NPF Awards Four Research Grants

The National Parkinson Foundation (NPF) has funded four new grants in Parkinson’s disease (PD) research that will span over a two-year period and total $1 million dollars. The grants target key scientific questions about gender differences, cognition and inflammation in Parkinson’s.

1. **Determinants of sex differences in caregiving for Parkinson’s disease**: Nabila Dahodwala, MD, University of Pennsylvania, Philadelphia, PA.
   
   Dr. Dahodwala will study common issues that result in differences in caregiving and explore options available to improve caregiving. The study will first analyze data from NPF’s Parkinson’s Outcomes Project and then evaluate barriers to effective caregiving. Drawing on these study findings, Dr. Dahodwala will design an approach to help clinicians address caregiving challenges and to engage clinic social workers to improve the lives of people with PD.

2. **The relationship between microglial activation and β-amyloid deposition in PD-mild cognitive impairment (MCI) and PD-dementia**: Antonio Strafella, MD, PhD, University of Toronto, Toronto, Canada.
   
   Dr. Strafella previously received a grant from NPF to research how patients with mild cognitive impairment differed from those without this condition. He will now focus on inflammation, studying... continued on page 2

APRIL IS PARKINSON’S AWARENESS MONTH

The Edmond J. Safra National Parkinson’s Wellness Initiative Expands

“People with Parkinson’s disease are getting fit and learning how to advocate for themselves—all under one roof.”

Continued on Page 3

NPF Helpline Answers 50,000 Calls

"Since the phone rang for the first time in 2010, the National Parkinson Foundation’s lifesaving Helpline (1-800-4PD-INFO) has responded to more than 50,000 calls.”

Continued on Page 4
As I travel across the country on behalf of the National Parkinson Foundation (NPF), I’m continually reminded of how the Parkinson’s community is fighting back at every level – people living with the disease, their families, and the researchers and healthcare professionals who treat them.

Whether I’m at our signature fundraising walk, Moving Day®, or at a community exercise class, I’ve witnessed our mission in action. We are helping people with Parkinson’s disease live their best possible lives now.

There are great things on the horizon for the Parkinson’s community. At the start of this year, the Board of Directors of the National Parkinson Foundation and the Parkinson’s Disease Foundation (PDF) announced that they signed a letter of intent to merge the two non-profit organizations. Both NPF and PDF have a strong track record of funding promising scientific research while enhancing patient care for people living with Parkinson’s disease. The Boards of both organizations recognize the potential of the combined entity to be a dynamic and comprehensive “next generation” organization.

We look forward to sharing more developments with you in the year ahead. Thank you for believing in a better tomorrow.

Sincerely,

Paul Blom
Interim CEO

P.S. NPF wants to see how you #Move4PD. Order your free NPF sweatband at www.parkinson.org/move4pd.
The Edmond J. Safra National Parkinson’s Wellness Initiative Expands to Chicago and Tampa

People with Parkinson’s disease (PD) are getting fit and learning how to advocate for themselves—all under one roof. The Edmond J. Safra National Parkinson’s Wellness Initiative will help people in Chicago and Tampa live better with PD by offering weekly Parkinson’s-tailored exercise classes, a care partner support group, and seasonal educational and social events.

This initiative follows a medical-community partnership model, which makes it unique among Parkinson’s fitness programs. NPF Center of Excellence (COe) healthcare professionals train Jewish Community Center (JCC) staff on PD, so they are best able to meet participants’ needs—inside and outside the fitness center. In turn, JCCs use their expertise in establishing inclusive wellness programming to deliver high-quality, Parkinson’s-specific classes and events in a community-based setting.

In late 2015, NPF awarded grants to the JCCs of Chicago and the Tampa JCC & Federation, and to the NPF COe in each city—Northwestern University Parkinson’s Disease and Movement Disorders Center and University of South Florida Byrd Parkinson’s Disease and Movement Disorders Center—to adapt the Edmond J. Safra National Parkinson’s Wellness Initiative for their communities.

Of the treatments available today, exercise remains the most promising way to try to slow the impact of Parkinson’s. Our goal at NPF is to partner with leading community organizations to help ensure that people have access to safe and Parkinson’s-appropriate exercise programs, said Peter Schmidt, PhD, NPF’s Chief Mission Officer.

The national initiative, which is based on the groundbreaking Edmond J. Safra Parkinson’s Wellness Program—NYC, has seen class enrollment double in Boston and Washington, D.C., since each program launched.

