

PARKINSON

REPORT



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PARKINSON
FOUNDATION

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**Thank you
to our Sponsors**

Introducing Moving Day:

People Who Move Change the World



It's a walk, it's a community event, it's a celebration of movement. It's Moving Day, the new chapter event for the National Parkinson Foundation. Many NPF chapters already host local fundraising events, but this signature event will take a traditional walk and transform it into a celebration of movement. The theme of Moving Day is: "People Who Move Change the World."

Studies have shown that movement—yoga, Tai Chi, dance, Pilates, or even walking—is beneficial and proven to help manage the symptoms of the disease, improving flexibility and mobility. Plus, researchers now believe that vigorous exercise, such as biking or running, may slow down or delay progression. The event is designed to create greater awareness—not just of the importance of movement, but of Parkinson's disease itself, a movement disorder.

Moving Day is not your traditional 5-mile walk/run. Each event will feature a 'movement pavilion' with demonstrations of a variety of stretches, exercises and more!

"NPF, in partnership with our chapters, will move the Parkinson's community," says Robin Boettcher, NPF's Vice President of Chapter and Community Partnerships. "It will be a day to move and a day to move others and a day to move the needle

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Letter from the President

The National Parkinson Foundation has launched some new and exciting initiatives that we'd like to share with you.

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Living with Parkinson's: Rich Clifford, Former NASA Astronaut

"I had never heard of the disease," recalls Clifford of that day.

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Paintball for Parkinson's

"We wanted to support something that is near and dear to our heart," said Thom Williams, president of the International Stunt Association.

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Introducing Moving Day: People Who Move Change the World

...continued from cover

of awareness about Parkinson's. Movement is critical for people with Parkinson's—let's move the rest of the world to raise awareness of the disease and the daily obstacles people with Parkinson's face."

Each family-friendly event is meant for all ages and abilities. Funds raised at the events will be used to provide national and local services, including an extensive network of support groups for patients and caregivers, educational materials, informational meetings and weekly therapeutic exercise programs, as well as to support research to beat Parkinson's!

Three Moving Day events are scheduled for this fall	October 1, 2011 North Park in Pittsburgh, PA
MOVING DAY 	October 9, 2011 Washington Nationals Ballpark and Navy Yard in Washington, D.C.
	October 22, 2011 Atlanta Braves Stadium in Rome, GA

In the months ahead, chapters in the three locations—Rome, GA, Washington, D.C. and Pittsburgh, PA—will market the event to individuals and friends and family teams with a special emphasis on corporate teams. At least six additional NPF chapters are expected to hold Moving Day events in spring 2012.

Get Moving! Find a local event near you at www.npfmovingday.org. Register online and set up your own personal or team fundraising page! We hope to see you at one of our Moving Day events. For more information on sponsorship, please call 1-800-327-4545.

Letter from the President



The National Parkinson Foundation has launched some new and exciting initiatives that we'd like to share with you. First, you've probably noticed our new look in this issue. We officially unveiled this in April to coincide with National Parkinson's Awareness Month. You will see this refreshed look reflected on our website, Parkinson.org, in our e-Newsletter, *Parkinson's Today*, and in our print publications.

So, why the transformation? In 2010, we took a strategic look at how we interact on a local level. We spoke to all 39 chapters, and travelled across the country, meeting with many families touched by Parkinson's. What we found is that NPF needed to play a much stronger role in creating awareness on a national level and ensuring a consistent high level of services in the chapters, and the connection between local and national needed to be seamless. To achieve this, we needed to have a common brand and a unified voice that chapter and national would both embrace.

Paul Blom of the Minnesota chapter (formerly known as the Parkinson Association of Minnesota) put it this way, "Our relationship with NPF has always been positive and mutually beneficial. The missing ingredient has always been the lack of a cohesive brand. NPF has responded beyond my expectations to fill this need."



Created with our chapters for our chapters, the new brand is meant to spark connection and work to create greater awareness. By the end of next year, all NPF locations will carry the same brand, and commit to the same high level of program standards—and NPF will supply the resources to do it. Because people with Parkinson's and their families deserve the very best resources available to help them no matter where they live!

Thanks for your support,

Joyce Oberdorf
President and CEO



Parkinson's Awareness Month

Making Things Happen

April is Parkinson's Awareness Month. What better time to make things happen in a bigger way. So how can you get involved? Read, share your story or plan a fundraising event. In short, challenge yourself to spend some time each day raising awareness for Parkinson's disease. To show you just how easy it can be, we've created a month's worth of tips to get you started. Once you decide to take action, you'll be surprised by the difference you can make. Why not start today?

