New Developments in Deep Brain Stimulation: Achieving a Better Quality of Life

Kay Mixson-Jenkins’ life was turned upside down when she was told she had Parkinson’s disease. Suffering from severe dyskinesias, she couldn’t enjoy simple activities with her family. But after undergoing deep brain stimulation (DBS) surgery at the University of Florida in Gainesville, an NPF Center of Excellence, her life improved dramatically. “Now I can cut my own food, dress myself and dance with my husband,” she said. “I have a future to look forward to and that is wonderful.”

While DBS has yielded life-changing results for Mixson-Jenkins and others whose medications no longer adequately control symptoms, specialists continue to pursue ways to make the therapy easier, safer and more effective. “Parkinson’s disease affects the brain in very complex ways and we have only so far scratched the surface of the best techniques and approaches for using stimulation to treat this disease,” said Michael Okun, MD, NPF’s National Medical Director.

In DBS surgery, a neurosurgeon and interdisciplinary team implants one or alternatively two leads (wires) deep in the brain and wires them to a pacemaker-like device implanted below the collarbone. Electrodes near the tip of each lead emit electrical pulses, regulating the chaotic brain cell activity that causes motor symptoms. At present, DBS is typically used to treat individuals who are in the advanced stages of the disease. One of the challenges facing people with Parkinson’s is recognizing the most beneficial time to have this therapy.

...continued on page 2
New Developments in Deep Brain Stimulation: Achieving a Better Quality of Life

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“The right time for DBS is different for individual patients,” said David Charles, MD, Chief Medical Officer of the Vanderbilt Neuroscience Institute, and Director of the Movement Disorders Clinic at Vanderbilt University Medical Center, an NPF Center of Excellence. “There is an optimal time that DBS can be particularly helpful. It’s a combination of age and how long a person has had Parkinson’s disease.”

One way to take advantage of this therapeutic window is to start learning about DBS as soon as you experience levodopa-associated dyskinesias, Dr. Charles recommends. Once you reach the point where your symptoms no longer have any response to medications, the therapeutic window has probably closed and the therapy won’t be very beneficial.

Currently, researchers are studying the benefits of DBS on patients in earlier stages of the disease. Last month, Dr. Charles and the team at Vanderbilt received approval from the FDA to conduct a multicenter study to test the safety and tolerability of DBS in early stage Parkinson’s disease. “The hypothesis is that DBS applied early in the course of Parkinson’s will slow the progression of disability,” he said. That would be a major breakthrough.

**GOOD CANDIDATES FOR DBS**

- Still respond to levodopa with some good time throughout the day.
- Experience Parkinson’s symptoms that interfere with daily activities, including off periods with bradykinesia, rigidity or tremor; unpredictable on-off phenomena; motor fluctuations; bothersome dyskinesias; and tremor that is not completely responsive to medication.
- Do not have significant depression or dementia.
- Have realistic expectations.

To learn more about DBS, visit www.parkinson.org/dbs.

Download a free copy of NPF’s newly revised DBS publication at www.parkinson.org/books.

Letter from the President

This past year has been marked by the launch of even more NPF programs for people living with Parkinson’s and their families. We truly believe that all people deserve access to expert Parkinson’s care and information no matter who they are, where they live or how much money they have.

It is a lifelong commitment to the underserved that has been a strong tenet of our retiring Chairman of the Board, Dr. Bernard Fogel. For six years, Dr. Fogel led the Board as a strong advocate of our mission to focus on improving the lives of patients today. His passion to help—and help mightily—stemmed from seeing his own father struggle with the disease for decades.

Now he passes the Chairman’s baton to John Kozyak. Both John’s mother and father have Parkinson’s and he has seen firsthand the difference that education and support can make in a person’s ability to live a better life now and he is strongly committed to the cause. A prominent attorney with a national profile, John, too, has a long history of serving the underserved.

As president and CEO, it has been my honor to work side-by-side with wonderful leaders such as Dr. Bernard Fogel and John Kozyak. Together, on behalf of the million Americans with Parkinson’s and their families, we are committed to doing whatever it takes to beat Parkinson’s.

Thanks for your support,

Joyce Oberdorf
President and CEO
Patient Input Informs NPF Grant Funding Opportunities

NPF has launched a new grant cycle with the goal of developing the next generation of leaders in Parkinson’s disease (PD) by supporting their research in areas voted as most important by the Parkinson’s community. Grant funding is available in three high-impact focus areas: cell-to-cell transmission studies, cognitive change in PD and database studies. These three focus areas were identified as the most important research targets by people living with PD via an online poll conducted in November 2013.

