure gait disturbance in people with Parkinson’s. As many people with PD know, the only sure cure for freezing is the watchful eye of a neurologist. With a smartphone, however, patients can now record episodes of freezing as they go through their daily lives. The hope is that this app will enable doctors to better understand patterns of freezing and also serve as a measure in clinical trials testing new therapies—such as drugs and physical and occupational therapy—to reduce freezing. Once the app has been tested, Dr. Shapiro will send it home with patients so they can track episodes of freezing in real time. This simple device could one day become an important way for researchers to measure the progression of PD.

**Patient Centeredness Questionnaire for Parkinson’s Disease:** Bastiaan Bloem, MD, PhD, Radboud University Nijmegen Medical Center, Nijmegen, the Netherlands.

Today, many doctors try to focus on patient needs and preferences when delivering care. This new approach is called patient-centered care and nowhere is this more important than in Parkinson’s care. Because people with PD and their doctors need to balance multiple factors—including education, therapy, medication and sometimes surgery—doctors and patients must consider the implications of every choice together. Until now, hospitals assessed patient centeredness using a form filled out by hospital staff alone, without patient input. But, Professor Bloem has developed a patient centeredness questionnaire that will be filled out by patients. Bloem will use the tool to evaluate twenty NPF Centers of Excellence and then determine how much and in what ways the centers succeed in focusing on the goals of the people they serve.

For more information about NPF’s research initiatives, visit www.parkinson.org/research.
Currently, there are multiple pharmaceutical companies that manufacture generic formulations of carbidopa/levodopa, dopamine agonists, monoamine oxidase inhibitors and anticholinergics. As part of our mission of improving the health and well-being of people with Parkinson's disease (PD), NPF is investigating whether these formulations are appropriate alternatives. Research like this helps guide our efforts to find additional ways to improve the quality of care you receive.

A recent review supported by NPF provides compelling evidence that if you're in more advanced stages of PD, switching from a brand-name drug to the generic version, or from one generic to another, may have adverse effects. At this time, we believe the standards for monitoring and approving generic drugs for PD may not be strict enough to ensure that generic alternatives are always equally safe and effective.

If you're taking a brand-name medication and are offered a generic substitution for one of your Parkinson's medications, you should consider this decision carefully. The FDA requires that generics show an "essential similarity" to their brand-name counterparts prior to market approval. This means that a generic drug must contain the same active ingredients and get into the bloodstream in a similar manner as the brand-name it replaces. However, in some cases, this standard is still not high enough.

This is important to know because a well-calibrated drug regimen is vital for effectively managing symptoms of PD. We know that inaccurate doses and inconsistent timing can cause Parkinson's drugs to be less effective or even result in serious complications for the patient. For instance, if there's too little of the drug in the bloodstream, motor and non-motor symptoms may worsen. If blood levels are too high, side effects can become unbearable. Therefore, switching to a generic version, which may be slightly weaker or behave differently, could have serious implications for some people, especially for those in the later stages of the disease.

Using generic drugs may be more cost-effective, but these cheaper versions may not always be an appropriate treatment option, especially if your current drug regimen is well-tolerated and controlling your symptoms. Ultimately, you should work closely with your physician to develop an individualized treatment plan. Alternatively, in some cases a weaker generic formulation can be an advantage in therapy.

If you make the switch to a generic, be sure to follow these tips:

- Keep a diary to track your progress as well as any side effects you experience.
- Record all dose adjustments that your physician makes (higher or lower).
- Report problems to your physician immediately.
- Not all generic medications act the same, so try to stick with a single drug manufacturer (you may need to ask your pharmacist to special order for you).

Finally, if efforts to tailor your drug therapy with a generic drug prove unsuccessful, ask your doctor to appeal to the insurance company for the brand-name drug. In the appeal letter, be sure to include a detailed explanation of the adverse effects you experienced while on the generic medication.

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.
November is National Family Caregivers Month. Many experts agree that the most important factor for living successfully with PD is having an empathetic and supportive spouse or caregiver. For this issue of the Parkinson Report, we focus on commonly asked questions about Parkinson’s disease caregiving from our “Ask the Doctor” web forum. NPF also offers a “Caregiving” forum which is unmoderated and open to all with caregiving questions. We encourage all patients, families and friends who are touched by PD to log on to www.parkinson.org and to take advantage of this informative and free resource.

