

The Ups and Downs of Dopamine: Impulse Control and Parkinson's

An Interview with Dr. Daniel Weintraub

For people with Parkinson's disease (PD), managing the disease often comes down to a daily balance of dopamine — the neurotransmitter that is lost in PD. The challenge is to work with dopamine replacement therapies to find a balance between high and low levels.

Dopamine medications have improved life for millions of people worldwide. But now there is evidence that the vital neurotransmitter that eases PD symptoms can also work against them. Over the past 10 years, there has been increasing discussion in the PD community about impulse control disorders (ICDs), a phrase that is used to describe unhealthy levels of gambling, shopping, eating and sexual activity. Researchers think that some people with Parkinson's who exhibit these

behaviors may be experiencing a side effect of some of the dopamine replacement therapies used to treat Parkinson's disease.

Are you concerned that you or a loved one may be affected? How can you identify these behaviors and talk to your doctor about them?



To answer these and other questions about ICDs, *PDF News & Review* sat down with Daniel Weintraub, M.D., a Parkinson's clinician and researcher from the University of Pennsylvania.

Along with several of his colleagues, he compiled the largest study of ICDs ever conducted and the results appear in the May issue of *Archives of Neurology*.

Read his insights on page 6 and call PDF's HelpLine at (800) 457-6676 with your questions.

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NEWS IN BRIEF

Sleep Disorder Can Precede Parkinson's Diagnosis by Decades

A recent study makes the observation that REM sleep behavior disorder can be the first sign of Parkinson's disease (PD) for some people, and can actually precede the onset of the classic motor symptoms — such as tremor, stiffness or slowness of movement — by more than a decade. The research appears in the July 28, 2010 online edition of the journal *Neurology*.

REM is the abbreviation for the "Rapid Eye Movement" phase of sleep when dreaming occurs. REM sleep behavior disorder, or RBD, is a sleep disturbance in which violent dreams or nightmares are acted out by the sleeper. The dreamer may scream or yell in his or her sleep, or engage in violent movements as if enacting a fight or attempting to run from an assailant. In most cases, the sleeper has no recollection later of the nocturnal violence; but for the bed partner, the experience can be frightening. RBD has been linked to Parkinson's disease and other Parkinson syndromes, especially diffuse Lewy body disease.

Researcher Bradley F. Boeve, M.D., at the Mayo Clinic in Rochester, MN,

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Quilted Journeys

The Experience of a Participant in the Parkinson's Quilt Project

See page 9 for full story

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Help to Ensure the Best Nursing Care for People with PD

Tell a Nurse about a New Free PD Online Course

- ▶ **Nurses:** View the free online course, *Parkinson's Disease Across the Lifespan: A Roadmap for Nurses* and earn continuing education credits.
- ▶ **People living with or affected by Parkinson's:** Bring this article to your doctor's office or local hospital and ask them to participate.
- ▶ **Nursing Educators:** Show the online course to your students and ask them to complete the online tests at home.

<http://support.pdf.org/nursing>



Nurses are often a first point of contact for people living with Parkinson's disease (PD). Not only do nurses provide medical care, but they also play a key role in ensuring that people with Parkinson's have the best possible quality of life. Yet many nurses do not have access to current treatment and care strategies to assist people and their families through the complex health system.

A new online course — *Parkinson's Disease Across the Lifespan: A Roadmap for Nurses* — ensures that nurses have the opportunity to learn the latest in Parkinson's comprehensive care. Designed by Parkinson's nurse specialists, the course was taped in front of a live audience on May 21 at the New York Academy of the Sciences in New York City and webcast to hundreds more nurses throughout the US.

Now available online, the course includes modules discussing the challenges of Parkinson's throughout the lifespan, and the vital role that nurses can play in managing

care. Modules are led by Parkinson's nurse specialists, physical therapists and people with PD.

Nurses can earn continuing education credits by watching four modules, each of which is approximately one and a half hours in length, and by taking brief exams following each one.

Nurses can complete the course at one sitting, or can finish each module separately. The course will be available online, 24 hours a day, seven days a week, until June 1, 2011.

Lisette Bunting-Perry, Ph.D., R.N., a member of the course faculty, said it all:

“The exceptional collaboration among PDF and other Parkinson's organizations has made this a milestone for movement disorder nursing. This course addresses a critical gap in improving the quality of life for people living with Parkinson's. Nurses now have access to information to provide evidence-based practice across a continuum of care.”

This online course is a collaborative effort by PDF, the National Parkinson Foundation (NPF) and the American Parkinson Disease Association (APDA).

This program has been made possible by grants from Kenneth M. and Susan Granat Weil, Teva Neuroscience, Edmond J. Safra Foundation, Medtronic and Ipsen.