1. Write a letter to the editor of your newspaper, sharing a story of how a treatment, program or event has impacted your life.
2. Visit the calendar of events on our website.
3. Share your personal Parkinson's story with a friend, neighbor or family member.
4. Visit our website and read the *"What's Hot in PD?"* blog.
5. Start blogging.
6. Spend time with someone who has Parkinson's disease.
7. Visit our website and read a news story about Parkinson's disease.
8. Phone a friend or neighbor and share that news.
9. Send a letter to your local TV or radio station in praise of a healthcare professional who made a significant difference in your life.
10. "Like" the National Parkinson Foundation on Facebook.
11. Follow the National Parkinson Foundation on Twitter.
12. Talk to your local YWCA, community center or hospital about offering exercise or dance classes geared toward people with movement disorders.
13. Locate your National Parkinson Foundation local chapter.
14. Invite an expert to give a Parkinson's-related talk at an area library, community center or hospital.
15. Volunteer for a local chapter event.
16. Join us in New York City on April 16th for the Parkinson's Unity Walk!
17. Plan an NPF Team Hope community awareness and fundraising event.
18. Participate in a local fundraiser.
19. Join a local support group, or start your own.
20. Attend a seminar or talk on Parkinson's disease.
21. Ask a question on the online forum "Ask a Doctor."
22. Create art. Find new ways to express your journey with Parkinson's disease: take a painting, writing or photography class.
23. Visit our website and read a personal story or share your own.
24. Start a daily exercise routine.
25. Tell someone with Parkinson's disease how exercise has helped control your symptoms.
26. Visit our website and download a publication on living with Parkinson's.
27. Research local health centers offering rehabilitation services for people with Parkinson's.
28. Share that information with anyone who could benefit.
29. Ask for help when you need it.
30. Call NPF's national Helpline today: **1-800-4PD-INFO.**

To find a resource near you visit, www.parkinson.org/search or call 1-800-4PD-INFO.

A Week at Kripalu:

Navigating a New World

Last fall, the National Parkinson Foundation sponsored the first-ever yoga retreat, “Navigating a New World: Wellness Retreat for Recently Diagnosed Parkinson’s Patients & Their Care Partners” at the Kripalu Center for Yoga & Health in the Berkshire mountains of Massachusetts. This four and a half day program was designed for people in the early stages of Parkinson’s disease and encouraged them to take charge of their health and learn from leading medical and holistic professionals.

Over sixty people attended this retreat—the newly diagnosed brought along family, friends and care partners. Each day offered a combination of educational sessions, taught by the country’s foremost movement disorder neurologists and Parkinson’s specialists, and experiential workshops on the benefit of meditation, yoga and conscious communication taught by senior Kripalu faculty.

“Kripalu is a magical place. It gives you a break from the daily norm and allows you the unique opportunity to connect with others facing the same challenges from Parkinson’s. This is where people begin to create a community and support system,” explained NPF’s president and CEO, Joyce Oberdorf.

One of the highlights of the program was the daily “Let Your Yoga Dance for Parkinson’s” session with Megha Nancy Buttenheim. Buttenheim had everyone dancing to the beat with user-friendly moves that integrated breath and freestyle movements.



Emily Stamos, one of the retreat attendees commented on her experience,

“My experience at the Kripalu Yoga Retreat was life-altering. I was newly diagnosed with PD and had many questions. During the week, I learned everything I needed to know, from the importance of exercise to the benefits of meditation to helpful advice on lifestyle adjustments to information on current research and studies.”

Stamos also shared, “Mainly, it was wonderful to spend the week with my two daughters and for the three of us to be a part of a positive, healing community in such a beautiful setting. Since my return, I practice daily some aspect of the newly gained knowledge and advice. Thanks to Kripalu staff and the National Parkinson Foundation staff for being so accessible to us and providing this opportunity. It was GREAT!”

On the last day of the program, it was clear that a close-knit community had formed. The group shared their feelings about the week: energetic, optimistic, empowered, encouraged and informed. Many of the participants felt that they were now able to take better care of themselves and their families through the practice of yoga, meditation and healthy eating. The Kripalu faculty reminded us that the changes we desire cannot happen all at once; rather, we must look at ourselves as a work in progress and focus on incremental changes that we can make each day.