“JCC Chicago believes strongly in providing a foundation for lifelong health and wellness within the communities we serve. The generous support from NPF and the Edmond J. Safra Philanthropic Foundation enables us to create programs for those living with Parkinson’s who otherwise have very limited access to the specialized exercise and movement activities that are so critical to maintaining their health,” said Todd Braman, Chief Operating Officer of JCC Chicago.

The Edmond J. Safra National Parkinson’s Wellness Initiative is offered in Boston, Chicago, New York, Tampa and Washington, D.C. All are welcome to attend classes, regardless of religious affiliation. Parkinson’s exercise classes are offered at a low cost and JCC membership is not required to participate.

This program is funded through the generous support of The Edmond J. Safra Philanthropic Foundation.

For more information visit www.parkinson.org/wellness.
NPF Helpline Answers 50,000 Calls

Since the phone rang for the first time in 2010, the National Parkinson Foundation’s (NPF) lifesaving Helpline (1-800-4PD-INFO) has responded to more than 50,000 calls. Every call is a one-on-one, personalized conversation, where one of NPF’s Parkinson’s disease specialists provide a caller with answers to Parkinson’s questions, health professional referrals or emotional support.

“We’re more than just an information line. We truly care about the people we serve and that’s the key to our success,” said Adolfo Diaz, NPF’s Director of Patient Services. “Whether you have yet to receive a diagnosis, are recently diagnosed with Parkinson’s, or caring for a family member with the disease, we are here to help you understand your condition, your care and the latest groundbreaking research on how you can live your best life with Parkinson’s.”

The NPF Helpline is staffed by a team of specially-trained nurses and social workers who empower callers with information and referrals tailored to their situation. Since the free service began nearly six years ago, the NPF Helpline has made more than 9,000 referrals to Parkinson’s health professionals.

Although Gary Harris is a full-time nurse, he still found navigating the health care system on behalf of a father living with Parkinson’s a daunting experience. Luckily, there was help. Recently, while advocating for his father during a hospital stay he reached out to the NPF Helpline and became the 50,000th caller.

“As I sat bedside, watching my father deteriorate day by day, and nobody helping, I was feeling total frustration in that moment,” he said. “My father’s doctor was not listening to me and I was really grasping at straws.” Following several calls to the NPF Helpline, Gary was able to get his father the care he needed and deserved.

Like Gary, many callers face serious situations involving medication side effects, hospitalization and caregiving, yet they have nowhere to turn for assistance.

“IT’s nice to have a compass like NPF that can lead you through the rough waters, Gary said. Callers from across the country seek support and advice from the NPF Helpline on a range of issues. Of all the issues addressed by NPF information specialists, the top five are about understanding symptoms, managing the disease, coping with the progression of the disease, referrals to Parkinson’s specialists and raising awareness.

In addition to its phone support, the NPF Helpline provides print materials covering various aspects of the disease in both English and Spanish. Since the NPF Helpline first started, nearly 300,000 free educational books and tens of thousands of Aware in Care kits have been mailed to callers, NPF Chapters and Centers of Excellence.

Beth Coffman, who was diagnosed with Parkinson’s five years ago at the age of 74, is a firm believer that education is the key to her success in managing the disease. Thanks to the NPF Helpline, Beth knows she is doing the right things to stay on track with her health.

“When I talk with the Helpline staff they recommend NPF books, depending on our conversation,” said the retired teacher. “Everyone I speak with is very knowledgeable. Once when I called after receiving an NPF book on exercise I was told to reference a certain page. It was a relief to go through the materials together over the phone.”

While her mobility is restricted due to Parkinson’s, Beth remains active. “Right now exercise is imperative to me,” she

CALL THE NPF HELPLINE TO:

- Get a referral to a PD health professional or program in your area
- Receive emotional support
- Discuss PD symptoms and treatments
- Order an Aware in Care kit or PD educational book

www.parkinson.org
said. “I walk two miles a day, six days a week and my physician says it’s remarkable that I’m this physically healthy.”

The majority of the people living with Parkinson’s are older adults. “It’s very nice to have a person to talk to because many of us can’t function on the computer as well anymore,” she said.

When asked about the best advice she received from the NPF Helpline, Beth concluded, “That there’s hope and to keep the faith. Keep asking questions. We’re there for you; that kind of encouragement is exceedingly important. The idea is that you have this disease but you can still live a satisfying life.”

For the Helpline staff, every day starts with the challenge of helping even more people with Parkinson’s stay on the path of well-being and independence. Each year, an estimated 60,000 people are diagnosed with PD. The aim of this service is to enable everyone affected by this disease—people with Parkinson’s and their families—to have access to support that meets their individual needs.

