

Parkinson's Clinical Research: Changing the Way Business is Done

By Robin Elliott

In 2004, the Parkinson's Disease Foundation (PDF) launched Advancing Parkinson's Therapies (APT), an initiative designed to help accelerate the development of new therapies for people who live with Parkinson's disease (PD).

As we reported exactly five years ago in this newsletter, a primary obstacle to therapy development — and one on which we thought we could have the greatest impact — was the low participation in clinical trials among people with PD.

So, when we recently interviewed various colleagues who are involved in the therapy development process to hear their perspectives (as reported later in this article), we were not surprised to hear each one of them identify clinical trial recruitment as an ongoing barrier to therapy development. But we were interested to hear them identify additional roadblocks of an institutional nature, and speak of collaboration and inclusion of people with PD as potential solutions.

This is because over time our own thinking has also evolved. We have come to realize that while low recruitment is an important barrier to address to find new therapies, it is also symptomatic of more complex issues that require our attention.

So, what is our solution? At PDF, we believe that we can no longer afford to see people with Parkinson's disease as simply vehicles through which to test new medicines. Rather, we should see people with PD as primary partners in the processes of therapy development, trial design and implementation and peer education. Our panel's responses tell us that we are coming closer to this ideal, and this news comes at an auspicious time.

PDF's third Clinical Research Learning Institute in October graduated 40 people with Parkinson's newly-educated in the theory and practice of clinical studies. This brings to more than 100 the number of members of what we will now be calling the Parkinson's Advocates in Research (PAIR) program of PDF.

As these trained advocates partner with government, scientists and industry, we hope to increase knowledge, trust and transparency among the PD community. Look for more details in the Spring 2011 newsletter. And join with us in changing the way business is done — a new way that ensures a place for people with Parkinson's, from all walks of life, at the center of the clinical research process. *Mr. Elliott is PDF's Executive Director.*

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NEWS IN BRIEF

Alzheimer's Drug Reduces Falls in People with Parkinson's

A new study of the use of donepezil (Aricept®) in people with Parkinson's disease (PD) who have problems with balance shows that the drug reduced the number of falls experienced by one-half. The study, which appears in the October 2010 issue of *Neurology*, also suggests that the drug, widely used for the cognitive symptoms of Alzheimer's disease, may ease cognitive symptoms in PD.

Among the movement symptoms of Parkinson's, balance and gait difficulties are among the most common, with as many as two-thirds of people with PD suffering a fall each year. But they are also among the most difficult to treat.

Donepezil works by boosting the level of acetylcholine, a neurotransmitter that is depleted in the Parkinson's brain. Because earlier studies have linked low brain levels of acetylcholine to falls, the author of the new study, Kathryn A. Chung, M.D., of the Oregon Health & Science University, reasoned that donepezil might improve balance and reduce falls in people with PD. The problem is that the drug has also been shown to increase PD tremors.

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In the new study, Dr. Chung examined 23 people with PD who reported falling or nearly falling more than twice a week. Participants took donepezil for six weeks and a placebo for six weeks, with a three-week break in between. The average participant age was 68; 15 were male; and six had undergone deep brain stimulation.

Results

- Study participants who were taking donepezil were found to fall about one-half as often as those taking a placebo.
- Participants who reported experiencing the most falls before the start of the study showed the greatest improvement after six weeks on donepezil.
- The number of near falls among people in both groups was the same.

What Does it Mean?

Falls are a serious complication of PD. People with PD may be at risk for falling for a variety of reasons including slower reflexes, postural instability, inattentiveness, light-headedness and dyskinesia. Carbidopa/levodopa (Sinemet®) can help in only some of these areas, and additional treatment is needed. Although these results are encouraging, follow-up studies will be needed to confirm them and to understand how donepezil may help to prevent falls.

**Hallucinations and Sleep Disorders Are Unrelated in Parkinson's Disease**

Among people with Parkinson's disease (PD), sleep problems such as vivid dreams are not associated with increased risk of developing hallucinations, according to a study in the October 20, 2010 online issue of *Neurology*. Although people with PD who experience hallucinations often do have sleep difficulties, the two issues may not be related and they progress differently.

Sleep difficulties are common among people with Parkinson's. The most common sleep difficulties include sleep fragmentation (that is, the tendency to wake up multiple times at night); acting out

>> *Read more on page 8*



PDF Funding Opportunities

The Parkinson's Disease Foundation (PDF) is pleased to announce that it is now accepting applications for its 2011–2012 investigator-initiated Parkinson's disease (PD) grants programs.

PDF's diverse research portfolio has a single underlying objective: to fund the most promising Parkinson's disease science. PDF operates these programs under the philosophy that it is only by fostering the creativity of scientists and empowering them to pursue novel ideas that we will better understand Parkinson's and find new treatments and a cure.

This year's request for investigator-initiated proposals seeks "high-risk/high-reward" ideas that may have a significant impact upon Parkinson's science. Basic scientists, neurologists, clinical researchers and students are invited to submit proposals. Brief program descriptions follow.