The next yoga retreat will be offered October 31 through November 4, 2011. Please call 1-800-4PD-INFO for more information.

To watch a video of Kripalu participants in a session of “Let Your Yoga Dance” visit, www.parkinson.org/retreat.

Living with Parkinson's:

Rich Clifford, Former NASA Astronaut

When doctors told 42-year-old Rich Clifford that he had early Parkinson's disease, the first thing he said was, "Okay, fix it so I can get back to my racquetball." Hearing that kind of news after a routine flight physical left the NASA astronaut shocked.

"I had never heard of the disease," recalls Clifford of that day in October 1994. The fact that he had always been a sports enthusiast made his diagnosis even harder to absorb. In fact, he thought the one symptom he developed—his right arm didn't move when he walked—was probably from playing racquetball. When his diagnosis was confirmed, the reality hit him hard. "I refused to believe it," he said. But after taking comfort in his family, the West Point graduate made a decision: "I wasn't going to let this thing beat me."

Soon after, Clifford faced another setback. His senior NASA managers assumed his diagnosis meant he could no longer fully function, so they grounded him from flying. In response, he went on to perform a variety of flight tests and other activities to demonstrate his ability. As a result, they granted him a return-to-flight status, and assigned him to his third space shuttle mission, the STS-76 crew.

In March 1996, Space Shuttle Atlantis began a nine-day mission to the Russian Space Station Mir. During that space flight, Clifford performed a six-hour spacewalk, installing four experiment packages on the exterior of the Mir Space Station. Clifford remembers what it was like seeing the earth below him. "It's amazing to see the illumination of the earth's surface as the sun is coming up, it expands into every color of the rainbow," he said. "It's beautiful and awe-inspiring."

A year later, Clifford left NASA and joined the Boeing Company. These days, he is the Deputy Program Manager of Boeing's Space Shuttle Program.

Rich Clifford on the Russian Space Station Mir.



Rich Clifford in his NASA uniform.

"Parkinson's is not the end of your life," he said. "It's debilitating and it's progressive, but there are many ways of doing tasks differently, and living a full life."

It's been 17 years since his diagnosis, and Clifford has remained fit and kept his symptoms under control. "I have tremors every now and then, but overall I've got it under control," he said.

Over the years, Clifford has been asked, "How could someone with Parkinson's disease fly in space and live such an active life?" The answer, he believes, is simple. Don't give up. "I have some restrictions, but I still play golf, exercise and do a lot of other activities," he said. Furthermore, with the encouragement of his physician, Joseph Jankovic, MD, a neurologist at NPF's Center of Excellence, Baylor College of Medicine in Houston, Clifford now devotes his energies to motivating others. "I'm letting people know that you've got to live past the fact that you've got a disease," he said. "People look at me and wonder if I really have this disease, because I don't display many of the symptoms. But I treat the symptoms with medicine and exercise."

Still, Clifford credits his support system for his good fortune. "Dr. Jankovic has been a great support to me, along with my family," he said. "In the famous words of former NASA Flight Director Gene Kranz, 'Failure is not an option.' And I am continually reminded of this by my wife Nancy and my sons Richard and Brandon. Without their encouragement, I probably would've followed a different path."

Share your story about living with Parkinson's. Visit www.parkinson.org/community today!



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Michael S. Okun, MD, Kelly D. Foote, MD, Ramon L. Rodriguez, MD

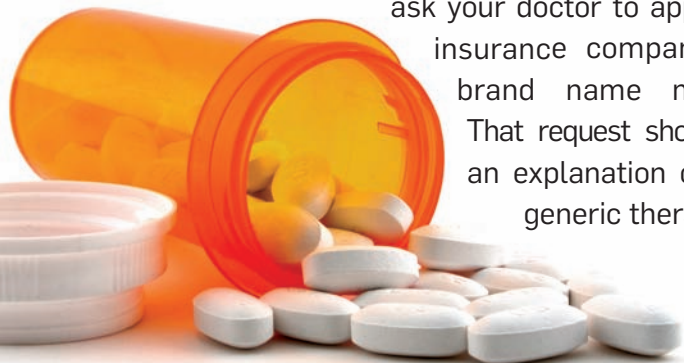
Top Questions and Answers from NPF's "Ask the Doctor" Forum

The **National Parkinson Foundation** continues to remain deeply committed to the outstanding care of patients with Parkinson's disease. The free web-based forums located on our website (www.parkinson.org) offer immediate and free access to experts in the field. In this issue, we highlight some of the most popular questions asked by patients and families. We invite everyone to visit us, read the daily posts, and to ask any question that may be on your mind(s). We have appreciated the direct interaction with the Parkinson's disease community, and we look forward to continuing the dialogue.