News In Brief

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was prompted to study the long-term course of REM behavior disorder after learning of people living with Parkinson's who mentioned experiencing their RBD symptoms for decades. In a retrospective study using the clinic's extensive medical records, the investigators sought to find persons with Parkinson's who reported vivid dreams many years before they developed the disease.

Results

In reviewing 550 medical records of people with REM behavior disorder and Parkinson's and related disorders:

- 27 individuals, or nearly five percent, had vivid dream enactment that preceded any diagnosis of Parkinson's by 15 years or more.
- Most of these individuals were men.
- Most developed a form of dementia related to Parkinson's.

What Does it Mean?

These results indicate that the processes that lead to PD may begin decades before motor or cognitive symptoms develop, much longer than previously believed. Knowing this may help doctors in the future to identify people in the early stages of Parkinson's and to develop therapies that could slow down or stop the progression of the disease before symptoms appear. The study does not mean that all persons with RBD will develop Parkinson's because the study population was pre-selected on the basis of already having PD. If REM behavior disorder is the first sign of Parkinson's in some individuals, the implication is that the biological changes of the disease begin earlier than expected.

Vitamin D May Protect Against Parkinson's Disease

A new study links relatively high blood levels of vitamin D with a reduced risk of developing Parkinson's disease (PD). The research was published in the July 2010 issue of *Archives of Neurology*.

Vitamin D helps the body to absorb calcium and to keep bones strong. Sources of vitamin D include sunlight and

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SPOTLIGHT

on Research

Supported by PDF

Exercise in Parkinson's

Around the country, communities are organizing dance classes for people with Parkinson's disease (PD). They are talking about the cyclists whose PD symptoms dissipate when riding their bikes and noticing that researchers are studying activities like tai chi and pole-walking. Whether you yourself have taken part in an exercise class or you have read these stories with interest, you may be wondering how exercise could benefit your life with PD.

The Parkinson's Disease Foundation (PDF) has also long been curious about this issue. To explore it, PDF convened a series of *Exercise in PD* workshops. The workshops are among several a year during which PDF brings together multi-disciplinary teams — researchers, doctors, people with PD and health professionals — to discuss research and to encourage collaboration amongst the community.

But wait, surely we all know exercise is beneficial for our health. So

why do we need to research the subject? The answer to that is we don't understand how exercise works. If scientists could understand if a certain type of exercise is most beneficial for Parkinson's and why, your doctor could then prescribe the best form to ease your symptoms. More intriguingly, some scientists and physicians suspect exercise may not simply relieve PD symptoms but may also delay its progression. If that's the case, we need to know not just why ... but how.

PDF-Funded Research: Exercise

PD4PD: Partnered Dance for Parkinson's Disease

Gammon Earhart, P.T., Ph.D.
Washington University School of Medicine

Unveiling Natural History of Quality of Life and Mobility Decline in PD*

Matthew Ford, P.T., M.A., Ph.D.
University of Alabama at Birmingham

**In partnership with the Davis Phinney Foundation for Parkinson's*

Participants in the *Exercise in PD* series have made strides toward answering these questions. They recently submitted a grant to the National Institutes of Health (NIH) requesting support for a large clinical trial. They note that this trial, designed during a 2009 meeting, will do something no other has before — study the impact of exercise on a group of people who are newly diagnosed with Parkinson's and

who are not already taking medication. How can we know if exercise will impact the progression of PD without removing the effects of medication?

The researchers will work with 200 people living with PD for up to 18 months to track how exercise impacts need for medication, quality of life, gait, mood and cardiovascular fitness. They will track changes in the brain of approximately 40 of these participants.

While this trial is an exciting development, the group also has other plans to form an ongoing association dedicated to exercise and Parkinson's research. Supported in part by PDF, it will provide a forum for professional collaboration and support of promising scientific studies.

One of its leaders, Roger Kurlan, M.D., of Overlook Hospital at the Atlantic Neuroscience Institute in New Jersey said, "PDF's workshops have introduced us to like-minded individuals across the country committed to understanding the effect of exercise on Parkinson's. We are much more likely to make progress because we are working together and sharing all of our results. Our group will ensure that this work continues — in the hope that one day we can give people with Parkinson's a tangible way to take charge of their disease and live well with it."

Taking Charge of PD through Exercise

Matthew Ford



- **Participate** in a clinical trial studying exercise: www.PDtrials.org
- **Read** PDF's fact sheet, *The Importance of Physical Therapy and Exercise for People with PD*: www.pdf.org/en/factsheets | (800) 457-6676
- **Watch** *Taking Charge of PD* to learn about exercise, and other ways to live well with PD: www.pdf.org/en/edu_events_texas

- **Locate** a local exercise class or at-home program: www.pdf.org/en/resourcelist
- **Find** a physical therapist: Call the National Resource Center for Rehabilitation hotline of the American Parkinson Disease Association at (888) 606-1688 or ask your doctor or support group

PDF thanks Ms. Ethel Allen for her support of this program.