Q How do I know if I have caregiver strain?
A Caregiver strain refers to a high level of stress experienced by a person caring for someone with a chronic illness or disability. Lack of emotional and social support can leave caregivers vulnerable to this condition. A study published in the journal Movement Disorders emphasized that “at risk” individuals for caregiver strain should be identified, evaluated and treated.

In the study, researchers from the NPF Center of Excellence in Oregon examined potential reasons for strain—including lack of personal resources and worry. What they found was that young spouses, ages 40 to 55, were at greater risk for strain than older caregivers, perhaps from the demands of children, work and other factors. However, Parkinson’s caregivers of all ages had high levels of strain.

If you think you might be experiencing caregiver strain, here are a few questions to consider. If you answer “yes” to several of these statements, you should discuss your answers with your doctor:

• Do you feel that you are under a lot of stress?
• Do you feel depressed, anxious or irritable much the day?
• Do you feel isolated, without much support or contact from family and friends?
• Are you carrying a 24-hour responsibility of caregiving without respite?
• Are you too busy to engage in daily activities to relieve stress?

Q What is the best way to cope with caregiver strain?
A A Swedish study that examined caregiver strain among PD patients and their caregivers found a correlation between the health status of the Parkinson’s patient and the stress levels of the caregiver. The factors that had the strongest impact on the caregiver included the status of the Parkinson’s patient’s motor and cognitive function, the duration of the patient’s disease and whether symptoms of depression were present in both the caregiver and the patient. More importantly, researchers found that improving the functional status of the patient and treating symptoms of depression in the caregiver were the most effective approaches for relieving caregiver strain. Most experts recommend the following ways to combat stress in caregivers:

• Get educated about the disease.
• Seek help from family, friends, community/religious organizations and health professionals.
• Exercise regularly and eat healthy.
• Get enough sleep.
• Take personal time each day to replenish your energy.
• Join a support group.
• If you have symptoms of depression or anxiety, get treated.
• See a counselor for help in dealing with difficult emotions.

For more information on taking care of the caregiver, read page 9.
Will group doctor visits play a role in addressing caregiver strain in the future?

Sharing a doctor’s appointment with other patients with a similar condition is an increasingly popular concept. One of the benefits is that it gives patients more time with their doctor. In a recent study from the NPF Center of Excellence in Rochester, New York, investigators asked an important question: Can group visits for PD care provide an alternative to regular doctor visits? Researchers concluded that although group care was feasible, it did not offer any overall improvement in quality of life.

Even so, group sessions were attractive to study participants because they got 90 minutes with their doctor, useful information on a specific PD topic and a personal visit with the doctor. Additionally, both patients and caregivers were allotted time for questions and discussion. Finally, the group visit provided patients with the opportunity to meet others with PD, fostering the sense that one is not alone when facing this disease. Whether group visits can help diminish caregiver strain is a promising topic for future study.

Selected references:

When you’re a caregiver for a spouse, parent or loved one, it can seem overwhelming just to get through the day. But keeping lines of communication open can be the key to calmer days. Here are some ways to promote communication:

✔️ **Ask for advice.** Establish a regular time to talk with a health professional or an experienced caregiver. You need to discuss issues that come up on a routine basis, no matter how trivial, with someone knowledgeable about Parkinson’s disease.

✔️ **Confide in someone.** Does at least one other person fully understand the day-to-day trials you experience? Find a friend or counselor that will listen to you and offer encouragement.

✔️ **Lay it on the line.** If you’re the primary caregiver for an aging parent, don’t avoid difficult discussions with your siblings. Ask for help with specific tasks such as taking your parent to a medical appointment, bill paying or shopping.

✔️ **Talk with your loved one.** Explain to your loved one what is going on, and why things are happening. Then be willing to listen.

✔️ **Call NPF’s national Helpline.** If you have questions or need support, call 1-800-4PD-INFO for more information.

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 website, and NPF does not endorse or recommend any such information.
Jane Davis, a Caregiver Who Carries On

In her memoir, *First Aid for Heroes*, Jane Davis, 59, talks about what it takes to spring back in trying times. As a volunteer First Aid nurse with the Red Cross at Ground Zero, she experienced, firsthand, the rescue and recovery efforts of 9/11. “We are all thrown curveballs in life, but it is how you decide to handle them that is empowering,” Davis said. “What I learned is that we can stay strong during and after a crisis.”

