Despite the dearth of funding of Parkinson’s disease (PD) research, the field is exploding with possibilities. A key question facing the National Parkinson Foundation (NPF) is: What can we do today for a better tomorrow?

NPF is expanding its efforts to support Parkinson’s research and programs throughout its Centers of Excellence (COE) network. With the generous support of The McCamish Charitable Fund, NPF recently awarded a $120,000 fellowship to train neurologists in the movement disorder specialty. NPF also awarded a first, annual $25,000 research grant to help talented, up-and-coming investigators accelerate their scientific careers.

NPF believes both programs will stimulate the search for better ways to treat PD and for game-changing discoveries that could, ultimately, lead to a cure, just two components of NPF’s strategic plan.

Researchers, clinicians and staff from our worldwide network recently gathered in Atlanta for our annual Centers of Excellence Leadership Conference, where NPF presented the 2015 McCamish Young Investigator Award to James W. Maas, MD, PhD.

The year-long research grant will allow Dr. Maas, a young researcher in the neurology department at University of California, San Francisco, to conduct research aimed at understanding cognitive changes in PD.

...continued on page 2
Over the past year, NPF embarked on a strategic planning process to develop an updated vision and plan. In the process, we listened to scientists, patients and families, community leaders and supporters like you.

What we learned...

First, we are committed to our role as the leading voice for Parkinson’s patients and families on care issues. We have long led the way in innovations and intend to continue.

Second, we will better align our programs with donor wishes by supporting more research. Today, the National Institute of Neurological Disorders and Stroke (NINDS) budget for Parkinson’s research has been reduced substantially. As a result, top-tier investigators, particularly young researchers, are finding it difficult to obtain funding. This is one area where we can do more in the future.

Third, in all of our networks and programs, we will focus our efforts on augmenting standards of excellence—a move that we feel will increase our capacity to deliver on our mission.

We hope that you are excited about the year ahead, as we strive to make life better for people with Parkinson’s on an even bigger scale. Together, we can beat this disease.

Sincerely,

Joyce Oberdorf
President and CEO

For more information, visit www.parkinson.org/research.
In an ideal world, every discovery coming out of the lab would result in medicines, technologies and practices that would benefit people with Parkinson’s (PD). Although the ideal is rarely achieved, the National Parkinson Foundation (NPF) has developed a new model for its Centers of Excellence (COE) program that aims to close the gap between ideal and real.

Among key initiatives, NPF will increase funding to investigators conducting pioneering research and align its research agendas. By aiming the work of clinicians, scientists and health care professionals at similar goals and sharing data, ideas and resources, we hope to amplify the network’s collective impact.

NPF’s vision is for an integrated research and care enterprise, where patient-focused clinicians deliver the latest care and newest therapies, and their research reflects the priorities of patients and families, said Peter Schmidt, PhD, NPF’s Vice President of Research and Professional Programs.

Another goal is to expand the network. In February 2015, the Movement Disorder Center at the University of California San Diego Health System was designated the 41st Center of Excellence in the global network. UC San Diego leads in research to understand the cause of PD, using stem cells to investigate interactions between genes and environmental factors that can lead to the disease.

“The movement disorder program at UC San Diego was intentionally modeled after NPF’s Centers of Excellence vision because of its comprehensive patient-centered focus,” said Irene Litvan, MD, Tasch Endowed Professor in Parkinson’s Disease Research and Director of the Movement Disorders Center at UC San Diego. “At UC San Diego, we are dedicated to translating scientific advances to our patients, and also providing our patients the opportunity to contribute to research and discovery.”

In October 2014, the Jean and Paul Amos Parkinson’s Disease and Movement Disorders Program at Emory University in Atlanta was designated an NPF Center of Excellence. Emory University is both a regional and international leader in Parkinson’s research, care and training.