Legal Issues and Parkinson's: Delegating Decisions for Health Care

By Janna Dutton, J.D.

If you or a loved one is living with Parkinson's disease (PD), it is likely that you have made decisions about



Janna Dutton, J.D.

your treatment plan, along with your health care team, a group that may include a movement disorders specialist, a physical therapist, a speech therapist and others.

At some point, however, all of us — whether we live with Parkinson's or not — may find ourselves unable to make necessary health care decisions. If we go under general anesthesia for surgery, for example, or if we become unconscious due to an accident, others will have to make medical decisions for us. For people who have Parkinson's, there is the additional possibility that communication difficulties, increased physical disability and/or cognitive impairment may interfere with our ability to convey preferences for different treatment options.

An important way to plan for these possibilities is to appoint a trusted person to be your health care agent, also called a proxy. In the Summer 2010 issue of *News & Review*, we began a four-part series on legal issues and Parkinson's by discussing the importance of long-term care. In this second article, we address how appointing a health care agent is essential to ensuring that your health care wishes will be carried out.

What is an Agent for Health Care?

When you designate an agent for health care, you are appointing someone who will make decisions on your behalf when you cannot.

Once you have appointed an

agent, he or she may have legal decision-making powers immediately, but you will continue to have the right to make your own health care decisions until you need assistance. You can also put in place restrictions delaying your agent from making legally enforceable decisions for you until a doctor determines you are unable to do so. This option will take additional time and paperwork.

“It is important that the person you choose is someone with whom you can communicate honestly so that he or she understands and carries out your wishes.”

What Decisions Can an Agent Make?

The details vary according to state laws, but in general, your designated health care agent can be empowered to make any and all decisions concerning your personal care (e.g., home health care or assisted living decisions), your medical treatment and your hospitalization. The choice is yours as to whether the agent's power is to be limited or whether he or she has the flexibility to make all decisions for you.

Your agent may have authoriza-

tion to speak with your doctor during appointments. He or she can communicate your preferences regarding changes to the dosages of your medications or your treatment regimen in general. The agent can also voice any objections — religious or otherwise — to certain types of care.

Your agent can authorize adjustments to your care as your situation changes. Additionally, he or she often must make decisions about care at the end of life, such as whether to initiate such interventions as withdrawing intravenous fluids, pain medications, antibiotics and feeding through a tube. In most states, your agent will also have authority to access your medical records and to direct the disposition of your remains.

The most important thing to remember is that your agent is required to make all decisions with due care for you, for your benefit, according to the terms of health care power of attorney documents you have signed.

Choosing a Health Care Agent

Whom should you choose as your agent? It should be someone whom you trust and know well. Many people choose their spouse, another family member or a close friend. While you can choose more than one person, having only one person in charge ensures that there will be no disagreement down the line among the people concerned for your well-being.

In making your decision, remember that your agent may have to serve as an advocate. He or she should be prepared to negotiate with health care providers to make sure your wishes are honored. It is extremely important that the person you choose is someone with whom you can communicate honestly so that he or she understands and carries out your wishes.

Your agent can be anyone over the age of 18. If you choose a doctor as your agent, remember that he or she will no longer be able to serve as

your care provider, in order to avoid a conflict of interest.

At any time, you can cancel your health care proxy, change the person you have designated, or update any instructions on your legal documents.

How to Designate a Health Care Agent

You can designate a health care agent by filling out a legal document called a health care proxy or a medical power of attorney. To find the form in your state of residence, contact the bar association or area agency for the aging in your state, or download it from the Caring Connections website (www.caringinfo.org). States differ in their requirements for witness signatures and notarization of the document, but in general, it is not necessary to hire a lawyer to create a legally binding document.

Communicating Your Wishes

Talk to the person you have chosen as your health care agent, and to your family members and health care providers, about your preferences for care. This decision may be one of the most important you will ever make, and the people you love and respect can help you choose the right course of action for you.

To think through your preferences and open up these conversations, it may help to write a living will, a legal document that puts in writing how you wish to be cared for during a terminal illness. Whereas the document appointing a health care agent grants power to an agent to make decisions

in many situations, including those that have not been anticipated, a living will provides a way for you to express your instructions for care in specific medical situations. States vary in their requirements for living wills, so if you want it to be legally binding, be sure that it is written in accordance with the laws of your state.

One resource that I recommend to help people to express their thoughts is “Five Wishes” (www.agingwithdignity.org). It is geared toward end-of-life issues, but don’t let that put you off from taking a look. This document asks questions, in a systematic way, about the kind of medical treatment you want or do not want, as well as how comfortable you want to be and how you want people to treat you.