As PDF's Director of Research Programs, James Beck, Ph.D., states, "By leveraging its research investments into supporting great ideas generated by the 'crowd' of scientists, PDF aims to facilitate the next big discovery in PD."

International Research Grants Program

Level of support: \$75,000, plus 10 percent indirect expenses.

Length of support: Two years, subject to review of first-year progress.

Eligibility: Independent investigators possessing a Ph.D. or M.D. with clinical, preclinical, or basic research proposals that will directly impact Parkinson's disease or its treatment. Not open to postdocs or fellows. **DUE: Tuesday, February 1.**

Postdoctoral Fellowships for Basic Scientists

Level of support: \$42,500, plus \$5,000 research allowance.

Length of support: One year, competitively renewable up to three years total.

Eligibility: Postdoctoral fellows within five years of receiving their Ph.D., who have the support of a mentor. **DUE: Tuesday, February 1.**

Postdoctoral Fellowships for Clinical Neurologists

Level of support: \$55,000, plus \$5,000 in research allowance.

Length of support: One year, competitively renewable up to two years total.

Eligibility: Clinicians within three years of completing a residency in neurology, who have the support of a mentor. **DUE: Tuesday, February 1.**

PDF-PSG Mentored Clinical Research Award

(Funded by a grant from PDF to the Parkinson Study Group.)

Level of support: \$75,000 per year.

Length of support: One year.

Eligibility: Clinicians and scientists who are within five years of having completed formal training. Fellows may apply. Applicants must identify an appropriate mentor or mentors with extensive research experience. Either the applicant or the mentor must be a member of the PSG. An applicant may have co-mentors. **DUE: Friday, March 25.**

Summer Fellowship Program

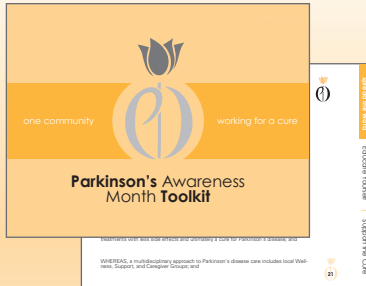
Level of support: \$3,000.

Length of support: 10 weeks of laboratory research.

Eligibility: Students — advanced undergraduates, graduate or medical students — in their pursuit of Parkinson's-related summer research projects. Fellows must work under the close supervision of a sponsor who is an expert in the Parkinson's community and can oversee the project. **DUE: Friday, January 21.**

Full details are available at www.pdf.org/en/grant_funding.

Get Ready for Parkinson's Awareness Month!



Every year, we recognize April as Parkinson's Awareness Month. Let's start planning now to ensure the world takes notice of Parkinson's in 2011.

How can you take part?

- **Spread the Word ...** let the public know about this disease that affects many millions of people worldwide.
- **Educate Yourself & Others ...** ensure that people with PD have access to the latest information about disease management and that the public better understands what it means to live with it.
- **Support the Cure ...** help to raise funds and participate in the search for new treatments and a cure.

PDF is offering a **free 30-page 2011 toolkit** with tips on ways to make a difference this coming April. Order it today and browse a sample of these tips below to get started early:

Spread the Word ...

Vote or participate in the PDF Awareness Month T-Shirt Design Contest. Design submissions are due by Tuesday, January 11. Voting closes Tuesday, March 1! The winning t-shirt will be available in April.
<http://support.pdf.org/tshirt>.

- Focus the media on PD! Use our press releases, statistics and tips to help you tell your story.
- Make Parkinson's Awareness Month official in your state or city, using a sample proclamation from the toolkit.
- Hang up posters from PDF around your community to publicize the need for a cure.
- Recruit supporters online. Update your Facebook status each day of Parkinson's Awareness Month and invite friends to join PDF's page.

Educate Yourself & Others ...

Shatter the myths of PD. Do you find that people around you do not truly understand Parkinson's disease? What do people need to know about how PD affects your life? Join in our video and photo campaign today at www.pdf.org/parkinson_awareness.

- Join PDF's *PD Expert Briefing*, "What's in the Parkinson's Pipeline?" by phone or online, in April.
- Bring the Parkinson's Quilt to your community, by renting an 8' by 8' panel to show the impact of PD.
- Distribute free educational materials from PDF at your local hospital, support group or awareness event.
- Find a support group in your community by calling PDF's HelpLine.
- Partner with your local library.
- Sign the Global Parkinson's Pledge! Can you help us reach one million signatures by 2013?

Support the Cure ...

Challenge those around you to raise funds for research by joining our "30 in 30" Parkinson's Awareness Month Challenge. Sign up to hold your own fundraising event in April, whether it's a bake sale, a walk or a 5K and we'll help you do it!
www.pdf.org/pdf_champion.

- Set up your own personal web page in honor of someone who lives with PD. You can include photos, personal stories and more. Visit www.pdf.org/en/pdf_champion.
- Attend an event, like the Parkinson's Unity Walk in New York in April, where the PDF Pacers will be walking. Find an event in your community or post one at www.pdf.org/event_calendar.
- Shop to Support. Buy mugs, hats and other items to show your support at www.pdf.org/en/shop_support_pdf.