In the past, Parkinson’s specialists at Emory University made the study of deep brain stimulation (DBS) the focus of their research, and today the DBS surgical technique they pioneered is used around the world, helping more people lead quality lives. Recently, researchers there concluded more than 20 clinical trials that have the potential to improve health in people with PD.

Currently, our COE network serves some 50,000 patients in the U.S. Still, with more than one million Americans diagnosed with PD and countless others who remain undiagnosed, the need to reach more people is urgent. NPF’s new model aims to help clinicians overcome some of the challenges they face in getting quality care to the patients who fall by the wayside.

That will be accomplished, in part, by developing metrics to measure and demonstrate the impact of care provided at our Centers of Excellence. The aim is to show that care interventions are reaching more people, especially those in underserved areas and rural areas, and that the care provided is resulting in a meaningful impact on patient lives.

Increasing access to high quality care for Parkinson’s patients has been the hallmark of NPF’s mission since its inception. And thanks to the philanthropic support of the Parkinson’s community, we are finding new ways to help people live better lives today.

For more information, visit www.parkinson.org/coe.

New Financial Assistance Program for Parkinson’s

The Patient Access Network (PAN) Foundation is an independent, nationwide organization dedicated to providing help and hope to underinsured patients who are unable to afford the out-of-pocket expenses for their prescribed medications. To discuss eligibility and to apply, call 866-316-PANF (7263). To learn more, visit www.PANfoundation.org.
As the inspiration for the 2012 Academy Award-winning film *Argo*, master of disguise Tony Mendez organized and led the high-stakes operation that rescued six American diplomats trapped in Tehran during the 1980 Iran hostage crisis. For this mission, the CIA awarded Mendez the Intelligence Star of Valor. Today, Mendez is on a new mission: using his personal experience and fame to increase awareness of Parkinson’s disease (PD). Nearly seven years ago, the retired spy was diagnosed with PD. He then began receiving care at Johns Hopkins University, an NPF Center of Excellence. Recently, he and his wife Jonna, who is also a retired CIA agent, were interviewed by Becky Dunlop, RN, and Michael Okun, MD, at the NPF Leadership Conference in Atlanta.

**NPF:** What led you to share your diagnosis with others?

**Tony:** It seemed to be the right thing to do. When I was diagnosed with Parkinson’s I knew very little about it.

**Jonna:** The idea to speak out about Parkinson’s happened gradually. But there was a moment when we thought maybe we could use his celebrity to bring more attention and awareness to Parkinson’s disease. Tony has always been on the side of “if you can do something, do it” and “if you have a shot at something, take the shot.” So he wanted to move forward and share his story publicly. But it’s a tough decision. We’ve discovered that so many people with Parkinson’s won’t talk about it.

**NPF:** What are some of the things that help you live better with Parkinson’s?

**Jonna:** Physical exercise is absolutely important to him. Having good friends over to our house is also important. Staying active and engaged in life keeps him moving forward. We’ve become more meticulous in arranging things—everything from securing area rugs to installing railings on the stairs. He’s just started falling. So it’s important to anticipate those areas of concern and prepare for them. And realizing he can’t be stressed anymore. His doctor told me, when his tank is empty, it’s actually empty. He needs more downtime. So I try to slow down and serve him.

**NPF:** Jonna, what are your tips for caregivers?

**Jonna:** As a caregiver, there’s a lot to learn. But organization is absolutely key. He takes his meds every two hours and if he misses them he pays a price. It’s really about keeping all the small things lined up. Then everything runs smoothly.

**NPF:** What is life like now, a couple of years post *Argo*?

**Tony:** The pressure is coming off me, and we’re starting to slip back into our own projects. We’ll probably paint and write and photograph a few thousand more pieces. Other than that, we’ll just hang out.

**Jonna:** When *Argo* won the Oscar for Best Picture, everything went nuts. This is the only big movie ever made about the CIA. Tony put his paintbrushes aside and we did nothing but travel and speak for two years. But things have calmed down. Everybody’s fifteen minutes ends and that’s probably a good thing. Now we pick and choose very carefully where we go and who we speak to.