In 2006, life threw Davis a curveball. She learned that her husband, Gary, had been dealing with a health problem. As an Army physician, he was almost certain that his tremor and twitching were symptoms of early-onset PD. Soon after, his self-diagnosis was confirmed. The Virginia couple, who had been married for nearly 30 years, felt heartbroken. “We knew our lives were going to change drastically,” she said.

Although Davis had worked as a registered nurse for over 30 years, she was unprepared for her new role as caregiver. But she decided to adapt as she had done before—while traveling around the country with her husband during his military career and raising two children—and take the bull by the horns. “I’m a real positive person, and I’m not going to let circumstances put me in a place where I can’t succeed with life,” she said.

At first, she started reading up on PD and accompanying her husband to doctor’s visits. By doing research, she discovered a clinical trial her husband could join as well as a local Parkinson’s support group. Then, she started going to his support group and spending time with other spouses. The friends she made offered both encouragement and practical advice on how to prepare for the future.

At the same time, she wanted to be sure she was taking care of the caregiver. “You are the well spouse, so you have to stay physically and emotionally healthy,” she said. “You have to stay strong.” In addition to exercising and eating well, Davis joined a WellSpouse™ support group. “It’s important to get involved with people who are going through a similar struggle as you. My friends are wonderful, but they don’t quite get it,” she said.

Two years ago, Davis got hit with another curveball right between the eyes. Her husband was diagnosed with cancer. While the cancer is in remission, there is no cure for his illness. Still, as her caregiving role continues to change, Davis says she intends to face each new challenge head on. “We let the tears fall, but then we keep moving forward,” she said. “He’s my best friend.”

Davis began writing as a way to express herself. In her memoir, she talks about her experiences as a nurse at Ground Zero as well as her personal curveballs as a caregiver. “I want people to realize that although you are faced with life-altering events, you can get through them and survive and even get stronger,” she said. “You just have to do everything you possibly can.”

To learn more about Jane Davis, or her book, *First Aid for Heroes*, visit www.janehdavis.com.

To share your personal caregiving story, visit www.parkinson.org/community.
Here’s an eye-opening statistic from the National Family Caregivers Association: More than 29 percent of Americans provide care for a chronically ill or disabled family member. Furthermore, about 23 percent of caregivers are age 65 or older. Certainly, if your spouse or loved one has a chronic illness like Parkinson’s, the time to begin preparing for this role is before disability or frailty becomes an issue. Jane Davis, who has been a caregiver for her husband for several years (see story on page 8), recognizes that caregiving is a tough job. That’s why she encourages all who care for others to stay committed to their own health and well-being from the very start.

DAVIS OFFERS THESE TIPS FOR STAYING STRONG:

- **Surround yourself with support.** For Davis, joining the WellSpouse™ Association (www.wellspouse.org), a community of spousal caregivers, provided much-needed support. “They tell me what I need to do now as well as how I should prepare for the future,” Davis said. “I could call them in the middle of the night, and they would listen, and that means the world to me.” Reach out to other people who are experiencing what you’re going through.

- **Don’t give in to self-pity.** It’s normal to be upset and even feel burdened when you first become a caregiver. That’s why you should give yourself time to adjust. “But don’t crawl in a hole and stay there,” Davis said. “You need to find ways to make life better, not only for your spouse but for yourself as well.” Start doing something you enjoy every day. If possible, join a yoga, tai chi or art class with your loved one. Find ways to stay connected and ease stress.

- **Find a mentor.** Realize that your role as caregiver will change over time and that it’s a continuous learning process. Having the guidance of someone who has already been through what you’re going through will have a positive impact on your life. By helping you face challenging situations and showing you how to rise above them, a mentor can help you stay strong. Look for role models among people you know.

- **Express yourself.** “As a caregiver, bottling up your emotions can backfire,” Davis said. “Just cry, release it and move on. Then it doesn’t paralyze you and keep you stuck. But the key is to move on from it, because you can’t let those emotions encompass everything.” There’s no one best way to process your emotions, but try to figure out what will work best for you. That may be getting thoughts and feelings down on paper or talking them out with a therapist.

- **Hire help.** “You need to be there for your loved one, but you also need to maintain your own identity,” Davis said. “You have to make a conscious decision to live life.” Find someone to relieve you of your caretaking duties for a couple of hours a day or week. Then go do something that’s uplifting.