Order a free Parkinson's Awareness Month Toolkit:
(800) 457-6676 | www.pdf.org/en/parkinson_awareness | info@pdf.org



* This PD Tulip was designed by Karen Painter, a person living with Parkinson's. PDF thanks Ms. Painter for sharing this tulip freely with the community to raise awareness of Parkinson's.

Clinical Research *Continued from page 1*

Our Panel



Investigator

Danna Jennings, M.D.
Clinical Research Director at
the Institute for Neurodegenerative
Disorders (Connecticut)

Investigators play a key role in identifying the questions that need to be addressed, designing the research protocols, monitoring the safety of participants and reporting on the results of a trial.



Government

Petra Kaufmann, M.D., M.Sc.
Director, Office of Clinical Research, National
Institute of Neurological Disorders and
Stroke (NINDS) (Maryland)

NINDS funds clinical research to test experimental therapies for Parkinson's, and gathers stakeholders to talk about issues that are important to the community and that can help increase the efficiency of clinical trials.

PDF What obstacles do you see in the development of Parkinson's therapies?

DJ The pace at which we are able to recruit people living with Parkinson's to trials. Problems with recruitment lead to delays in completing trials. These delays, in turn, not only increase costs, but also slow down the pace at which new medications can be developed. We realize that participating in research is not for everyone. We are always grateful to individuals with PD who are proactive about getting involved. As professionals, we also need to be more proactive about informing our patients and the PD community about existing opportunities to participate in research.

PK Participation in trials. Slow recruitment of people with Parkinson's slows down research. If we could speed recruitment, we could speed up the development of new therapies. Another obstacle is the lack of a good biomarker. A biomarker is, for example, a blood test or brain image finding that could help us decide early on in a trial if a new treatment has promise. Right now, if we want to assess the effects of a new treatment, then people with Parkinson's have to stay in trials for a long time. A biomarker could shorten that time.

PDF What improvements are you or others working on to tackle these obstacles?

DJ One of the best developments that has occurred in terms of education and recruitment is the development of accessible web-based sources, such as the website www.PDtrials.org, that provide comprehensive information about studies to people with PD. I also think that strengthening the relationship between the foundations that are behind the research, and the people with PD themselves, can be very helpful. Improvements in outreach and education to neurologists in the community are also important mechanisms for spreading the word about research opportunities.

PK We are working to increase trial efficiency by supporting the infrastructure of the process — for instance, through the grants we make to clinical research centers. (PDF does similar work in its support of the Parkinson Study Group.) We are also launching a biomarker initiative for Parkinson's disease. This will be an important step towards accelerating trials, so we hope that people with Parkinson's disease will participate.

PDF How are people with Parkinson's part of the process?

DJ We work regularly with a group of people living with Parkinson's. They help us by brainstorming ways to improve clinical trial recruitment and education efforts. We ask: what are the barriers to getting people to participate in our trials? This group may tell us that certain factors — for example, the lack of transportation to and from the study site or the need for a better understanding of what trial participation requires — play a role.

PK We make it a practice to engage people with PD in our work because they, after all, are the key stakeholders. For example, we invite people with PD to speak with us about their experiences in trials. I was a faculty member for PDF's Clinical Research Learning Institute, which is another way for NINDS to find out how people with PD view the research process. We encourage the inclusion of people with PD in trial planning, and on data safety monitoring boards. With PDF's training, people with PD can now be more equal partners in the process and can educate others.

Play a Part in Research *Join our research advocates in making a difference in the development of Parkinson's therapies.*

• **Get the Facts:** What should you know? Test your research IQ, find the facts and order our publications, so you know your rights before getting involved.

• **Find a Trial:** Ready to participate? Search for a trial by city, symptom or keyword by visiting www.PDtrials.org.



Person with PD

Paul Zimmet, D.D.S.
PDF Research Advocate (Class of '09)
Retired dentist (Virginia)

People with PD play an important role as participants in research studies and can serve as advocates to improve the development of therapies for PD.

PZ First, lack of awareness among people with Parkinson's about the variety of clinical trials and second, the pace of the drug approval process. Some people see trials asking for participants who are not on any medications yet, and think they do not qualify for any trials. But there are many other ways to participate, such as studies on the therapeutic value of exercise. In terms of drug approval, the time it takes to get it — seven to 10 years — is too long. We need to push medications through the pipeline more quickly.

PZ Part of our work as research advocates is to improve awareness and participation in trials through community education. We can do this by going out into the community and saying, "please consider getting involved!" I work with people living with PD, support groups, neurologists, and others in my community to accomplish this, and I have found that the personal touch makes a world of difference. Research advocates are also trained to provide input on studies, so I was able recently to attend a meeting at the National Institutes of Health (NIH) that addressed questions of Parkinson's trial design.

PZ PDF research advocates are finding places on formal advisory boards to ensure the input of people with PD in trial design. I was able to join an Institutional Review Board at Georgetown University, where along with researchers and doctors, I review 15–20 clinical trials a month. My job is to provide the patient point of view, and I do believe that my presence helps. We are trying to increase the representation of research advocates across the US — the more people that we have as advocates, the better chance we have to assure that the goals and results of trials are made transparent to people with PD.