Q Sinemet versus generic: Does it matter?

A People with Parkinson's disease (PD) have multiple motor and non-motor symptoms that require careful assessment and comprehensive treatment. Most patients combine several medications to manage their symptoms, and usually work closely with their doctor to create a regimen they can tolerate. To date, there's little research comparing generic levodopa-carbidopa with its brand name counterpart Sinemet. Even so, it's important to note that generics are carefully regulated by the federal government and contain identical ingredients. Still, some drugs, such as those to treat Parkinson's disease, require very consistent and precise dosages to control symptoms. And even slight variations could cause the drug to be less effective.

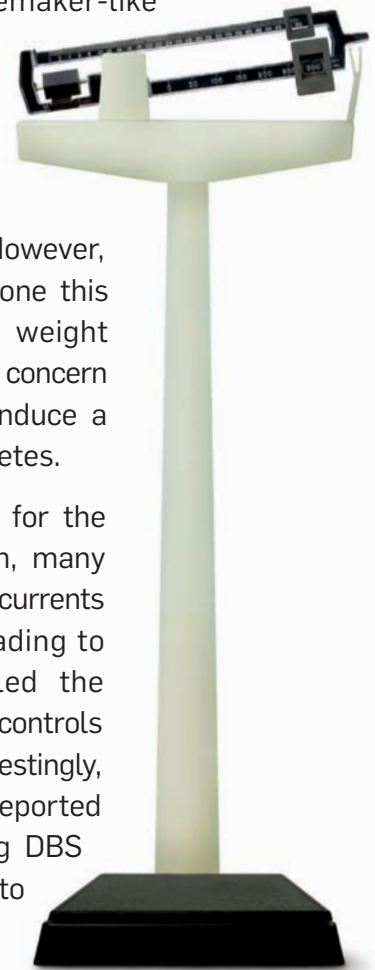
In light of the recent issues surrounding Sinemet's availability, if you must switch from brand to generic, stick with one prescription. Sometimes it will be a one-to-one switch, with no further adjustments in your regimen required. If the generic version is weaker simply increasing the dose, or dosing more often, will control your symptoms. If despite these measures, the generic drug is ineffective, ask your doctor to appeal to the insurance company for the brand name medication. That request should include an explanation of why the generic therapy failed.



Q Why do some people gain weight after deep brain stimulation surgery?

A Deep brain stimulation (DBS) is a surgical procedure that involves implanting a small battery-powered electrode deep in the brain. This pacemaker-like device regulates the abnormal neuron activity that causes Parkinson's-related movement disorders. DBS has shown promise in reducing tremors and other symptoms of PD. However, some people who have undergone this procedure report putting on weight months after the surgery. There is concern that this added weight could induce a metabolic disorder such as diabetes.

Although the underlying cause for the weight change is still unknown, many experts believe that the electrical currents the device emits may be spreading to a location of the brain called the hypothalamic center. That region controls appetite and signals satiety. Interestingly, some people with PD have reported carbohydrate cravings following DBS surgery. However, it's important to note that in past studies approximately 20 percent of people who underwent this procedure actually lost weight.



Q What do I need to know about FDA recalls on Stalevo, the patch and other Parkinson's disease drugs?

A Recently, the U.S. Food and Drug Administration (FDA) has been making headlines over several drugs used to treat PD. Drug recalls, reviews and safety alerts are an important reality for people with PD. Always talk to your doctor about the risk-benefit ratio of any drug currently under FDA review, and also inquire about potential alternative management strategies. Here's what you need to know.

A **FDA Drug Recall** refers to the removal of an over-the-counter or prescription drug from the market. For more information go to www.fda.gov.