Many of today’s leaders got their first grants from NPF. But with tightening budgets in Washington, mid-level researchers are increasingly finding it difficult to get the support they need to build careers as Parkinson’s researchers.

“We believe that the ideas that will change the course of Parkinson’s disease may already be in development, but we are afraid that the next generation of senior faculty who will shepherd these ideas into the clinic are not getting the support they need,” said Peter N. Schmidt, PhD, NPF’s CIO and Vice President, Research and Professional Programs.

The three high-impact focus areas include:

- **Focus area one: How Parkinson’s spreads from cell-to-cell.** In Parkinson’s, cells die because they are poisoned by a toxic form of the protein alpha synuclein. This protein starts in one part of the brain and spreads from cell-to-cell almost like an infection. If we could stop this spreading, we could stop the progression of PD in patients who already have it and prevent PD in people at risk. Understanding this process could lead to new targets for drugs that have never before been considered. This was the highest rated patient priority and the NIH announced recently that they believe cell-to-cell transmission is the number one priority in basic research.

- **Focus area two: Cognitive change in PD.** For many patients, the most troubling aspect of Parkinson’s is worrying that their thinking will change. When this happens, their reaction time slows, they may have trouble picking the right word to say, and their ability to prioritize and sequence information can be affected. For this second highest-rated patient priority, NPF will support further research into the biology of cognitive change and also interventions that build on these new findings to improve the lives of people with Parkinson’s.

- **Focus area three: Database studies.** Drilling through multiple sets of research data to find common threads or hidden gems of information is a cutting-edge technique—what is now called big data. NPF will leverage big data techniques in Parkinson’s by funding studies looking at combinations of study databases: early and late disease, data from multiple sources or those that combine insights from the general population. Many ideas that are changing health today came from looking back at data using these big data approaches.

This grant cycle will fund programs based on scientific merit, as determined by the NPF’s Clinical and Scientific Advisory Board (CSAB) in a peer-review process. Grant winners will be announced in the next issue of the Parkinson Report.

In addition to this grant funding, NPF continues to fund the Parkinson’s Outcomes Project, the largest clinical study of its kind that is currently tracking more than 7,500 people with Parkinson’s who receive care at an NPF Center of Excellence.

For more information about NPF’s research initiatives, visit www.parkinson.org/research.
Using Technology to Manage Parkinson’s

From tablets to apps to social media, Angie Hott, a self-described tech-phobe, makes it clear that it’s not for the love of gadgetry that she uses these different technologies. It’s about relationships. “We are a family that lives with Parkinson’s disease every day, and we all use technology to connect in different ways,” said the 48-year-old mother of four. “I’d feel so lost without it.”

After her husband Dan was diagnosed with Young-Onset Parkinson’s disease six years ago, at the age of 50, Angie started a blog called, “Excuse Me, Can I Tell You Something?” “For me, it was a way to sort out my feelings about his diagnosis,” she said. “It’s a great place to share information. When I write a blog post, I hope that it reaches who it’s supposed to reach.”

Living in rural West Virginia, Angie and Dan don’t have access to a local Parkinson’s support group where they can get advice and encouragement. So the couple turns to social media, Google and apps to get answers to their questions.

Through technology, I’ve found so many resources for me as a partner and for Dan and our kids, Angie said. At first, we were like this is terrible, but if you connect with people you can make your own support group and feel better about living with Parkinson’s.

Interacting with today’s high-tech world can be a daunting experience. But Angie encourages others to take the bull by the horns and take advantage of the different technologies out there.

“Once I got over feeling like a novice for having to ask my teenager to install NPF’s app Parkinson’s Central for me, I began reaping the benefits. So many doors have opened that allow me to learn more about this illness,” she said. “What I love most about using technology is connecting with people all over the world who are just like me.”

SCARED OF TECHNOLOGY? ANGIE SAYS DON’T BE AFRAID TO TRY SOMETHING NEW.

☑️ Reach out. “If you don’t know how to use something or you’re searching for a particular resource, just ask,” she said. “People are there to help.”

☑️ Be optimistic. “Mistakes are just opportunities to learn more,” she said. “Who knows, hitting that wrong button may lead you to a new connection.”