- *Become an advocate: Use our tips to become part of the movement ... educating your community and ensuring the voices of the Parkinson's community are heard.*



Industry

Kimberly A. Moran, Ph.D.
Associate Medical Director — CNS
UCB, Inc. (Georgia)

Our goal is to develop safe and effective medications that directly address unmet needs in Parkinson's, for example, the non-motor symptoms of PD, such as anxiety, depression and gastrointestinal symptoms.

KM Inefficiencies in the drug development process. As a scientist, I have been privy to some great discoveries that will help us understand and treat PD. But only one in 10 molecules actually becomes a new drug. Problems arise when translating discoveries made in the lab to clinical trials that may benefit people living with PD. For example, scientists have discovered targets in the brain that play a role in PD, but we haven't narrowed down the right therapy to attack that target. Also, difficulties are observed when designing the correct trial design for a specific PD population (i.e., early or advanced PD).

KM Collaborative opportunities are the way to improve the process. My company is looking for collaborative relationships — with companies, academic centers, health care providers and patient organizations — to take efficiency to a new level and bring medications to people sooner. For example, we try to guide scientists who have developed new molecules to translate them into medications. We partner with nonprofits to increase awareness. Trials can move no faster than the pace at which they are able to enroll participants, so getting word of appropriate trials to the appropriate people with PD is key to their success.

KM There are many ways people with Parkinson's can play a role in studies. Right now, we have a person with Parkinson's at most of our meetings, which provides us with the context that reminds our staff why we are here. My grandfather had Parkinson's. I like to think that my work every day is potentially benefitting people living with PD and that we are working as fast as we can to provide better medications and to educate doctors so they know the best way to treat Parkinson's.

Learn more at [www.pdf.org/clinical trial inv](http://www.pdf.org/clinical_trial_inv)

Legal Issues and Parkinson's: Delegating Decisions for Financial Management

By Janna Dutton, J.D.

Making well-informed choices for medical care is usually foremost in the minds of people who live with Parkinson's disease (PD) and their care partners. However, a condition of making good care choices is making good financial planning choices.



Janna Dutton, J.D.

At some point all of us — whether or not we live with Parkinson's — may find ourselves unable to make necessary financial decisions. For a person with PD, there is the possibility that symptoms or cognitive changes may interfere with the ability to manage finances. I recommend that each of us make arrangements so that another designated person or institution will be able to manage our finances in the event that this occurs.

In the Summer and Fall 2010 issues of *PDF News & Review*, we reported on the importance of long-term care and delegating decisions for health care. This third article in our four-part series on legal issues that are encountered in Parkinson's addresses how appointing a power of attorney and/or establishing a living trust, can help to ensure that your wishes for the management of your finances and property are carried out.

What is Power of Attorney?

A durable power of attorney for property is a document that allows another person to make financial decisions and transactions on your behalf. When you sign a durable power of attorney document for property or finances — the terms vary according to what state you live in — you give authority to another person, your agent, to make financial decisions and trans-

actions for you. You keep your right to make your own decisions, but share this authority with another person — either when you ask them to or when a physician certifies that you are not fully capable of managing your own assets. The word “durable” means that, if you become incapacitated, the power of attorney remains effective.

Remember, you are the one who decides what powers to give your agent. These powers can be limited or broad, and might include the authority to buy property or to make investments.

It is very important that the document setting forth your power of at-

“A condition of making good care choices is making good financial planning choices.”

torney for property be drafted with your overall care and financial plan in mind. For instance, if you are planning to apply for Medicaid in the future, you may want to make gifts or other plans that will enable you to shelter some of your assets from seizure under the Medicaid rules. Usually a financial agent has no authority to do this unless provisions are specifically added to the power of attorney document. Another power you might give your agent is authority to transfer your principal residence to your spouse in the event that you move to a skilled nursing facility.

In most cases, a power of attorney document is effective as of the day it is signed. That means — if you wish it —

your agent can immediately take over tasks like paying bills or any other powers that you grant in the document.

Choosing an Agent: Who and Why

You can appoint any trusted adult — a spouse, partner, friend, family member — as “attorney-in-fact,” the legal name for the agent. Alternatively, you may wish to name a nonprofit agency, corporation or other entity to serve in this role. Just as it is when you are choosing an agent for your health care, so it is with property: it is important to choose someone who is willing, capable and attuned to your wishes. When the agent chooses to act for you under the document, the law specifies that it must be with due care for you, and for your benefit. The agent has a duty to keep good records of what he or she has done with your finances and to preserve your estate plan. The agent should not be acting to benefit him or herself to your detriment. A fact sheet with more details is available from the Family Caregiver Alliance at www.caregiver.org.

What are the advantages of creating durable power of attorney — over, say, simply opening a joint bank account with someone who helps to manage your finances? With a durable power of attorney, your agent does not have access to your assets and credit for his or her own use. It also ensures that your assets are eventually distributed according to your will.

However, a word of caution is in order: there are unfortunately, cases in which power of attorney documents have been used for financial exploitation. In fact, some states have recently amended their statutes to try to curb the misuse of powers of attorney. You need to be quite careful when choosing your agent. Care partners or family members who observe a loved one's agent engaging in any misuses of authority can take action to protect the person with PD. One option is to have a legal guardian appointed.

