NPF’s Landmark Patient Registry Enrolls 8,000 Parkinson's Patients

The National Parkinson Foundation (NPF) has now enrolled more than 8,000 people with Parkinson’s disease (PD) in its Parkinson's Outcomes Project, the largest-ever clinical study of Parkinson's disease. The study, conducted at 20 expert clinics in four countries, aims to identify and explain how expert care delivers better outcomes for people with PD.

“From data collected in the Parkinson’s Outcomes Project, we know that medication use patterns vary across expert Parkinson’s disease clinics,” said Peter Schmidt, PhD, Chief Mission Officer of NPF. “We have the ability to establish and disseminate the first-ever standardized treatment protocol to make life better for anyone living with Parkinson’s.”

NPF’s longitudinal study, now in its seventh year, evaluates the full range of factors associated with PD: medications and other treatments, motor symptoms, cognition, anxiety and depression, and caregiver...

continued on page 2
burden. NPF has already shared key learnings from the study with the Parkinson’s community:

- Regular neurologist care could save the lives of thousands of people each year.
- Increasing physical activity to at least 2.5 hours a week slows and potentially reverses the decline in quality of life.
- Depression and anxiety are the leading factors impacting the overall health status of patients.

This year, data from the study was used to examine medication use patterns across expert PD clinics. With 10 different classes of medication used to manage PD, half of the subjects were treated using nine combinations. More importantly, different centers employed different approaches to medication. In other words, the very best Parkinson’s care is not systematic, rather it reflects the preferences of the neurologist as well as the patient.

Using our Parkinson’s Outcomes Project as a platform, we hope to scientifically determine the optimal strategy for managing Parkinson’s treatment and developing a treatment protocol. For example, at some centers, a simpler medication regimen results in a lower incidence of falls for the person with Parkinson’s. Based on this information, NPF can update the Parkinson’s Outcomes Project dataset about medication usage across the Centers of Excellence network. A standard PD treatment protocol will ensure that the best care can reach everyone living with Parkinson’s.

What makes this project truly innovative is that it not only follows thousands of patients over time, but that it studies everyone with Parkinson’s, from the newly-diagnosed to people who have lived with Parkinson’s for 20 years or more. We’re working to ensure that every patient receives the best possible care, no matter where they’re seen, said Thomas Davis, MD, Director of Movement Disorders at Vanderbilt University, Study Co-Chair.

Six studies using data from NPF’s Parkinson’s Outcomes Project were presented at the 20th International Congress of Parkinson’s Disease and Movement Disorders in Berlin, Germany, in June 2016.

NPF plans to enroll 10,000 people with Parkinson’s in the study at NPF Centers of Excellence across the world.

For more information about the Parkinson’s Outcomes Project visit www.parkinson.org/outcomes.

#Move4PD Parkinson’s Awareness Month 2016
Thanks to everyone who sent in a photo of all the different ways we can #Move4PD!

Winner of #Move4PD Photo Contest  
Runner-up of #Move4PD Photo Contest  
Fan favorite of #Move4PD Photo Contest
How to Help People with Parkinson’s Maintain their Identity and Dignity

Rabbi Rena Arshinoff strives to help people find shalem and shalom (wholeness and peace). She specializes in the spiritual needs of people with Parkinson’s disease (PD) and movement disorders. People with Parkinson’s experience physical, cognitive and spiritual changes that need to be addressed, while maintaining a sense of dignity and identity.

Rabbi Arshinoff identifies factors that play the largest roles in helping someone with Parkinson’s maintain their identity and dignity:

- **Relationships:** Even if speech is not possible, people with PD respond to a familiar face, a memory, a touch, a compliment and presence. Keeping and strengthening relationships is essential to helping someone maintain their identity.

- **Attentiveness:** Each person is created uniquely and deserves recognition. Rabbi Arshinoff finds the most powerful tool is to speak directly to the person with PD instead of a caregiver. This small act means a lot, especially if the voice has weakened. Really listen, even if you find your ear practically next to their mouth.