The following drugs have been recalled:

- **Cisapride (Propulsid)** Used to help gastrointestinal emptying issues. It was recalled for heart-related safety issues.
- **Tolcapone (Tasmar)** Used to treat on-off fluctuations and to extend the longevity of each Sinemet dose. It was recalled due to several cases of fatal liver toxicity. However, it was reintroduced after the FDA mandated a black box warning. Tolcapone now requires liver function tests, but is considered to be safe.
- **Pergolide (Permax)** Used to stimulate dopamine receptors (a dopamine agonist). It was recalled because of an association with heart valve damage.
- **Rotigotine (Neupro)** A dopamine agonist transdermal patch that was recalled due to a delivery problem. The FDA will allow it back on the market after it is reformulated.
- **Levodopa-carbidopa-entacapone (Stalevo)** The FDA recently announced it was reviewing the drug for a potential increase in cardiac risk. Stalevo remains on the market pending this FDA review.

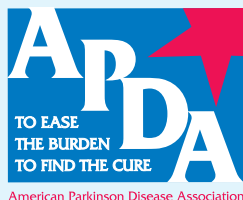
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Tips for Daily Living

The saying goes that knowledge is power—and that phrase has never been truer than for people with Parkinson's disease.

Here's how to stay on top of your medical treatment:

- ✔ **Build your own health files:** Keep a copy of your medical records, including diagnostic test results.
- ✔ **Take notes:** Jot down questions that come up in-between scheduled doctor's appointments.
- ✔ **Keep a medication schedule:** Download a weekly schedule to write the times and doses of each medication you take.
- ✔ **Know your drugs:** Read up on the latest FDA alerts, reviews and recalls. Make it a habit to visit www.fda.gov.
- ✔ **Speak up:** Discuss changing symptoms and medications with your doctor. Post a question in NPF's "Ask the Pharmacist" online forum—it's free!



SAVE THE DATE

2011 Midwest Parkinson's Disease Conference
and Young Onset Parkinson Conference

June 17 - 18 | West Des Moines, IA

For more information:

www.parkinson.org/yopc

What's Hot in Parkinson's Disease?

Should I Get a DaTscan or PET scan to confirm my diagnosis of Parkinson's?

The FDA recently approved **DaTscan**, a new imaging test that will help doctors confirm a diagnosis of Parkinson's disease (PD). DaTscan is expected to be widely available later this year.

Imaging techniques such as PET scans and DaTscans examine the function of the brain rather than its anatomy. Using these tests, doctors are able to see small details inside the brain. By revealing changes in brain chemistry, such as a decrease in dopamine, these tests help doctors identify PD and other similar diseases. PET scans show glucose (sugar) metabolism, and DaTscans focus on the dopamine system.

In PD cells are lost in the basal ganglia, which is the area of the brain associated with movement. Since it is normal to lose some of these cells as we age, neuroimaging tests are useful for determining whether brain changes are due to normal aging or to a degenerative disease.

Here is how DaTscan works: a chemical solution that gives off "light" is injected into a person's veins. This solution "tags" neurons where dopamine normally attaches. A special camera called a SPECT scanner then visualizes the distribution of these so-called dopamine transporters (DaT) within the brain. The pictures enable doctors to evaluate the density of healthy dopamine neurons: the areas that "light" up indicate surviving brain cells. If regions remain dark, early brain degeneration may be diagnosed.

DaTscan is the only test that will be widely available. If you have been diagnosed with Parkinson's and are responding well to dopaminergic therapy, a DaTscan would most likely not be helpful. DaTscan is approved to help doctors tell essential tremor from PD—confusion that might occur early in the disease. It is important to keep in mind that these tests should be performed by an experienced team who have performed a large volume of PD scans, because experience is vital for accurately reading these imaging results.

Recently, in some studies attempting to diagnose Parkinson's earlier in its course, researchers found that a subset of people believed to have PD turned up with a negative scan. Some did not develop the progressive symptoms of PD. These findings underscore the importance of following patients over long periods to ensure both accurate diagnosis and appropriate treatment.

PET scans are FDA-approved for the diagnosis of dementia, but not for the diagnosis of PD. However, if you or your relative has cognitive impairment, the scan can be ordered to test for the presence of Alzheimer's changes. People with PD may also have Alzheimer's disease. The cost can range from \$2,500 to \$5,000. Many academic medical centers perform PET scans for free under research protocols.

In summary, in cases where the diagnosis is uncertain, a DaTscan or PET scan can be very useful. But if you have already been diagnosed with Parkinson's, and your medications are controlling your symptoms, a PET or DaTscan would add little new information.

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.

Paintball for Parkinson's

Car chases, sword fights, high falls. Hollywood's stunt men and women perform these spine-tingling feats everyday. Last November, the International Stunt Association (ISA) pulled off another challenge without a hitch. They held a paintball tournament to raise money and awareness for Parkinson's disease.