To read other blogs written by caregivers, visit www.parkinson.org/caregivers.

Download the Parkinson’s Central App Today!

Parkinson’s Central is a free app for people with Parkinson’s and their caregivers. www.parkinson.org/parkinsonscentral
One common dream shared by people with Parkinson’s disease (PD) around the globe is the hope of a pill-free existence. Now new findings from the first double-blind and controlled study of a pump-based continuous infusion therapy of a gel containing the drugs levodopa and carbidopa suggest that this dream may soon become a reality.

Duodopa therapy involves continuous delivery of an intestinal gel containing the same drug formulation as Sinemet. The gel is delivered directly into the small intestine via a surgically placed tube that passes through the stomach and connects to an external medicine cartridge and portable pump.

For the clinical trial, participants with advanced PD and motor fluctuations were randomized to receive either immediate-release oral levodopa/carbidopa pills plus a placebo (inactive) intestinal gel (pump therapy), or levodopa/carbidopa intestinal gel plus oral placebo pills.

Each participant was given intestinal gel and pills every day. Since the study was blinded, neither the participants nor the investigators knew what treatment was being administered. The trial was conducted at 26 major medical centers across the US, Germany and New Zealand. The aim was to determine if the pump-based therapy was safe and effective.

The study authors were most interested in improving the amount of time spent in the off state. After 12 weeks of therapy, off-time improved by four hours in the group that received levodopa/carbidopa intestinal gel (pump therapy) compared to 2.1 hours in the group that got levodopa/carbidopa pills. In addition, the amount of on-time without troublesome dyskinesia was better in the pump group than in the pill group (4.1 vs. 2.2 hours).

For people with motor fluctuations, the data suggest that the pump outperforms standard medical therapy. Still, the study didn’t include participants with severe dyskinesia. And it’s unclear how this therapy will perform in more severe and disabled patients.

One major drawback of the pump approach is that it requires placement of a small feeding tube. These types of tubes can serve as points for infection and other complications. In the current study, device complications were present in 89 percent of participants. But in most cases, the complications were addressable, and were lower than in previous pump trials.

Another drawback of the pump approach is that it requires ongoing maintenance and programming by a qualified professional. Additionally, the site where the tube connects to the stomach needs to be monitored for infection.

While this technology is a powerful symptomatic therapy, it does not cure or stop the progression of the disease. And, in most cases, continuous infusion therapy will not address dopamine-resistant symptoms such as walking, talking and thinking.

Today, Duodopa therapy is approved and available in 43 countries. Based upon these findings, this therapy will probably be approved in the US in the near future. For some people in the Parkinson’s community, a “pill-free existence” is truly on the horizon.

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.
Q Recently I have noticed that my thinking and memory are getting worse and my wife and I are having a hard time adjusting. What can I do to manage this problem?

A Almost everyone with PD experiences some changes in their memory and thinking processes, but these changes can range in severity from mild to severe. What you’re experiencing may be Parkinson’s-related, but in some cases it’s actually depression. We usually begin with a neuropsychological examination which helps us screen for cognitive decline. If changes in your cognitive ability are serious enough to interfere with daily living, we consider cholinesterase inhibitor drugs (Aricept, Exelon), or Namenda, or both. While there is no perfect formula for addressing memory dysfunction, we usually start with one of these medications, reassess your condition over time and then decide if we should continue the medication, or, alternatively, add a second agent. If depression is the underlying problem, prescription antidepressants and psychotherapy can be very effective treatments.

Q Is it common to experience dysphagia during a meal? I can be really hungry and about half way through the meal I start finding it hard to swallow. What can I do?

A Yes, it’s possible for the muscles to fatigue part way through a meal, thus making swallowing more difficult. Dysphagia (difficulty swallowing) is a common problem for people with PD. The symptoms may include frequent coughing during meals, coughing while drinking or taking medications, a wet gurgly sounding voice and unexplained weight loss. Swallowing difficulties can interfere with your ability to get food and liquids to “go down” as well as to take medications. Swallowing problems can have a serious impact on your quality of life. Dysphagia can also result in aspiration pneumonia, which is one of the leading causes of death in people with PD.

In order to figure out what’s causing your swallowing problem, you should consult with a speech-language pathologist and consider a swallowing study. Ask your physician for a referral to a speech therapist and choose one who has a lot of experience working with people with PD. In addition to identifying the specific causes of your dysphagia, the speech therapist will recommend treatment strategies (including swallowing
exercises) that will help you enjoy your meals and reduce fatigue during eating.