- **Identity:** Parkinson’s can make people feel unfamiliar with their own body or mind. Spiritually, it can be likened to wandering the wilderness. Encourage ongoing participation in enjoyable and meaningful activities. Directly acknowledge the loss of roles, but also recognize previous professional and personal accomplishments.

- **Community:** In Judaism community is integral. It is important for people with PD, especially those with cognitive symptoms, to remain part of a community. Isolation is often a precursor to decline. PD programs and groups provide stimulation, exercise, a friendly environment and act as a respite for family. Religious services also provide a sense of community.

- **Memory:** A person with PD can experience changes in memory. To help boost memory during a conversation: smile, touch, describe your last visit and what you discussed. Revisit shared memories like travels, hobbies and interests.

- **Burden:** People with PD often say they feel like a burden. Rabbi Arshinoff addresses this spiritually by proposing that as an image of God one is not a burden. Has God ever been a burden?

- **Shmirat Haguf (care for the body) for Family:** PD can affect the entire family. Caregivers get burnt out – physically, emotionally and spiritually. They need support and respite too. It is vital for caregivers to take care of themselves and ask for help.

- **Search for Hope and Dignity:** People with PD, their family and friends should speak often. Learn body language identifiers. Directly ask the person with PD how they feel emotionally and spiritually. Discussing current interests helps remind them of their personhood. Relive past achievements and recognize current ones, no matter how small they may seem.

Rabbi Rena Arshinoff spoke at the 2016 NPF Centers of Excellence Leadership Conference, where leaders from NPF’s 41 Centers of Excellence presented cutting-edge research and expert care findings.

For more information visit
www.caremap.parkinson.org/spiritual-tools

4th World Parkinson Congress
Portland, Oregon, USA
Sept. 20–23, 2016
REGISTER TODAY!
www.WPC2016.org
A Day in the Life of a Center Coordinator
Joan Miravite, NP, Mount Sinai Beth Israel

Joan Miravite, NP, loves to go to work. “The best part of my job is that I can actually see people get better through great care and evidence-based medicine,” said Miravite, the Center Coordinator for the National Parkinson Foundation (NPF) Center of Excellence at Mount Sinai Beth Israel in New York City.

Miravite’s fast-paced, action-packed days start when she arrives at the Center at 8 a.m. Miravite manages a busy multidisciplinary movement disorders clinic. Before her first patient arrives for a 9 a.m. appointment, she responds to numerous emails and voicemails from patients. “I get a lot of requests for referrals, prescription refills and patient care questions,” she said.

While every person who comes through the door is different, most of the patients she sees have undergone deep brain stimulation (DBS) surgery. “I see each patient for an hour, talking to them and figuring out if there are any changes I need to make to their medication or stimulation,” she said. “I make sure that my patient is doing well and understands all the instructions.”

Miravite’s passion for her patients is matched only by her expertise in movement disorders and DBS. Over the past 15 years, Miravite has specialized in DBS programming. Day-to-day, she’s involved in educating doctors, nurses and patients about DBS. “I really appreciate the change I see in patients after they have DBS surgery,” she said. Miravite is also involved in research aimed at understanding how to better treat movement disorders with DBS.

Helping people with PD thrive may not be easy, but Miravite is dedicated to involving patients in their condition and treatment. Recently, Miravite saw a new patient who had undergone DBS surgery to manage his symptoms. After she made a big change to his DBS settings, he saw a great improvement in his symptoms. The patient was so grateful for the care he received from Miravite and the whole team that he decided to host a fundraiser to benefit the center. “It’s a nice honor to be recognized for taking good care of someone,” she said. I am really happy with the impact we have on our patients.”