"We wanted to support something that is near and dear to our heart," said Thom Williams, president of the organization. The event was an opportunity to rally around fellow stuntman John Cade, who was diagnosed with Parkinson's disease. Cade, who's in his 50's, has been dangling from the edge of skyscrapers and jumping out of burning cars for over 25 years.

Other members of ISA also have been touched by the disease.

"I hope one day we can figure out how to beat it," said stuntman Adam Hart, whose father was diagnosed with Parkinson's disease last year.

"Sometimes the best way to get a serious message out is to have some fun, because that's when people are most open and receptive."

With that in mind, the Second Annual Stunt Tournament was held at the Hollywood Sports Park in Bellflower, California on November 13th, 2010. The competition attracted some 200 folks to the field. The rule of the game was that each team attempted to capture the flag without being shot with paintballs. "It's a long day, with bruises and scrapes, but a really good time," Williams said.

Hollywood Sports Park in California



When trophies were handed out at the end of the tournament, Team Awesome took first place. "It's a real close-knit, caring community, and this event meant a lot to John," Williams said. "It jump-started his efforts to get more information, and connected him with people at the National Parkinson Foundation." In addition, area companies donated prizes for a silent auction. Overall, the event raised \$3,200 for the National Parkinson Foundation.



Thom Williams (third from right) with the winning team.

"We are very grateful to Thom Williams and all the stunt men and women who participated in the International Stunt Association's Second Annual Stunt Tournament to support the National Parkinson Foundation! It was a day of fierce competition in Los Angeles to support a great cause: ending Parkinson's disease," said Shannon Sullivan, NPF's VP of Strategic Initiatives.

For more information about starting your own community fundraiser, visit www.parkinson.org/teamhope.

Out of the Park for Parkinson's



Gordon Beckham, second baseman for the Chicago White Sox, presented a check to the National Parkinson Foundation for \$60,000, which was raised through his *Out of the Park for Parkinson's* fundraising campaign. During the 2010 baseball season, Gordon Beckham pledged a donation to the National Parkinson Foundation for every home run that he hit, and his fans joined him by making pledges of their own.

Beckham presented the check in January to NPF President and CEO Joyce Oberdorf at a special event for Out of the Park donors during Sox Fest weekend in Chicago. NPF recognized Beckham for his outstanding community leadership by presenting him with a 2011 HOPE Award. Gordon Beckham and his family understand the challenges of Parkinson's firsthand: his grandfather has been living with the disease for nearly a decade.

"I'm honored and humbled to receive this award from NPF," Beckham stated. "I want to dedicate this to my grandfather who suffers from Parkinson's—this is for him. Hitting homeruns for Parkinson's was a huge thrill for me and I'm excited to continue the fight in the 2011 season. Together, we can knock Parkinson's out of the park!"

"On behalf of NPF and the million people living with Parkinson's in the United States, I would like to thank Gordon Beckham and the Chicago White Sox for helping us raise awareness of Parkinson's disease. We are truly looking

forward to the continued success of this campaign in 2011," said Joyce Oberdorf.

All proceeds benefit the National Parkinson Foundation, which has a strong presence in Chicago, supporting the work of Northwestern University's Parkinson's Disease and Movement Disorder Center, NPF Center of Excellence, as well as the local NPF chapter, the Parkinson Association of Illinois.

NPF President and CEO, Joyce Oberdorf, accepting a check from Gordon Beckham.



**Fans of Gordon Beckham can visit
www.outofthepark.org
to make a donation, or follow
Out of the Park on Facebook and Twitter.**

Help is a Phone Call Away... NPF's National Helpline 1-800-4PD-INFO

Get Your PD questions answered today:

- What is PD?
- Do you know where I can find a specialist in PD?
- How can I learn more about new PD clinical trials?
- What exercises are best for people with PD?
- Where can I find assistive devices?
- How can I find a support group or educational event in my area?
- Which NPF publications do you think will be most helpful to me?
- What are the non-motor symptoms of PD?
- I've been denied disability. What should I do?
- What are the early warning signs of PD?

The NPF Helpline is open Monday through Friday from 9:00 am to 5:00 pm (eastern time).

You can also e-mail us at:

helpline@parkinson.org

Our highly trained PD information specialists are bilingual in English and Spanish.



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*Renowned flautist
Nestor Torres.*

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specialists answer
medical questions about
Parkinson's disease.

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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.



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