Guiding Your Own Care

Appointing a health care agent is a challenging process of thinking about your values and fears, and talking with your loved ones. But doing it early, when you have this luxury to talk with your family, helps you take control of your health care and your life, and will ease decisions for your family later on.

With a plan in place, you and your family can have confidence that your wishes will be carried out.

Ms. Dutton is an Eldercare Attorney with Janna Dutton & Associates. She recently presented this topic at one of PDF’s PD ExpertBriefings. Her next article will address financial management for people with PD.

Learn More:



PD ExpertBriefing:

Legal Issues: Planning Ahead When You are Living with Parkinson's

www.pdf.org/en/parkinson_briefing_legal_issues

This one-hour online seminar, led by Janna Dutton, J.D., provides tips on navigating the legal issues that face people living with Parkinson’s. Ms. Dutton covers issues such as care plans, advance directives and wills.

Creativity and Parkinson’s

Share Your Works

Join the more than 250 people with Parkinson’s who are sharing their creative works online as part of the Creativity and Parkinson’s Project.



Order Your 2011 Calendar

2,000 of you voted for the stunning cover image that graces this **free** 12-month calendar featuring the **artwork** of people with PD.



www.pdf.org/en/creativity

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The Ups and Downs of Dopamine *Continued from page 1***What are ICDs?****N&R What are impulse control disorders in Parkinson's disease (PD)?**

DW In Parkinson's, the term "impulse control disorders," or ICDs, is commonly used to refer to a group of behaviors — gambling, shopping, eating and sexual behaviors — that are compulsive or impulsive in nature. While pathological gambling has been the main focus in PD, our report and other scientists have now demonstrated that all four are relatively common.

N&R How common are ICDs among people with Parkinson's?

DW Our study demonstrated that, when measuring at one point in time, about 14 percent of people with PD experience one or more of the four behaviors mentioned above. We believe the true prevalence for these behaviors occurring *any-time* during PD may be higher — my personal guess is that it's between 15 and 20 percent. Additionally, we found that if a person experienced one ICD, he or she had a 25–30 percent chance of experiencing two or more.

When we compared men and women, we found that both groups experience ICDs generally and compulsive gambling at similar rates. However, we found that men are more likely than women to have issues with sexual behavior, whereas women are more likely than men to experience compulsive buying and eating.

N&R How do ICDs impact the lives of people with PD?

DW There is a wide range. For some people, ICDs may be mild, or just a minor nuisance (for example, increased focus on eating sweets with a 10 pound weight gain). This group may be reluctant to make any changes to their PD medications because they value the medication's benefits over relatively minor ICD symptoms.

For others, the impact of ICDs may be more severe. People who experience compulsive gambling and compulsive shopping may lose large sums of money, even to the point of bankruptcy. Those who binge eat may experience significant weight gain, causing discomfort and embarrassment and possibly increasing vascular disease risk factors. And some of those who experience compulsive sexual behaviors may begin engaging in unprotected sex or sex outside of an established relationship, placing themselves and others at risk physically and emotionally. ICDs typically impact not only the person living with PD, but also his or her loved ones.

Medications Linked to ICDs**N&R Is it true that Parkinson's medications cause ICDs? Can you explain why?**

DW We think that because people living with Parkinson's so often have long-term exposure to dopamine replacement therapies, some may develop hypersensitivity. Hypersensitivity may in turn lead a person to "overreact" to medications. One common form of this overreaction is dyskinesia, the twisting and writhing movements that some people with PD experience. ICDs may be another example of how the body overreacts to a dopamine medication.

N&R Which medications are linked to ICDs?

DW The focus to date has been on two classes of medications — dopamine agonists, and levodopa, the gold-standard anti-PD medication that is usually taken as Sinemet®.

In our recent study, my colleagues and I found that ICDs are most strongly associated with dopamine agonists. The two most commonly used by people with Parkinson's, and which we studied, are pramipexole (Mirapex®) and ropinirole (Requip®). We also found that ICDs were relatively common in people taking pergolide (Permax®), an agonist no longer prescribed in the United States. Our study suggested that levodopa may also be associated with ICDs. But the odds of having this problem are less likely with levodopa use than with use of dopamine agonists.

A less frequently used medication called amantadine (Symmetrel®), is under suspicion as well. However, some studies have suggested it may actually be effective as a treatment for pathological gambling in PD, so more research is needed.

N&R Will a person develop an ICD immediately after beginning one of these medications?

DW Sometimes a person will experience an ICD months after beginning a medication, but often there is a significant lag time of a year or more. My sense is that most people with an ICD know that something is different, but they may not see it as a significant problem or attribute the same importance to it as their loved ones will. For example, if a man experiences a higher than normal sex drive, he may think that it is still normal, but his wife may see it otherwise.