Miravite juggles the demands of her patients while still supporting her colleagues and responding to their requests. She makes calls to figure out where she can send patients for their best physical, occupational or speech therapy options. She recruits patients for clinical trials. Once a week she trains movement disorders fellows in DBS programming and managing DBS-related complications. “We see patients...continued on next page
together all day, doing programming and talking to patients, changing settings or medications, depending on what the patient is experiencing,” she said.

In addition, she acts as a liaison between NPF, the Center of Excellence team and patients, their families and caregivers.

“Joan Miravite is the epitome of NPF’s vision for Centers of Excellence care,” said Peter Schmidt, PhD, Chief Mission Officer of NPF. “She serves as the link among the diverse providers and functions of the clinic and does outreach into the community, linking up all the components of best care and she is an expert DBS clinician herself.”

Miravite’s responsibilities keep going. She runs the center’s Men’s PD Support Group, in addition to support groups for essential tremor and dystonia. She also organizes speakers to talk about various topics on a monthly basis. She wants to get her patients to think innovatively about how they can improve their health and wellbeing. Her recent speakers included a comedian who spoke about laughter as medicine, physical therapists who spoke about the benefits of dancing, in addition to speech therapists and yoga instructors. She also runs two DBS support groups.

To Miravite, the biggest challenge is just to get everything done every day, and to do it well. But she credits the NPF Center of Excellence designation with helping to keep her team focused on delivering patient-centered care and developing best practices.

“It’s a great feeling to know that you can have a positive, real-world impact on patients and their families,” she said. “It’s a challenge, but a great honor to enter a patient’s life. They open their hearts to you and bring you in.”

I work in a Center where we all collaborate with each other. It’s rewarding that we can make such a difference as a team. This group effort is what creates a bond, she said.

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Q: I heard that there’s a new blood test for Parkinson’s disease on the horizon. Will this test detect Parkinson’s earlier?

A: Currently, many groups around the world are working to develop tests that will measure levels of proteins in the bloodstream and other biomarkers for PD. Most recently, researchers from La Trobe University in Australia have developed a potentially effective blood test for PD. The researchers turned their attention to mitochondria, cellular powerhouses responsible for energy production. The researchers say mitochondria are working four times as hard as they should in people with PD. This overproduction in the mitochondria may be leading to toxic byproducts in blood cells. The Australian investigative team conducted a preliminary test on 29 people with PD and nine healthy control subjects and the test proved to be reliable. The research team has received significant grant funding to further develop the diagnostic test and it could be available within five years.

Highly accurate, specific blood tests have the potential to improve the lives of many people with PD. A blood test could identify those at risk and help facilitate early intervention. Another important use for a blood test could be in monitoring the symptomatic treatment of current PD sufferers, especially in those enrolled in drug trials. But these tests must be pursued cautiously and with an open mind as to how they will affect both the population at risk and people currently living with PD. As we move forward, it’s important that patients and their families have close communication with their doctors. This will be critical in deciding which test, or which battery of tests, would work best.

Q: My dad’s vision has deteriorated in the past year. He has been complaining about excessive moisture or tears in his eyes. One doctor says he has glaucoma and another says he doesn’t. He has real trouble reading. Is there a connection between reduced vision and Parkinson’s? Are vision problems likely a symptom of Parkinson’s?

A: Like your father, many people with PD report vision problems. Some vision changes related to PD include double vision, which can occur due to medications, or because the eyes have trouble working together, also called convergence insufficiency. Special prism glasses can correct this issue. Dry eyes and decreased blinking can also be related to PD. Sometimes PD affects the ability to see contrasts, but in general visual acuity is not impaired in people with PD. Parkinson’s medication, especially anticholinergics, can cause blurry vision. Additionally, people with PD can experience involuntary closure of the eyes. This phenomenon has been referred to as blepharospasm (uncontrollable muscle contraction). Your father should see a neuro-ophthalmologist. It’s always best to be evaluated and treated by an expert, rather than to guess if the vision problem is related to PD or not. Remember, as we grow older it’s normal to experience age-related eye problems. These changes usually have nothing to do with PD.
People with Parkinson’s disease (PD) need to be on the alert for melanoma, the most deadly form of skin cancer. Skin cancer is the most common cancer in the U.S. and it’s even more of a threat for people with PD. Here are some precautions you can take to stay safe this summer.