**Meanwhile, here are some general safe swallow strategies:**

- During meals and when taking medications, sit upright with your hips flexed at 90 degrees.
- After a meal, remain sitting for 45 minutes to allow gravity to aid digestion.
- Eat smaller and more frequent meals to avoid taxing the swallowing muscles.
- Swallow twice after you eat or drink something.

**Q** My father has Parkinson's and complains of constant pain in his lower back and legs. Can anything be done? I heard acupuncture treatments can help.

**A** Back pain is a very common issue for all people, whether or not they have PD. What many patients don’t realize is that some pain associated with PD is responsive to dopaminergic therapy. First, talk to your father’s doctor about the possibility that his pain is Parkinson’s-related, and whether increasing the dose of carbidopa/levodopa or adding a dopamine agonist may address this issue. Next, a neurologist should perform a full examination, order appropriate imaging and counsel your father about options for therapy. In most cases, surgery will not be the first-line approach. Finally, physical therapy and other options such as massage and acupuncture may help reduce pain. Acupuncture has been reported by many people living with Parkinson’s as a relatively safe approach, though at this time further research is needed to confirm this observation.

*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.*

**Tips for Daily Living—Ways to Boost Your Brain Function**

Looking for ways to stimulate your brain and fight off memory loss? Try incorporating some of the following activities into your daily routine.

- **Play games.** Practicing brain games or playing board games that are mentally challenging are good ways to improve your mental focus and memory.
- **Learn something new.** Whether it’s a language or a musical instrument, learning something new can also help your brain.
- **Challenge your recall.** Next time you make a list, whether it’s for groceries or home repairs, try memorizing it.
- **Learn to relax.** Ongoing stress and worry can lead to depression or anxiety, which can interfere with clear thinking and memory. Regular meditation can help you let go of worries.
- **Meet new people.** Whether it’s volunteering at your local museum or joining an online support group, regular social interaction is another great way to keep your mind nimble.
Moving Day® Spreads Across the Country

Moving Day®, a walk for Parkinson’s, is now in twenty-four markets across the United States. To date, we have had nearly 40,000 people participate in the walk raising a total of five million dollars! Thanks to the support of our National Honorary Chair, Katie Couric, we have been able to air public service announcements to raise awareness and funds for NPF’s national signature event. In 2014, NPF is proud to announce new walks in Boston, Los Angeles, Phoenix, San Francisco, Silicon Valley and Tampa.

As a patient at the Center for Movement Disorders and Neurorestoration, University of Florida, an NPF Center of Excellence, Gabriel has become a passionate advocate for research and support for those with Parkinson’s disease and those who have yet to be diagnosed.

“All in all, there is no time to be down about things. I asked myself what can I do to help find a cure for Parkinson’s? Gabriel said. Twenty-five years ago, I brought the Orlando Magic basketball team to Central Florida and I’m here to bring magic to Orlando one more time.”

Moving Day is made possible through the generous support of our national partners: UCB, Right at Home and US WorldMeds.

Check out the Event Calendar on page 9 for a list of spring walks.
To find other Moving Day walk locations visit www.npfmovingday.org.

Moving Day team in Florida.

This April, Moving Day is headed to Orlando, FL, to benefit the NPF Central Florida Chapter. John Gabriel, who is serving as the Honorary Chair of Moving Day Orlando, has earned the reputation for having one of the sharpest minds in all of basketball.

As the director of scouting for the NBA’s New York Knicks, he’s still very much a player in the league, but now he’s facing his toughest opponent yet—Parkinson’s disease.
2014 NPF Spring Event Calendar

**APRIL**

- **4/5:** Moving Day® Orlando, FL—Presented by the NPF Central Florida Chapter  
  Register online: [www.movingdayorlando.org](http://www.movingdayorlando.org)

- **4/5:** Parkinson’s Day, Miami, FL—Presented by the NPF South Florida Chapter  
  Register online: [www.npfsouthflorida.org](http://www.npfsouthflorida.org)

- **4/22:** Free Webinar: “Stem Cells for PD: Fact or Fiction?”  
  Register online: [www.parkinson.org/webinars](http://www.parkinson.org/webinars)