How to Designate Power of Attorney

To designate someone to exercise power of attorney on your behalf, contact an attorney who is aware of your overall financial and care plan to draft the document for you. Pre-printed forms may not be specific enough to describe the arrangements you wish to make. In addition, many banks and financial institutions have their own forms. You, your agent and your attorney should meet to ensure that everyone understands the document.

A person must be mentally competent at the time that he or she signs a power of attorney for property or finances. A person is presumed to be competent unless a court finds otherwise. If there is a question about this, the person with Parkinson's and/or his or her family should seek the opinion of a physician and investigate the possibility of neuropsychological testing, which tests cognitive functioning. Most physicians will order this testing before they will make a determination about decision-making ability.

Living Trusts

The living trust is another good tool for arranging your finances so that another person or institution can manage your assets if you are no longer fully able to do so. It is an agreement that you make — with either yourself or another person or institution as trustee — to hold assets that you transfer to the trust for your benefit.

The powers and responsibilities of a trustee are similar to those of an agent who is acting under power of attorney for property. Again, the powers and responsibilities are limited and controlled by the terms of the trust document. This can be an alternative to a power of attorney or — if you have property rights not held within the trust — the two can be used together.

How does it work? Here is an example: Eliza sets up her living trust document and signs it, and then appoints herself as trustee. She establishes the trust by transferring ownership of her assets to the trust. So instead of owning the assets outright, Eliza deeds her real estate and transfers her brokerage account, so that the

statement and title read: “Eliza, trustee of the Eliza living trust.” In her trust, Eliza can appoint whomever she wants to act as her trustee in the event that she becomes incapable.

Most banks have minimums for setting up a trust. Although the minimum does not apply when a family member is acting as trustee, there will be other expenses, and it is advisable to conduct a cost/benefit analysis to determine if a living trust is worth the expense to create and maintain.

Summary

Remember that your *financial* agents have no authority in *medical* affairs, so you still need to have a separate Power of Attorney for Health Care and a care plan in place. Designating authority to trusted persons to manage your finances if you become unable to do so is an important step in planning for life with Parkinson's.

Ms. Dutton is an Eldercare Attorney with Janna Dutton & Associates. She recently presented this topic at one of PDF's PD ExpertBriefings. Her next installment will discuss Medicaid.

Coming Up:

New PD ExpertBriefings Series Announced!

Join PDF for these upcoming free interactive educational programs designed for people living with Parkinson's, family members and health care professionals.

Physical Therapy & PD: What You Need to Know

Tuesday, January 25
1:00 PM – 2:00 PM ET

Faculty: Heather J. Cianci, P.T., M.S., G.C.S.
Dan Aaron Parkinson's Rehab/GSP

Cognition & PD

Tuesday, March 22
1:00 PM – 2:00 PM ET

Faculty: Alexander I. Tröster, Ph.D.
University of North Carolina
at Chapel Hill

How Can You Participate?



BY TELEPHONE: At registration, phone participants will receive a unique number and pass code to use on the day of the seminar.

BY COMPUTER: At registration, online participants will receive tips for testing their computers.

Did you miss a
PD ExpertBriefing?

Several recorded seminars — covering topics such as nutrition, the care partnership, the PD pipeline and more — are available for you to watch any time of day on our website.

Not online?



Then contact us to order a free set of DVDs.

Pre-registration recommended: (800) 457-6676 | www.pdf.org/parkinsononline | info@pdf.org

News In Brief*Continued from page 2*

dreams (REM sleep behavior disorder); and vivid dreams. Traditionally, vivid dreams were considered an early manifestation of hallucinations — a common problem in mid- or late-stage PD, which can actually be exacerbated by some PD medications — and were treated similarly.

To understand hallucinations and sleep disorders, researchers at Rush University Medical Center, led by Christopher G. Goetz, M.D., followed 89 people with PD for 10 years. At the time of enrollment, 60 participants had never hallucinated but reported a range of sleep disturbances, and 29 had experienced hallucinations.

The average age of the participants was 68, and the average time since PD diagnosis was about 10 years. All were taking levodopa, and about half also took other PD medications, including those for sleep. The researchers used standard assessments to rate the quality of participants' sleep and the presence and frequency of hallucinations at six months, 18 months, four years, six years and 10 years.

Results

- During the 10-year study, the percentage of participants who experienced hallucinations nearly doubled, and among those who experienced them, the hallucinations were more frequent and more severe.
- Acting out dreams was the only sleep disturbance that was found to progress over time, reported by just 12 percent of participants at the beginning of the study and by 33 percent by the end. Other common disturbances — such as frequent waking during the night, vivid dreams and daytime sleepiness — did not worsen over the course of the study.
- People who reported sleep disturbances at the start of the study did not have an increased risk of hallucinations.
- No association was found between dosages of levodopa and hallucinations.

What Does it Mean?