**Protect yourself from sun exposure.** Wear protective clothes and a hat. Sunscreen alone may not be enough to protect you from skin cancer.

**Examine yourself from head to toe.** Melanoma can occur in hidden spots that can be easily overlooked. Once a month, look for odd marks and black spots on your skin and nails. Ask a loved one to help you.

**Know your spots.** Look for a skin growth, mole or beauty mark that changes in size, color or texture.

**Schedule a yearly screening.** Show your dermatologist any potential trouble spots.

**Get treated.** If diagnosed with skin cancer, get treated right away. Early intervention has been shown to result in a nearly 100 percent cure rate.

When consumed in moderation, energy drinks are safe. But it’s far better to rely on other long-term practices to boost your energy.

The information published in this “Ask the Doctor” Forum is not intended to replace, and should not be interpreted or relied upon as professional advice whether medical or otherwise. Accordingly, please consult your own professional for all advice concerning medical, legal, or other matters published in connection with this Forum. NPF assumes no liability of any kind for the content of any information transmitted to or received by any individual or entity in connection with their use of the “Ask the Doctor” Forum on the NPF Website, and NPF does not endorse or recommend any such information.
The U.S. Food and Drug Administration (FDA) has approved pimavanserin (Nuplazid™), a first-in-class medicine to treat hallucinations and delusions associated with Parkinson's disease (PD). This new drug addresses a critical unmet need for the treatment of psychosis in PD, which affects up to 40 percent of people with Parkinson's.

Common high potency antipsychotic drugs (Haldol, Olanzapine) suppress hallucinations, but usually worsen PD motor symptoms, such as rigidity, slowness and walking. They can also increase mortality. As a result, one of two atypical antipsychotics—quetiapine (Seroquel) or clozapine (Clozaril), both dopamine antagonists—are widely used to treat the hallucinations and delusions in PD. These drugs work without worsening common motor symptoms.

Quetiapine and clozapine have major shortcomings. Quetiapine has not been consistently effective across several PD clinical trials. Still, Parkinson's experts believe it's moderately beneficial, particularly in treating mild hallucinations. Clozapine has been shown to be highly effective, but requires weekly blood monitoring to check for a potentially life-threatening side effect called agranulocytosis, where the drug attacks the bone marrow. The inconvenience of blood draws have limited clozapine's use.

Though we think dopamine receptors play an important role in psychosis, serotonin has also been a factor. Pimavanserin, a breakthrough therapy that works in a new way, is a selective serotonin 5-HT2A inverse agonist that works without blocking dopamine receptors. Instead, it targets serotonin receptors. Pimavanserin doesn't worsen the motor symptoms of PD and is thought to have few or no motor side effects, such as dyskinesia or parkinsonism. In addition, the emerging safety profile has shown it to be superior to other antipsychotics.

Like any powerful drug, there are risks associated with pimavanserin. All antipsychotics available to the public have been linked to increased mortality. Dr. Daniel Weintraub and colleagues from the University of Pennsylvania, an NPF Center of Excellence, performed a study aimed to examine antipsychotic use in PD. Researchers compared 180-day mortality rates of patients who initiated antipsychotic therapy to those who did not. The analysis showed that use of an antipsychotic in PD was associated with a more than double the risk of death. The risk was higher for the older, stronger antipsychotics, such as Haldol.

Additionally, clozapine, which is known to suppress psychosis without worsening parkinsonism, has been shown to reduce nursing home placement and to restore meaningful life in many patients with PD psychosis. However, few patients in Dr. Weintraub's study were prescribed this drug.