“This milestone is so significant because the need for this vital service is growing tremendously,” said Paul Blom, NPF’s Interim CEO. “That’s why building awareness for this service continues to be a priority for the National Parkinson Foundation.”

The NPF Helpline is made possible through the support of generous donors in the Parkinson’s community.

Call the Helpline at 1-800-4PD-INFO (1-800-473-4636). The Helpline is open Monday through Friday from 9 a.m. to 5 p.m. EST and can be reached via e-mail at helpline@parkinson.org.
When should a DaTscan be used in clinical practice?

A DaTscan is a relatively new imaging technology that is used to support a potential diagnosis of PD. The test is most commonly ordered when the PD diagnosis is uncertain and the doctor wishes to untangle the diagnosis of PD from a disease with similar symptoms (e.g., essential tremor). This uncertainty occurs most frequently early in the disease. The DaTscan works by injecting a chemical into a vein, which travels to a place in the brain that processes dopamine. A special camera image creates detailed pictures of the brain’s activity. If your DaTscan image is normal, it is unlikely you have PD and other diagnoses should be considered, such as essential tremor or dystonia. In the vast majority of cases, a neurologist or movement disorders specialist can separate essential tremor from PD based on an in-person examination and the response to dopamine replacement therapy. Imaging within DaTscan has been shown to be particularly useful in cases of drug-induced parkinsonism (DaTscan image is normal). A positive DaTscan image alone is not enough to confirm the diagnosis of PD. In cases where there is uncertainty in diagnosis despite multiple follow-up visits and the response to dopamine is uncertain, imaging within DaTscan may be useful. DaTscan imaging will not however differentiate between PD and other parkinsonisms (corticobasal syndrome, progressive supranuclear palsy (PSP), multiple system atrophy (MSA)). A normal scan would strongly suggest a diagnosis other than PD.

My husband freezes early in the day, but by late afternoon his freezing is gone and he walks quite swiftly. What can I do to help him get unstuck earlier in the day?

A Many people with PD experience “freezing” episodes, which are characterized by the inability to move. While the exact causes of freezing are still unknown, the episodes usually occur when a person is “off dopamine” or just prior to the next scheduled dose of PD medication. To better manage your husband’s freezing episodes, start by talking to his doctor about the nature of the episodes. Determine when the episodes occur and whether there is a relationship to medication wearing off or to under-medication. In many cases, an adjustment in dose or frequency (or both) can improve this symptom. In some cases, higher doses of dopamine are helpful, but in rare instances higher doses can actually lead to freezing. Be prepared for some trial and error testing. Physical therapy can also be helpful, and using the right assistive devices can lead to creative solutions. Walkers with laser lights to cue steps, music and metronomes all improve freezing in some patients. As PD progresses, it is possible that the gait and freezing issues will not respond to medication changes. Here are some strategies callers have shared with our Helpline to break a freezing episode:

- Shift weight (e.g., rocking) from one side to the other with assistance so as not to fall.
- March or count.
- Place a foot perpendicular to the frozen foot of the person with PD and ask him or her to step over it.
- Pay attention to freezing triggers and preparing strategies in advance to address them.
- Be aware that some physical therapy tricks may actually increase the risk of falling.
When you have Parkinson's disease (PD), it can be difficult to talk to friends, family and coworkers about your condition. Here are some tips that can make it easier for you to tell others about your diagnosis.

**Prepare in advance.** Choose a time and place that will put you at ease. Decide beforehand what you need and be forthright about asking for it.

**Start with those you're close to.** Open up about your challenges and needs with people you feel most comfortable with. Over time, talking about your condition will get easier.

**Talk to friends or family at one time.** The aim is to stay in control of how and when you tell people. Talking to a number of people at once may also make it easier for you to receive honest feedback.

**Don't be afraid to raise the subject with children.** The key is to respond honestly to their questions about your condition.

It is important to remember to stay calm and never push or rush a person with Parkinson's when frozen. Also remember that many falls happen as a person with PD tries to make a turn over a foot that is stuck to the ground. You should focus on fall prevention as the primary strategy whenever freezing is encountered.

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**Q** I was extremely surprised to have electroconvulsive therapy (ECT) presented as an option by my partner's psychiatrist. What are the benefits and dangers of using ECT for severe drug-resistant depression associated with Parkinson’s?