N&R PDF *News & Review* | **DW** Daniel Weintraub, M.D.

More questions? (800) 457-6676

N&R How do you treat ICDs?

DW The most common treatment is to lower the dosage of or to remove the medication that has caused the problem, presumably the dopamine agonist. In mild to moderate cases, a person may elect to stay on his or her medications, but in moderate to severe cases, the doctor will feel obligated to take that person off of it completely.

N&R Do ICDs disappear entirely when the medication is removed? How long does it take?

DW My anecdotal answer is that ICDs “usually” subside for people who clearly did not experience the ICD previous to that time and developed it in the context of taking a dopamine replacement therapy for Parkinson’s. I have treated people who said they felt back to normal within a matter of days to a week, and others who said the change took weeks or months. There is a much smaller subset of people for whom ICDs persist despite the discontinuation of medications.

There is another subset of individuals for whom going off a medication is not an option. Perhaps their symptoms are too severe, or they’re receiving psychological benefit from the medication. Recent research suggests that some people may experience withdrawal symptoms when going off medications. I haven’t yet seen this in my own practice, but it’s something I now consider when removing medications from a regimen.

N&R Are there additional treatments for those individuals?

DW People who have significant motor fluctuations and have lived with PD for several years may be candidates for deep brain stimulation (DBS) surgery. Since a person can typically decrease his or her medications after DBS, this often will ease his or her ICD. A few other strategies have been explored, such as use of antidepressants, but there is little evidence at this point of their efficacy.

Scientists are also investigating novel treatments to resolve ICDs. My colleagues and I are studying an opioid antagonist called naltrexone. Other teams are studying a class of medications called glutamate antagonists, but the evidence on these strategies is limited at this point.

N&R What does the future hold for diagnosing and treating ICDs in people with Parkinson’s?

DW We hope the new compounds under investigation will help to treat ICDs, or that the newer dopamine replacement therapies may not have ICDs as a complication. In addition, I think we need to develop tools to improve diagnosis and care. I am a psychiatrist, so it is easy for me to discuss ICDs as part of every single visit, but not all people with Parkinson’s have access to a psychiatrist. Their neurologists may be saddled with many other issues to cover during an appointment.

In these cases, it would be helpful to develop screening instruments, such as surveys that can be self-completed by people with Parkinson’s and their families in the waiting room. These would provide the doctor with data that they might not have the time to gather during the visit. In 2009, we published a self-complete questionnaire called the QUIP in *Movement Disorders*. It takes less than five minutes to complete and is available for doctors to use in their clinical practice.

N&R Should people with Parkinson’s be concerned about their risk of developing ICDs?

DW I think they should be aware that these side effects exist and be attuned to any change in behavior, or pre-occupation with a new behavior. For example, increased Internet use (of gambling or adult websites) could be a sign of compulsive gambling or sexual behavior, but this doesn’t mean everyone using the Internet has a problem.

N&R How can people living with Parkinson’s and their families bring up this topic with their doctors?

DW I think clinicians have an obligation from day one, when they are prescribing dopamine replacement therapies, to let people know — not just about ICDs — but about the whole range of side effects that can occur with levodopa and dopamine agonists. This would include other non-motor effects, such as sleepiness and the potential to develop hallucinations. I tell my patients that I want them and their families to be aware that a subset of people with Parkinson’s may experience changes in gambling, buying, eating and sexual behaviors. I encourage them to talk to me about any changes in behavior.

“Similarly, I would encourage all people with PD, along with their families, that if they have noticed any change in such behaviors, to bring this up immediately with their physicians.”

News In Brief*Continued from page 2*

certain foods. Studies have suggested that low levels of vitamin D increase the risk of PD as well as other chronic diseases. In fact, people diagnosed with PD tend to exhibit low vitamin D levels.

In this new study, Paul Knecht, D.P.H., and colleagues at the National Institute for Health and Welfare in Helsinki, Finland, performed the first long-term investigation into the relationship between vitamin D levels and the incidence of PD. They studied blood samples drawn from nearly 3,200 healthy men and women in Finland between 1978 and 1980 as part of a national health survey.

At that time, participants were between ages 50 and 79. By 2007, 50 of the participants had developed Parkinson's. Researchers thawed the blood samples, analyzed vitamin D levels, and assessed any relationship to PD.

Results

- People with the highest levels of vitamin D had a 65 percent lower risk of developing Parkinson's than those with the lowest levels.

What Does it Mean?