Evidence suggests that use of the atypical antipsychotics clozapine and quetiapine, and now pimavanserin, will not significantly worsen parkinsonism and therefore are justified to treat PD psychosis. Importantly, recent research shows that not treating psychosis can lead to a worse outcome.

Psychosis in PD is very common. Pimavanserin may be a great alternative for some people with PD, especially since it does not worsen motor symptoms. Patients and doctors should consider all concerns and the risks of not treating psychosis. Psychotic symptoms increase risk of mortality, caregiver burden and nursing home placement. People with Parkinson's and their families should talk to their neurologists about all options, or call the NPF Helpline.

Author: Michael S. Okun, MD, NPF National Medical Director

Read Dr. Okun's monthly column, “What’s Hot in PD?” online at www.parkinson.org/whatshot.
Shirley Bealor drives 120 miles roundtrip to see her movement disorder specialist and 80 minutes roundtrip to her Parkinson’s disease (PD) support group.

More than 10 years ago Shirley and her partner, Elizabeth, visited Calvert County, MD, on a road trip and decided to move there. They loved the bay, the seafood and the small-town feel. “Shirley then started having some tremors and telltale signs of PD,” Elizabeth said. It wasn’t long before she was diagnosed with Parkinson’s.

Shirley’s research led her to the Georgetown Movement Disorders Program, an NPF Center of Excellence, where she has received expert care from day one and underwent deep brain stimulation (DBS) surgery in December 2014.

While DBS helped, Shirley still lives with a myriad of PD symptoms. She has dyskinesia, fatigue and uses a walker for balance and support.

“The invisible symptoms are actually the most frustrating. Food doesn’t move through the digestive system like it used to, swallowing, choking, speech changes, loss of bladder and bowel control – these are difficult to treat and make daily life especially challenging,” Shirley said.

One day in her Georgetown doctor’s office Shirley and Elizabeth noticed a poster for Moving Day® D.C. They signed up and created Team Tenacity, the name stemming from Shirley’s stubbornness and determination to fight PD.

The retired principals turned their pottery hobby into a team fundraiser. Shirley asked potters across the nation for a handmade pottery donation. They received more than 60 pieces. Between pottery sales and donations they raised more than $10,000 for the fight against Parkinson’s.

They met with the Office of Aging, the CEO and neurologist in the county hospital and asked them to tell others about the new group. They hosted meetings throughout the county to inform people. Additionally, they met with people who have PD and caregivers one-on-one to tell them about what the support group can offer. Next, they will continue to build their base and find a central location to host meetings.

Three women attended the first informational meeting. Two had never met anyone else with Parkinson’s.

“They were overwhelmed by having more information, hearing my story and meeting each other. They were almost in tears. It just made it worth everything, Shirley said.

Shirley and Elizabeth have seen what works best by attending support groups in other counties. Their goal is to establish a support group that brings the people of Calvert County new PD resources, speech therapists and group exercise classes, but most importantly support and a sense of community.

“They’re terrific. I’m so looking forward to a support group here,” Pat Jost, Calvert County resident, said. “They follow through. If Shirley and Elizabeth have anything to do with it, we’ll get it.”

Just because Shirley and Elizabeth are starting a support group doesn’t mean they forgot about Moving Day® D.C. Team Tenacity had a great turnout and raised money for the fight against Parkinson’s. “I like to see how many people are there, and that are just so dedicated – from the volunteers to the care partners who are there with loved ones. Their dedication assures and moves me,” Shirley said.