**A** Electroconvulsive shock therapy uses electrodes and an electric current to elicit a brief seizure in the brain. The treatment lasts just a few seconds, and patients wake up a couple minutes later. ECT is commonly administered six or more times over one month. Scientists are still unclear exactly how it works. You might think of ECT as resetting the software for the brain (i.e., we have all experienced the need to reboot our home computer). The therapy is largely under-utilized because of the stigma attached to it, due in part to the Hollywood portrayal of the therapy. Studies have shown that ECT offers tremendous symptom relief for depression associated with PD that does not respond to medications or depression that responds to medication in an incomplete fashion. There is some evidence that it may improve motor symptoms, especially in the short term. In the past, there were greater risks of ECT that seem to be related to suboptimal administration. Today, however, ECT is a very safe treatment. One drawback is that ECT patients often develop varying degrees of mild memory impairment, such as forgetting phone numbers or directions, however this usually resolves over time. Another treatment option worth considering is transcranial magnetic stimulation (TMS), which is a safe and effective depression treatment that is recommended for people who do not respond to antidepressant medication. TMS works by using a magnet to stimulate an area of the brain that is important to improving mood.

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*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.*
Finding new uses for old drugs is an exciting approach that could lead to breakthrough treatments for Parkinson’s disease (PD). Nilotinib (Tasigna) is an FDA-approved drug for chronic myelogenous leukemia that is currently being considered as a potential disease-modifying treatment for Parkinson’s.

Over the last several years, researchers have been exploring nilotinib’s potential to alter the abnormal protein buildup in PD also referred to as Lewy bodies. As Parkinson’s progresses, these deposits accumulate in the brain. In recent years, there has been great interest in developing drug therapies that may hold the potential to clear out these toxic protein deposits. The hope is that this approach could slow down or stop progression of the disease.

Nilotinib is part of a class of drugs called C-Abl tyrosine kinase inhibitors. These drugs decrease the activity of the protein C-Abl and signal cells to block and clear the buildup of toxic proteins in the brain. Previous laboratory studies have shown that nilotinib reverses the loss of dopamine neurons and improves motor behavior in animal models.

Investigators at Georgetown University Medical Center in Washington, D.C. (Drs. Fernando Pagan and Charbel Moussa), a National Parkinson Foundation Center of Excellence, recently reported on results from a small Phase 1 clinical trial using nilotinib for PD. The primary purpose of the study was to test the safety of nilotinib treatment in patients living with PD. The study results were presented at the annual meeting of the Society for Neuroscience in October 2015.

This preliminary study involved 12 patients who received a low daily dose of nilotinib for six months. The findings showed that the drug significantly improved clinical symptoms in study participants, including cognition, motor and non-motor function. In addition, positive changes were seen in the cerebrospinal fluid biomarkers including alpha-synuclein, amyloid beta and Tau.

Although there is much excitement surrounding this potential treatment for PD, patients and families should be aware of several things. First, results from this study have yet to be published beyond the conference proceedings as a paper in the peer-reviewed literature. Next, because the study was very small, larger studies will be needed to establish this cancer drug as a safe and effective treatment for PD. The dosages used for this study were less than those used for chemotherapy.

Future studies will be needed to identify the optimal dosing and administration to take advantage of the full potential of nilotinib, if it is found beneficial. Finally, there was no blinded comparison to a placebo or to another therapeutic approach, but this will likely be addressed in a future planned trial.

NPF recommends that patients only pursue this investigational drug through a clinical trial. You can visit www.clinicaltrials.gov to learn more about clinical trials taking place in your area. If you are interested in learning more about the results of this clinical trial, visit Georgetown University at www.medstargeorgetown.org.

The good news is that other similar FDA-approved drugs are now also being investigated as potential drug options to treat PD. It is an exciting approach, because these drugs have already been proven to be safe in patients. Most importantly, people with PD and families should feel reassured that the scientific discoveries that led Parkinson’s scientists to repurpose nilotinib may also lead them to other C-Abl strategies in the near future.

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.

NEW BOOK ON PARKINSON’S

**10 Breakthrough Therapies for Parkinson’s Disease**

by Michael S. Okun, MD
NPF’s National Medical Director

Order your copy today on Amazon.com!
Jennifer Hingyi has attended Moving Day® four times in four different cities and will attend more. After participating in Moving Day® Orlando 2014 with her team, “Jen’s Angels,” she realized that she enjoyed the walk and fundraising for people with Parkinson’s disease (PD).

Once Jen was diagnosed with Parkinson’s, she wanted to get involved with the PD community. She decided to start with Moving Day® Orlando because it’s where her father lived before he passed away from Parkinson’s-related complications.