The authors offer the hypothesis that low levels of vitamin D may be directly or indirectly associated with a greater risk of developing PD. More study is needed to understand the role of vitamin D in PD. This study and others cannot prove that

exposure to a vitamin can protect against PD. Vitamin D requires sunlight for its production but the participants of the current study in Finland had much less exposure to sunlight than do most people in the United States. This study highlights the importance of maintaining adequate levels of vitamin D; people with PD are advised to talk to their doctors about the necessity of supplementation and appropriate dosages.

Deep Brain Stimulation Works Equally Well at Two Brain Sites

A multicenter, randomized and blinded clinical trial reported in the June 3, 2010, issue of the *New England Journal of Medicine*, has found only a minimal difference between two alternative brain targets in the effectiveness of deep brain stimulation (DBS), which is a surgical intervention for Parkinson's disease (PD).

The study is the largest to date to examine the two targets in the brain — the subthalamic nucleus (STN) and the internal segment of the globus pallidus (GPi). The research team, led by Kenneth Follet, M.D., Ph.D., of the Iowa City Veteran Affairs Administration, arranged for half of the 299 participants to undergo surgery at each of the two targets. Neurologists assessed PD symptoms of all participants every three months for two years.

Results

- Participants who underwent STN stimulation and those who underwent GPi stimulation experienced equal benefit,

as measured by the motor component of the widely-used United Parkinson's Disease Rating Scale.

- People in both groups experienced improvements in quality of life measures and both were able to reduce their medication intake during the 24 months following surgery.
- Those in the STN group experienced a larger reduction in medication use than the GPi group (about 1.5 tablets of standard Sinemet 25/100 per day). In cognitive performance, both groups experienced a slight deterioration, but those in the STN group showed a greater decline in one aspect of visual processing.
- The STN group also showed a slight increase in depression, while the GPi group showed a slight decrease.

What Does it Mean?

One of the central questions about DBS since the procedure was approved more than a decade ago has been where to place the electrodes: the STN or the GPi. From this large and well-controlled study, the verdict is a tie: the two target sites appear to be equally effective overall in terms of motor function, individual satisfaction and adverse effects.

This said, people with Parkinson's should be aware that the doctor's choice of target may be based on factors unique to the situation of a particular person — including cognitive status, medication usage, medical and psychiatric health.

What Does it Mean?

Wondering what the latest Parkinson's headlines mean for you?

Read PDF's take on scientific studies by visiting our online science news.



www.pdf.org/science_news

Give PDF Your Opinion

What do YOU want to read about in PDF *News & Review*?

Help us improve our newsletter for you by taking this short online survey.

www.pdf.org/survey10

Sharing Stories

Quilted Journeys

By Sharon Standish

“Amazing” is a good word to describe my experience as part of the Parkinson’s Quilt Project. For this



Sharon Standish

project, the Parkinson’s Disease Foundation (PDF) invited all people all over the world to create personal quilt panels — each of which provides an open window into that

quilter’s journey living with or affected by Parkinson’s disease (PD). I am thankful to be united with other quilters to try to promote awareness and to support the drive for a cure.

As for my own journey, they all start somewhere, so let’s go to the beginning. I am 46 and was diagnosed with PD three years ago. Looking back I now realize, as I’m sure most of our readers do, that I had symptoms for a couple of years before I was diagnosed.

My first symptoms were pain and rigidity on my left side. My left shoulder was very painful, my left hand would not open all the way, I could not straighten my arm and my left leg would not cooperate. My family thought I had a stroke. I had a CT scan, but it showed nothing, which was frustrating. Then I went to physical therapy to build up strength. I was finally sent to a neurologist. He did not give me a diagnosis, but gave me a prescription for levodopa/carbidopa.

It was a miracle drug! I felt back to normal and I could not wait to thank the doctor. At my next appointment, I gave the doctor a hug and showed him how well the medication was working. Then he asked me to please sit down. His smile turned into a look of concern as he broke the news about my diagnosis of Parkinson’s.

It is hard to believe that it has only been three years since that day. Since then, I have experienced adverse side



More than 600 quilt panels will be shown at the 2nd World Parkinson Congress in Scotland.

effects to most of my Parkinson’s medications and have been diagnosed with dystonia, sleep apnea and melanoma.

I have had many difficult moments on this journey with PD, but I have never been alone. To recognize the support and friendships I have had along the way, I made my first panel for the Parkinson’s Quilt in honor of Booth Gardner Parkinson’s Care Center, where I am thankful to be a patient.

The panel’s crazy pattern, filled with twists and turns, represents my journey with PD. The words surrounding it reflect how my doctor and staff have helped me — with compassion, teamwork, support, education and hope — to navigate through the process and to enjoy the best quality of life possible.