To find a Moving Day® walk near you visit www.npfmovingday.org.
2016 Fall Event Calendar

SEPTEMBER

9/11: *Moving Day®* Columbus, OH
Register online: www.movingdaycolumbus.org

9/11: *Moving Day®* Buffalo, NY
Register online: www.movingdaybuffalo.org

9/19: NPF Caregiver Summit, Portland, OR
Register online: www.parkinson.org/summit

9/20 to 9/23: 4th Annual World Parkinson Congress, Portland, OR
Learn more: www.wpc2016.org

9/24: *Moving Day®* Chicago, IL
Register online: www.movingdaychicago.org

OCTOBER

10/2: *Moving Day®* Rochester, NY
Register online: www.movingdayrochester.org

10/15: *Moving Day®* Boston, MA
Register online: www.movingdayboston.org

10/15: *Moving Day®* Los Angeles, CA
Register online: www.movingdaylosangeles.org

10/22: *Moving Day®* Lexington, KY
Register online: www.movingdaykentucky.org

10/23: *Moving Day®* Atlanta, GA
Register online: www.movingdayatlanta.org

10/29: *Moving Day®* NC Triangle, NC
Register online: www.movingdaynctriangle.org

NOVEMBER

11/5: *Moving Day®* Dallas/Fort Worth, TX
Register online: www.movingdaydfw.org

11/6: *Moving Day®* Boca Raton, FL
Register online: www.movingdaybocaraton.org

11/13: *Moving Day®* Miami, FL
Register online: www.movingdaymiami.org

Visit NPF’s Event Calendar at www.parkinson.org/events.

NPF CAREGIVER SUMMIT

September 19, 2016
Portland, OR
Parkinson.org/summit
My participation on the National Parkinson Foundation (NPF) governing board is more meaningful today than it was 20 years ago,” said Marshall R. Burack, member of the NPF Board of Directors and NPF Legacy Society.

When Marshall first became involved with the NPF board more than two decades ago he didn’t know anyone with Parkinson’s disease (PD). Since then he’s attended numerous Moving Day® walks and fundraising events, where he’s met hundreds of people with PD. The disease hit home when his Aunt was diagnosed. His experiences have personalized PD for him and made him want to continue providing immediate benefits to people with Parkinson’s.

Marshall was convinced to leave a planned gift to NPF after witnessing the staff and board’s unwavering commitment to the Parkinson’s community.

“NPF has improved the lives of thousands of people living with this disease,” Marshall said. “My gift shows my everlasting support. It’s a good idea to give to NPF because the organization makes incredibly efficient use of donor contributions, has low organizational expenses, and a substantial amount goes directly to its mission to make life better for people with Parkinson’s, which is extremely worthwhile.”

Marshall’s planned gift to NPF will mature over time. “My gift is a relatively painless way for me to provide more substantial support to the organization in the future.” As a Legacy Society member, Marshall’s gift will provide immense financial benefits to NPF’s research initiatives for many years to come.

As a Florida attorney specializing in health care law, Marshall has donated his legal services, time and in the very distant future, a planned gift to NPF. What started as a way for him to volunteer in a health-related nonprofit turned into a more than 20-year contribution to the Parkinson’s community.

For more information about NPF’s Legacy Society, please contact Amy Gray, Senior Vice President, Constituent and Community Relations, for a confidential conversation: e-mail her at agray@parkinson.org or call 305-537-9906.

Supporting the Future of Parkinson’s Care and Research Today

Marshall R. Burack, Esq

For more information on planned giving options please visit www.parkinson.org/plannedgiving.

Run to Beat Parkinson’s!

Team Hope™ for Parkinson’s Endurance Events

- **October 9, 2016** – Bank of America Chicago Marathon
- **October 16, 2016** – IRONMAN® 70.3® Arizona
- **October 30, 2016** – Marine Corps Marathon
- **November 6, 2016** – TCS New York City Marathon
- **February 5, 2017** – Humana Rock ’n’ Roll New Orleans Marathon
- **April 30, 2017** – Big Sur International Marathon

For more information please contact Sara Teeter at teamhope@parkinson.org or call 305-537-9951.
Support our mission to help every person diagnosed with Parkinson’s live their best possible life now. Your gift will help us fund better research, better treatments and better lives.

Give Now: www.parkinson.org/donate