Her son, Joey Hingyi, joined Jen in her first Moving Day® walk, and continued to support her by attending all four. “My son makes a point to go. It doesn’t matter what he’s got going on,” Jen said.

For her first walk Jen’s team consisted of Jen, Joey, her aunt, uncle and her two Great Danes, Ella and Maverick. They all donned blue shirts that read “Jen’s Team of Angels” on the front and “Never Give Up” on the back, with the exception of her dogs, who wore custom-made team bandanas.

Natalie Dobrolinsky, Jen’s best friend of 39 years who lives in Illinois and was a caregiver for Jen’s father, surprised Jen by showing up to her first Moving Day®.

Jen’s fur angels have accompanied her to Moving Day® Orlando, NC Triangle and Tallahassee. Together with Jen’s son, the four of them have driven more than of 1,040 miles for Moving Day®.

The Great Danes particularly enjoyed Moving Day® NC Triangle because of its dog-friendly activities.

Jen enjoyed Moving Day® Chicago the most, where she liked being a part of such a large turnout and enjoyed the full array of activities for children and adults.

After Jen was diagnosed with Parkinson’s, she realized that she had to exercise more. “I was doing just stationary bike at home, but then I decided that that wasn’t enough and I was tired of feeling like crap,” Jen said. “So I started going to the gym, and then I started working with a trainer, and that seems to really keep me motivated.”

Jen is on her feet at work six days a week as a dog groomer in Columbia, SC, where Ella accompanies her every day. Exercise has helped her overcome the constant fatigue she used to feel at work and has allowed her to finish each Moving Day® walk with vigor.

Jen has not allowed Parkinson’s to beat her. After four walks, “Jen’s Angels” has raised more than $9,300, an amount Jen thinks modest. She plans to attend up to two Moving Day® events in 2016 in new cities.

“She seems to be more upbeat since we started our Moving Day® adventures,” Natalie said. “Jenny and I have had the best times going to the Moving Day® walks and when one is done, we start planning for the next one.”

Natalie wants to attend Moving Day® Minneapolis or Miami next because they are two of the longest running Moving Day® events. Jen does not know which city will be next. All she knows is that if she can drive there, her dog is coming too.

Jen and Natalie enjoyed their first Moving Day® so much they decided they weren’t stopping at one. Seven months and nearly $2,000 in fundraising later, they were en route to their next adventure, Moving Day® North Carolina Triangle with Joey, Ella and Maverick in tow. “My dogs are my support team,” Jen said.

For a full list of upcoming Moving Day® events, visit www.npfmovingday.org.
### 2016 NPF Spring Event Calendar

#### APRIL

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Visit NPF’s Event Calendar at [www.parkinson.org/events](http://www.parkinson.org/events).
PARKINSON Report / Spring 2016

11

NPF Legacy Society

Legacy Society members are a select group of donors who have recognized NPF in their wills, trusts, estates and other planned gifts. Their generosity and forethought will help thousands of people with Parkinson’s live better lives in the years to come.

We depend on the generosity of people who direct philanthropic support to extend NPF’s services. There is no greater way to make a difference than by making NPF part of your legacy.

Please join the circle of people who have already made NPF part of their estate plans. A planned gift to NPF is truly a gift that keeps on giving.

If you would like more information about how you can become a member, please visit www.parkinson.org/plannedgiving.

You can also contact Amy Gray, Senior Vice President of Constituent and Community Relations, at agray@parkinson.org or 305-537-9906.

Run to Beat Parkinson’s

Parkinson’s doesn’t wait, so why should we? Every nine minutes someone is diagnosed with Parkinson’s disease. When you run with Team Hope™ for Parkinson’s, you will run a memorable course and achieve a personal goal, but for the 1 million Americans living with Parkinson’s, it means so much more.

- April 24, 2016 – Big Sur International Marathon
- May 7, 2016 – Santa Barbara Wine Country Half Marathon
- June 1, 2016 – National Running Day
- 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

For more information, please contact Sara Teeter at teamhope@parkinson.org or 305-537-9951.

Member Spotlight

“I currently own five pairs of running sneakers, each set patiently awaiting their turn for a tour through New York City’s bustling sidewalks and streets. Some shoes have holes, others no tread, two are bright pink and barely used, while others are faded and brown. These shoes give me hope, and remind me each day that I can take steps towards defeating Parkinson’s disease, steps that support my father’s steps, as well as those of millions of others.”

– Amy Bukszpan