This study disproves the common notion that vivid dreams are a simply mild form of hallucinations. The authors also point out that no hallucinations should be considered “benign,” as this symptom most often becomes chronic and progresses over time. In addition, the finding that four study participants never developed hallucinations suggests that there may be factors that protect against hallucinations. Further study is needed.

**Experts Reach Consensus on Deep Brain Stimulation for Parkinson's**

A consensus on the use of deep brain stimulation (DBS) for Parkinson's disease (PD) made by 50 international experts was published in the October 2010 issue of *Archives of Neurology*. In 1997, DBS was approved by the US Food and Drug Administration for Parkinson's. Since then, this procedure has become a standard treatment for some people with PD who experience disabling tremors, wearing-off fluctuations and dyskinesias.

Yet DBS is a complicated procedure, and many questions remain. This panel met in New York in 2009 to address them.

Results

Some of the panel's most important recommendations included:

- People with PD who are most likely to benefit from DBS are those whose motor symptoms are not well-controlled by medication or who cannot tolerate side effects of medication.
- Those most likely to benefit are people who do not do not have significant active cognitive or psychiatric problems.
- DBS surgery is best performed by an experienced team and neurosurgeon who have expertise in surgery deep within the brain that uses three-dimensional imaging to guide the procedure.
- Complication rates vary widely, with infec-

tion being the most commonly reported.

- The benefits of DBS for improving motor symptoms such as dyskinesia and tremor seem to be long-lasting.
- DBS, when used in the two most commonly treated areas of the brain — the subthalamic nuclei or the globus pallidus pars interna — is effective in addressing the motor symptoms of PD.
- Treatment in the subthalamic nuclei may cause increased depression in some people with Parkinson's disease.
- Surgical electrical removal of a part of the brain affected by PD is an effective alternative to DBS that should be considered in appropriate candidates.

What Does it Mean?

The new report can help people with PD and their doctors make informed decisions when considering DBS. It confirms that people with certain PD symptoms such as tremor and dyskinesia can benefit from DBS. As with any surgery, there are risks, and it can take three to six months of adjustment to tune the implanted apparatus so that it works effectively.

In addition, Parkinson's disease continues to progress after DBS and the surgery does not address all facets of the disease. Over time, people may still develop problems, such as gait impairment, balance difficulties, and nonmotor symptoms, such as cognitive impairment, that the surgery does not benefit.

PDF recommends that people with PD and their families considering DBS seek out a center that has long-standing experience with DBS and resources dedicated to the surgical treatment of PD.

Learn More

The choice of whether to have surgery depends on many factors. To learn more, order the PDF booklet, *Deep Brain Stimulation for Parkinson's Disease* by calling (800) 457-6676, emailing info@pdf.org or visiting www.pdf.org.

PD Medication Update:

The medication entacapone/carbidopa/levodopa, (Stalevo®) is under review by the US Food and Drug Administration (FDA) for possible increased risk of prostate cancer and increased risk of certain cardiac events in some individuals. No new conclusions or recommendations about the use of this drug have been made. People living with Parkinson's should not stop taking their medication unless directed to do so by their doctor. For updated information, visit www.pdf.org/en/meds_treatments.

Daughter Takes Inspirational Online Journey

When Linda Giorgilli first signed up for Facebook, one of the world's largest social networking sites, she thought it would be a nice way to connect with friends.



Linda Giorgilli

Yet, in the past two years, it has become a lot more than that: a place where she has been able to share a very special part of her life — namely, her experience caring for her late father who lived with Parkinson's disease (PD). As she says, she is, "in awe" of what has transpired.

Ms. Giorgilli's father was diagnosed with Parkinson's disease in 2001 at the age of 74. In 2008, his health began to deteriorate; and he and her mother decided to move from their native Baltimore down to Florida to be near their children. At this point Ms. Giorgilli made the decision to move in with them to care for her Dad. He had quite a life story: witnessing two atomic bomb testings, traveling on one of Admiral Richard Byrd's expeditions to the South Pole and with his wife, living, "a wonderful love story."

When she realized her Dad needed full-time assistance, Ms. Giorgilli left her job as a legal assistant to care for him. From then on, she spent every day with her Dad. She put herself to work learning about Parkinson's disease, going to seminars and reading constantly. She accompanied him to doctor visits, and helped him to shower and shave. She's quick to note the relationship was recip-

rocal. "In my lifetime, I will never receive a larger gift than knowing that we were able to rely on one another as we did."

When Mr. Giorgilli passed away in May 2009, Ms. Giorgilli found solace in part by writing about her time with her Dad. As a member of Facebook, she shared her writing with friends. She also joined PDF's Facebook page (www.pdf.org/facebook), which currently has more than 5,600 members.

As she watched people "writing" on the PDF page, seeking advice and sharing their stories, Ms. Giorgilli began responding to their inquiries about life with Parkinson's herself. She says "I'm not an expert, but I felt I had so much to share because of my time with my Dad. It was healing." But she says these individuals responded positively, and were touched by her stories. Soon, she found herself corresponding with various people each day, writing on PDF's "wall" (an open forum for discussion and questions). Within months she had over 40 new friends and had caught our attention as an inspiration!