I believe that on most journeys, the good moments outweigh the difficult ones. So, my second panel gives thanks for the positive effects of living with PD — to God for his mercy and inspiration; to my family for always being with me; to my friends for standing by me; and to the new bold attitude PD has given me. While my friends and family help me to weather the storms and look for the sunshine each day, my new attitude has made me much more willing to take a chance, to try something new. I find that I am being much more creative — sewing quilt panels, drawing, and writing stories (my first children’s book, *Ganly Delivers Parcel and Post*, was just published).

While this panel presented a difficult task, creating it, for me reflected the process of living with PD: it was at times challenging but also fun; tearful but also laughable; frustrating but also gratifying when the job was finished.

I am thankful for the opportunity to be creative and to PDF for empowering all of us, to show the world what those who live with PD can do to help one day to make a cure possible.

Sharon Standish resides in Marysville, Washington.

Bring the Parkinson’s Quilt to Your Community in 2011!

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.

The quilt will be available for display for a modest fee to cover expenses starting in January 2011.

www.pdf.org/en/quilt

pdfchampions[®] in action

At the Parkinson's Disease Foundation (PDF), we meet all types of PDF Champions, our grassroots fundraisers. They come young and old, short and tall and they hold all types of events, ranging from bake sales to golf tournaments. Some even run marathons. Three recent stories particularly inspired us and we think they will inspire you too. The actions of the Cabello and Zwick families and a group of friends in Long Island, NY, remind us that the fight against Parkinson's comes in all shapes and sizes and that every donation makes a difference.

Lemonade Stand Supports PDF

June 14, 2010

Dear Parkinson's Disease Foundation,

I just wanted to let you all know about something special my kids did. One Saturday in May, my children, Matthew, age 10 and Juliana, age eight and their friend, Canyon, decided to operate a lemonade stand in front of our house. They had been outside for a while and had already needed a refill on the lemonade when I went out to check on them. I was wearing my Parkinson's Awareness Month T-shirt and they asked me about it. So I explained what PDF was and a little about Parkinson's disease.

My son said, "Hey! That gives me an idea. Let's donate the money we make to PDF to help Honey!" (Honey is their Grandmother who has Parkinson's). They all agreed to donate it. I was very proud of them and think it is a great thing to do with their money!

Please accept the donation of \$20.40 from my children's lemonade stand.

Thank you.
Rhonda Cabello

Thank you, Cabello family!



Golfing for a Cure

On August 11, 100 golfers gathered at the Farms Country Club in Wallingford, CT, for the Fourth Annual Zwick Pro-Am.

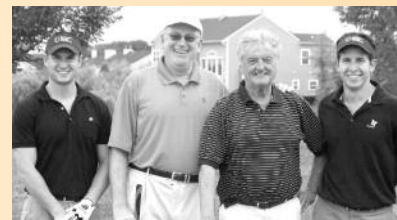
Named for long-time club member Lenny Zwick, who lived with Parkinson's for 25 years, the tournament featured 18 holes, a luncheon, a silent auction and an awards dinner. Among the friends and family of Mr. Zwick who participated were his wife Susan, daughter Stacey and event organizer Dave Melillo.

The Pro-Am raised over \$50,000 to benefit the research programs of PDF. **Thank you Zwick family!**



Mother and daughter, Susan (l) and Stacey Zwick with Dave Melillo

On June 22, over 100 friends of PDF gathered on the east end of Long Island, NY, for Tour for a Cure, choosing one of two festive events — 18 holes of golf or a tour of Long Island's finest wineries with the East End Wine Tasting. Golfers and wine tasters reunited for a buffet dinner, raffles, a silent auction and an awards ceremony — raising nearly \$25,000 for PDF's programs. **Thank you Long Island supporters!**



Brett Joshpe, Jeff Radov, PDF Executive Director Robin Elliott and Josh Bernstein

For more stories, visit www.pdf.org/en/pdf_champion_action.



New Members Elected to PDF Board of Directors

PDF warmly welcomes to its Board of Directors two new members: Stephanie Goldman-Pittel and George Pennington Egbert III. Both individuals bring great passion for the cause, arising from their personal connections to Parkinson's disease (PD) and from their extensive backgrounds in philanthropy.

Ms. Goldman-Pittel, active with PDF for many years as a member of the leadership committee for the annual gala, was honored with her family at the 2007 event for their contributions to PDF's research programs. She is currently the President of the UJA Federation of New Jersey, following several years of service as Vice President of the Women's Division, which awarded her its Rising Star Award in 2005. She also serves on the Board of the Lighthouse International. Ms. Goldman-Pittel and her husband Andrew have three children.

Mr. Egbert, along with his sister Melissa Egbert Sheehan, was instrumental in forming, in 2008, the Young New Yorkers Against Parkinson's committee, which sponsors PDF's annual *Celebrate Spring* fundraiser. He is a Vice President at Barclays Capital. His philanthropic activities include roles as Chairman of the Young New Yorkers for the Philharmonic Committee, member of the Board of Governors of the Union Club of New York City and Chairman of its Younger Members Committee.