Order your free copy of “Caring and Coping” in NPF’s online store today, visit www.parkinson.org/books.
7 Tips for Hiring Good Caregivers

If you are looking for help with activities of daily living and are considering hiring an in-home caregiver, it’s important to be thorough in your efforts to evaluate each candidate, because recruiting and training a new caregiver can be time-consuming and expensive. What’s more, it’s a good idea to get assistance from a reputable hiring service that does background screenings. You may want to contact your local area Agency on Aging for further assistance.

Here’s a strategy to help you get started:

1. **Get organized.** The first step is probably the most difficult: be attractive to potential caregivers. The best way to influence new people is by being a good role model. Using a binder or notebook, write down your needs and preferences. Organize the information in lists so that it’s easy for anyone to understand. Include details about your condition, treatment and hobbies. Outline your expectations of the caregiver and what their responsibilities will be.

2. **Recruit people seeking to better themselves.** The most important task of any worker is to show up. One disadvantage of caregiving is that the work environment is unstructured. Sometimes the casual nature of the job can spill over into attendance. Therefore, to find a caregiver who will be reliable, start where other employers look – colleges and other service organizations where people volunteer to show up.

3. **Make room for their interests.** Since caregiving is not a career-oriented endeavor, you may have to make some compromises in order to attract the right match. If your caregivers have special interests, such as sports activities, do your best to accommodate their schedules. Consider flexibility to be your number one asset.

4. **Diversify your team.** As the saying goes, don’t put all your eggs in one basket. This tip offers two important pieces of advice. First, if your personal needs require full-time care, it’s not a good idea to be dependent on one person. Additionally, you’ll want to have options if circumstances change. Second, when you diversify you are more able to accommodate each caregiver’s schedule without sacrificing your needs.

5. **Offer caregivers a finder’s fee.** Offer financial incentives to your established caregivers for referrals. If the new person sticks around for at least six weeks, your caregiver earns a finder’s fee. On the other hand, if the new hire doesn’t work out, you lose nothing. By engaging your established caregivers in this networking process, you’ll give them a vested interest in a successful outcome.

6. **Look for common interests.** When getting to know a new caregiver, it’s very important to be cautious. For safety reasons, conduct a telephone interview before inviting the candidate into your home. During the phone interview, ask the person about his or her hobbies, interests and life goals. The manner in which the person answers these questions will let you know if they are compatible with your lifestyle. It is not imperative for you to share the same interests as your caregiver but it certainly makes the time spent together more meaningful if you do have something in common.

7. **Interview several candidates.** Ask a friend or family member to be present at all interviews. This not only ensures your safety but it will give you another set of eyes and ears to better judge the candidate’s qualifications. Afterward, discuss their observations, insights and opinions. Be mindful not to be impulsive and hire the first candidate you meet, no matter how desperate you may be for help.

Fay Mikisika is the author of the *CaregivingTool: For Managing Your Caregivers* and *Repair & AfterCare: For Post-Op Home Recovery*. She has been a caregiving recipient for over 27 years. For more information about the CaregivingTool, please visit www.caregivingtool.com or call toll-free 1-888-440-4465 (PST).

**For more caregiver resources, visit**
www.parkinson.org/caregivers.
Support NPF
Your Year-End Gift Will Change Lives

A time to love, laugh and give...
Please remember the National Parkinson Foundation in your year-end giving. Your gift will support critical research and education efforts to help improve the lives of individuals living with PD.

There are many ways to give:

- Make a donation online at www.parkinson.org/donate.
- Encourage your friends to give by hosting a Team Hope community fundraising event at www.parkinson.org/teamhope.
- Join our Legacy Society by recognizing NPF in your will, trust or estate at www.parkinson.org/plannedgiving.
- Honor a loved one with an honor or memorial gift at www.parkinson.org/memorial.
- Donate stock or mutual fund shares to receive an end-of-the-year tax deduction at www.parkinson.org/securities.

We deeply appreciate your ongoing support of our mission. From all of us at the National Parkinson Foundation, happy holidays and best wishes in the new year.

Save the Date: January 29, 2012
ING Miami Marathon & Half Marathon

Run with us in Miami! Join NPF’s Team Hope today. Visit www.parkinson.org/marathon.