Today, besides planning to continue her work in raising awareness for Parkinson's disease, she is also writing a book about her experience caring for her Dad. She says she will never give up on the Parkinson's cause. And the biggest surprise to her is what a difference a social networking site made.

As Ms. Giorgilli says, "The value of what unfolded with social networking — the power and strength that it gave me to cope with the loss of my father and fight for this cause — is immeasurable."



PD Online Forums

Linda was able to find friendship and support by using online forums. Here are a few online communities with active Parkinson's groups:

PDF Facebook: www.pdf.org/facebook

Neurotalk: <http://neurotalk.psychcentral.com/forum34.html>

Parkinson Information Exchange Network Online:
www.parkinsons-information-exchange-network-online.com

Bring the Parkinson's Quilt to Your Community!

Looking to raise awareness of PD? Holding an educational event with your support group? Display the Parkinson's Quilt to show the impact of PD.

8' x 8' quilt panels are now available for you to display, at a modest fee to cover expenses.

www.pdf.org/quilt



Remembering Glasgow: Report on the 2nd World Parkinson Congress

By Jean Burns

The 2nd World Parkinson Congress (WPC), which took place in Glasgow, Scotland in late September 2010, is now over. I worked and waited and dreamed about attending this event for a long time. Now in a blur, it has passed. Our Scottish hosts were terrific. They were universally kind and helpful. For me, the WPC was all about the people, including:

- **Pamela Quinn** and others around the world who created videos about Parkinson's disease;
- **The 600 plus people** represented by the Parkinson's Quilt. The quilts have become living statements from participants from around the world. What an amazing achievement and tribute by all involved!
- **People with Parkinson's**, who were all around the conference: attending scientific talks, listening to poster presentations, sharing personal stories, studying the quilt pieces, viewing the videos, meeting for dinner and forming friendships and alliances. And personally, the people from around the world who came up to tell me how much pdplan4life.com means to them. How incredible is that?

- **Tom Isaacs**, a person with PD and founder of the Cure Parkinson's Trust, was seemingly everywhere, giving brilliant presentations peppered with humor. One of his recurring themes was patient advocacy: "Include us (patients) as partners; we have valuable experiences and information to contribute!"

- **Bryn Williams**, also living with PD, the founder of Wobly Williams. He spoke at the welcoming ceremony and his moving words touched us all. Quoting Bryn:

"Now is the time to bring our urgency to bear and deliver a future of hope for the victims of this disease. Now is the time for a steady hand, a strong voice, and a keen sense of smell for the opportunities that await us. A steady hand. A strong voice. A keen sense of smell. I had them once. I want them back."

So do I, Bryn, so do I.

Jean Burns, pictured below, is a person living with PD who hails from Arizona. She is co-founder of pdplan4life.com, and served on the Communications Committee for the 2nd WPC and on the Advisory Committee for PDF's Parkinson's Quilt.

Highlights from the WPC



Jean Burns

The WPC included 40 sessions on science and quality of life, including topics such as genetics, new treatments, nonmotor symptoms and more.



WPC science updates from Dr. Beck: "mutations in the GBA gene may actually contribute to an increase in the levels of alpha-synuclein in nerve cells."

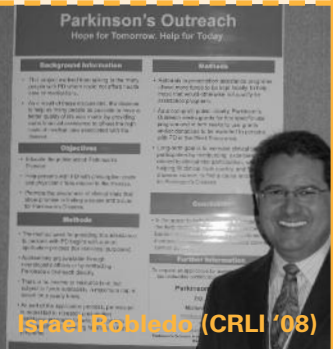
Read more: www.pdf.org/blog

"All of us ... working to fight the devastating effects of this disease ... learning, exchanging views, questioning and pushing the agenda forward."

~Diane Cook (CRLI '09)



15 PDF research advocates attended the WPC, eight presented posters, six reported on the blog, and one (Pam Quinn), won the video competition. Watch: www.pdf.org/youtube (click Favorites)



Israel Robledo (CRLI '08)

The WPC brings together people living with Parkinson's, care partners, researchers, clinicians and health care professionals to create a worldwide dialogue that will help expedite the discovery of a cure and best treatment practices for Parkinson's disease.

Save the Dates: 3rd World Parkinson Congress ~ Montreal, Canada ~ October 1 – 4, 2013

The Parkinson's Quilt was first displayed at the WPC. View the panels above and 600 others by visiting www.pdf.org/quilt.

Pete Philomey
PpP Photography

Raising the Stakes, Raising Funds

On November 10, 2010, more than 200 guests “Raised the Stakes” for Parkinson’s at Capitale in New York City. Guests enjoyed games of chance, such as blackjack, and competed to win exciting prizes. After a gourmet buffet dinner, premium open bar and time on the dance floor, the lucky winners were announced — taking home prizes that ranged from airline tickets to a front row spot at the Macy’s Thanksgiving Day Parade! PDF thanks event co-chairs Jose Cruz, Amy Sole, Peter Dorn, Jeffrey Zyglar and Dan Spanton and the host committee for their hard work in making this event a success. View photos of this event at www.pdf.org/flickr.

pdfchampions[®] in action

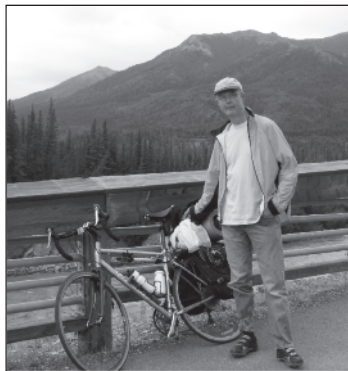
Left to right: Lauren Rand, Elyssa Sabloff, Erin Steinberg, Randi Neihaus, Paul Massie, Alana Salzberg, Genna Farber; Chair Jose Cruz and friends; guests enjoy a game of roulette.