- **4/26:** Visit the NPF Booth at the Parkinson’s Unity Walk, Central Park, New York City—  
  Presented by the Parkinson Alliance  
  Register online: [www.unitywalk.org](http://www.unitywalk.org)

**MAY**

- **5/3:** Moving Day® Twin Cities, MN—Presented by the NPF Minnesota Chapter  
  Register online: [www.movingdaytwincities.org](http://www.movingdaytwincities.org)

- **5/17:** Moving Day® Tallahassee, FL—Presented by the NPF North Florida Chapter  
  Register online: [www.movingdaytallahassee.org](http://www.movingdaytallahassee.org)

**JUNE**

- **6/14:** Moving Day® Kansas City, MO—Presented by the NPF Heartland Chapter  
  Register online: [www.movingdaykansascity.org](http://www.movingdaykansascity.org)

- **6/15-19:** NPF Wellness Retreat, Stockbridge, MA—Kripalu Center for Yoga and Health  
  Register online: [www.parkinson.org/retreat](http://www.parkinson.org/retreat)

- **6/17:** Free Webinar: “Balancing Act: Preventing Falls in PD”  
  Register online: [www.parkinson.org/webinars](http://www.parkinson.org/webinars)

*Visit NPF’s Event Calendar at [www.parkinson.org/events](http://www.parkinson.org/events).*

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The National Parkinson Foundation’s 2013 Annual Report, “Whatever It Takes to Beat Parkinson’s” is now available to view online:

[www.parkinson.org/annualreport](http://www.parkinson.org/annualreport)
Top 10 Ways to Raise Awareness During Parkinson’s Awareness Month and All Year Long!

1. **Do Whatever It Takes to Beat Parkinson’s®**
   - This national symbol for living well with Parkinson’s highlights the many ways you can fight the disease. Explore our interactive webpage and do whatever it takes today!
   - [www.parkinson.org/whateverittakes](http://www.parkinson.org/whateverittakes)

2. **Wear your Parkinson’s Awareness bracelet**
   - Purchase a pack of 20 *Whatever It Takes to Beat Parkinson’s* awareness bracelets to give to your friends and family.
   - [www.parkinson.org/store](http://www.parkinson.org/store)

3. **Advocate for quality care for people with Parkinson’s**
   - 3 out of 4 Parkinson’s patients don’t get their medications on time during a hospital stay. Order your free *Aware in Care* kit today by calling 1-800-4PD-INFO (473-4636).
   - [www.awareincare.org](http://www.awareincare.org)

4. **Walk for Parkinson’s at one of our 2014 Moving Day® events**
   - Every move you make and every penny you raise will help us fund our local chapters and bring us one step closer to beating Parkinson’s!
   - [www.npfmovingday.org](http://www.npfmovingday.org)

5. **Plan a community fundraising event through Team Hope**
   - Team Hope makes it easy for you to raise awareness and funds in your hometown.
   - [www.parkinson.org/teamhope](http://www.parkinson.org/teamhope)

6. **Attend the NPF Wellness Retreat with your care partner**
   - Join us at a four-day wellness retreat for people living with Parkinson’s and their care partners. The program includes daily yoga classes.
   - [www.parkinson.org/retreat](http://www.parkinson.org/retreat)

7. **Download our free smartphone app, Parkinson’s Central**
   - The latest information about Parkinson’s is at your fingertips. Download the app on your smartphone and share with your Parkinson’s support group.
   - [www.parkinson.org/parkinsonscentral](http://www.parkinson.org/parkinsonscentral)

8. **Reach out to your local NPF Chapter**
   - NPF has an extensive network of chapters across the country that host support groups, exercise and wellness classes and educational events. Find one near you.
   - [www.parkinson.org/search](http://www.parkinson.org/search)

9. **Join an online discussion in our “Ask the Doctor” forum**
   - Visit our online forum to ask your Parkinson’s questions—our team of specialists are here for you 24/7.
   - [www.parkinson.org/forums](http://www.parkinson.org/forums)

10. **Like us on Facebook and follow us on Twitter**
    - NPF provides daily updates on what is happening in the Parkinson’s community on social media. Be sure to like us on Facebook and follow us on Twitter to stay informed!
    - [www.facebook.com/parkinsondotorg](http://www.facebook.com/parkinsondotorg)
NPF Legacy Society

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 305-573-9940.

Have Fun. Give Hope. Beat Parkinson’s!

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

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