George Pennington Egbert III and Stephanie Goldman-Pittel

2011 Konecky Fellow Named for Long-time Friend

The Parkinson's Disease Foundation (PDF) is pleased to announce the award of a special 2011 Fellowship in Movement Disorders in loving memory of Ronald Konecky, a long-time friend of PDF who died in New York City in early June. It is one of several such fellowships that PDF funds across the country, including six at Columbia University, to ensure that the best young minds are attracted to Parkinson's disease science and care.



Ronald Konecky

This Ronald S. Konecky Fellowship will support the training of Christopher Hess, M.D., whose research interests include understanding impulse control disorders and bringing hi-tech video analysis methods to measure how Parkinson's disease progresses.

His work could help clinicians to accurately quantify a person's PD which will, in turn, speed the clinical research process as a whole.

Mr. Konecky was married for 49 years to Isobel Konecky, who has served on PDF's Board of Directors for 30 years and as its secretary for 20 years.

He was a noted entertainment lawyer who represented celebrities and major names in television news.

Tribute to a Founding PPAC-er

The Parkinson's disease community mourns the loss of Joanna T. Steichen, M.S.W., who died suddenly in July. Ms. Steichen was a founding member of PDF's People with Parkinson's Advisory Council (PPAC), a 13-member group founded in 2006 to provide PDF with perspectives on research-funding priorities, community needs and ways to better serve people living with Parkinson's through information and education programs.



Joanna Steichen

Ms. Steichen was diagnosed with Parkinson's in 2001. Among her various contributions to PDF, she was known for her passionate dedication to exploring the therapeutic value of creativity, dance and exercise for people living with Parkinson's disease. In this capacity, she served on the steering committees for both the PDF Creativity and Parkinson's project and the Parkinson's Quilt Project. More recently, she served as PDF's Team Captain at the Parkinson's Unity Walk.

Ms. Steichen was a practicing psychotherapist for 30 years, a clinical teacher, and the author of two books. She resided in New York City.

Reminder

Help us improve our newsletter by taking this short online survey. www.pdf.org/survey10

Calendar of Events



17th Annual Morris K. Udall Awards Dinner

Date: Wednesday, October 6
Place: Capital Hilton Hotel
Washington, DC

The Parkinson's Action Network (PAN) invites you to its annual fundraiser and awards ceremony. This year's leadership includes Dinner Co-Chairs: Diane and John Rehm, Honorary Chairman, Michael J. Fox, and Special Program Guest, Lonnie Ali. Honorees include, James Trussell, a former member of PDF's People with Parkinson's Advisory Council, US Senator Gordon Smith and US Representative John Spratt. For more information, call (202) 638-4101, email udalldinner@parkinsonsaction.org or visit www.parkinsonsaction.org.



2010 HOPE Conference

Date: Saturday, November 6
Place: Seattle, WA

The Northwest Parkinson's Foundation (NWPF) and the Washington State chapter of the American Parkinson Disease Association (APDA) invite people with Parkinson's and their families to learn how medications, diet and exercise can improve quality of life with Parkinson's. For more information, call (206) 748-9481, email info@nwpf.org or visit www.nwpf.org.

Raising the Stakes

Date: Wednesday, November 10
Place: Capitale, New York, NY

Join PDF for a night of casino games, prizes, cocktails, dinner and dancing! All proceeds from the event will benefit PDF's research programs. For more information, call (800) 457-6676, email info@pdf.org or visit www.pdf.org/en/raising_stakes.

Young Onset Parkinson Conference & Southeastern Parkinson Disease Conference

Date: Friday, October 15 – Sunday, October 17
Place: Sheraton Gateway Hotel, Atlanta, GA

The National Parkinson Foundation (NPF) and American Parkinson Disease Association (APDA), in collaboration with the Northwest Georgia Parkinson Disease Association and the APDA Information and Referral Center at Emory University present the third in a series of conferences for those living with young-onset Parkinson's disease. This conference will also offer programs for people living with Parkinson's disease of all ages. For more information, visit www.gaparkinsons.org.



Parkinson's Disease Foundation



Parkinson's Disease Foundation

Hope through Research • Education • Advocacy

FALL 2010

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November is National Family Caregivers Month

As an endorser of National Family Caregivers Month, PDF recognizes the contributions of caregivers and family members of people with Parkinson's. We commit ourselves to thanking, supporting, educating and empowering family caregivers.

Look for details on PDF's online seminar in November, designed to address questions from care partners, family and loved ones.

www.pdf.org/en/pd_online_education

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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