Doug’s “Wild Ride” Covers 400 Miles for Parkinson’s

This past summer, Doug Bahniuk of Cleveland, Ohio, completed “Doug’s Wild Ride,” a solo six-day, 400 mile bicycle ride across Alaska. In the process, he also raised \$33,000 for Parkinson’s disease (PD) research!

Mr. Bahniuk, 57, has lived with PD for 10 years and has been cycling since the age of three. He has become committed to working for the Parkinson’s cause, in part by becoming a PDF research advocate (he graduated from the Clinical Research Learning Institute in 2008). He has also organized several events to raise awareness for PD that involve his passions for cycling and exercise.

He chose the remote Alaskan course for his latest ride,



Doug Bahniuk

both because of its beauty and the challenge it presented.

On July 8, 2010 he began his Alaskan ride in Anchorage. He reached Fairbanks nearly a week later, having traveled the entire route alone. As he put it, “I wanted to both let people know what it’s like to live with the challenges of Parkinson’s and to bring attention to the fact that we can help to combat the disease through exercise and a positive attitude.”

The proceeds from “Doug’s Wild Ride” were shared between PDF and the Davis Phinney Foundation. Thank you Doug!

To learn more about the PDF Champions program and how you can get involved, visit www.pdf.org/en/pdf_champion.

Do you want to help guide our work in the Parkinson’s community?

If so, then apply for a spot on PDF’s People with Parkinson’s Advisory Council (PPAC). PPAC is an advisory board which provides the perspective of people with Parkinson’s and care partners to PDF’s program development and priority setting. People living with or affected by Parkinson’s disease are eligible to apply. The deadline is Monday, January 24, 2011.

Members of PPAC:

- Serve for one three-year term.
- Provide input on research, educational and advocacy programs.
- Identify unmet needs and look for ways to better serve the community.
- Serve as PDF ambassadors, liaising between PDF and the Parkinson’s community.

Apply and learn more:

(800) 457-6676 | info@pdf.org | www.pdf.org

Calendar of Events



Parkinson's
Disease
Foundation

**PD Expert Briefing:
Physical Therapy and PD**
Date: Tuesday, January 25
Place: Online or by phone

Join PDF for this upcoming free interactive educational seminar.

Pre-register by calling (800) 457-6676, emailing info@pdf.org or visiting www.pdf.org.



**17th Annual Research
& Public Policy Forum**
Date: Monday, February 28 –
Wednesday, March 2
Place: Washington, DC, also accessible online

Learn about the current legislative issues impacting the Parkinson's community and ways to advocate for better treatments and a cure. This year, participants can watch via live webcast.

For more information, call (800) 850-4726, email info@parkinsonsaction.org or visit www.thepanforum.org.



**17th Annual Parkinson's
Unity Walk**
Date: Saturday, April 16
Place: Central Park, New York, NY

Join the community for a two-mile walk which increases awareness and raises funds for PD research.

For more information, call (866) PUW-WALK/(866) 789-9255 or visit www.unitywalk.org.

Celebrate Spring

Date: April
Place: New York, NY

Enjoy a night of cocktails and dancing, while supporting PDF's research programs with the Young New Yorkers for the Fight Against Parkinson's committee.

For more information, contact Patrick Johnson at (800) 457-6676 or info@pdf.org.

Parkinson's Educational Seminar

Date: Tuesday, May 10
Place: New York, NY

Join PDF for a three-hour seminar on the latest in Parkinson's science. Lunch is included and registration is required.

For more information, contact Elizabeth Lee at (212) 923-4700 or info@pdf.org.

Bal du Printemps

Date: Tuesday, May 10
Place: New York, NY

Led by PDF Chairman, Page Morton Black, PDF's annual gala, *Bal du Printemps*, is an elegant evening to both celebrate some of the community and philanthropic leaders who work to advance the state of Parkinson's and to raise funds for PDF. For more information, contact Patrick Johnson at (212) 923-4700 or info@pdf.org.



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WINTER 2011

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www.pdf.org/survey10

The Parkinson's Disease Foundation® (PDF®) is a leading national presence in Parkinson's disease research, education and public advocacy.

We are working for the nearly one million people in the US who live with Parkinson's by funding promising scientific research and supporting people with Parkinson's, their families and caregivers through educational programs and support services. Since its founding in 1957, PDF has funded over \$85 million worth of scientific research in Parkinson's disease, supporting the work of leading scientists throughout the world.

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice. This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.

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