**NPF:** How did you get involved with NPF?

**Jonna:** Through friends. We kind of knew there was a Parkinson’s community out there, but we didn’t know who it was or where it was. Then we met a group of people from NPF and this new world opened up.

**NPF:** You’ve had DBS surgery. Where are you the most hopeful in Parkinson’s research?

**Tony:** A cure would be good!
Two potential disease-modifying treatments for Parkinson's disease, a vaccine and what is called monoclonal antibody therapy, are generating excitement among researchers. These ground-breaking approaches, which are forms of immunotherapy, allow patients to fight Parkinson's disease (PD) with their own immune systems.

PD is a neurodegenerative disorder associated with the accumulation of a brain protein called alpha-synuclein. These protein clumps, called Lewy Bodies, spread throughout the brain as the disease progresses. Many experts believe that much of the damage that occurs in PD is a result of the brain's failure to process and clear these proteins that proliferate out of control.

The concept behind the vaccination is simple: make use of the body's own healing powers. The PD vaccine is designed to stimulate the immune system to attack alpha-synuclein. The goal is to reduce levels of alpha-synuclein in the brain and, ultimately, slow or halt disease progression.

In a first-of-its-kind study, a PD vaccine called PD01A was tested on 32 Parkinson's patients who received four injections (one every four weeks). The primary endpoint of this phase 1 clinical trial was safety and tolerability. The preliminary study, which concluded in September 2014, revealed that the vaccine was safe and well-tolerated.

The study also showed that half of the patients developed antibodies against alpha-synuclein. The investigators believe that the presence of these antibodies was a positive sign. Why some patients did not develop antibodies is an unresolved question, but a follow-up study will assess the impact of a booster vaccine on the immune response in these patients.

Using a different approach, the companies Prothena and Roche are collaborating to develop a monoclonal antibody therapy that directly targets alpha-synuclein. Monoclonal antibodies are very specific molecules designed to attach to and help destroy certain cells. Prothena's therapeutic monoclonal antibody PRX002, developed for for the treatment of PD, entered a phase 1 clinical trial in April 2014. This study will evaluate the safety and tolerability of the drug.

What's the difference between monoclonal antibody therapy and a vaccine? Monoclonal antibodies are made in a laboratory and injected into the bloodstream as direct therapy, whereas the PD vaccine works by priming the immune system to produce antibodies against alpha-synuclein.

It's important to realize that not all experts believe that eliminating these brain proteins will result in clinically meaningful changes and disease modification. Additionally, we must keep in mind that one highly publicized attempt to target amyloid in Alzheimer's patients led to serious safety concerns and meningoencephalitis (inflammation of the brain).

What you need to know about the PD vaccine and monoclonal antibody therapy is that both therapies are still in the very early stages of testing. But the idea of using the body's own immune system as a defense against PD is novel and promising.

Safety, tolerability and clinical efficacy will need to be demonstrated before the vaccine and monoclonal antibody therapy can move into the next phase of clinical testing.

Our hope is that the reduction of Parkinson's-associated brain proteins will translate into disease modification. A similar approach is also being tested in other diseases such as Alzheimer's, diabetes and atherosclerosis. These therapies are definitely something to get excited about because they could change how we treat PD.

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/whatsshot.
I am preparing for my first visit with a movement disorder specialist (MDS). What are the top questions every new patient should ask their MDS on their first visit?

This is a great question, because knowing what to ask and preparing your questions before your first visit will go a long way in facilitating the best possible care. Here are some of the top questions you may want to address with your doctor:

At this time, what is the best plan to address my symptoms?

Before your visit, make a list of your symptoms. Start with the ones that are bothering you the most and present them in priority order. In many cases addressing your chief concern first will alleviate some of your other symptoms. During the visit, be prepared to discuss your problems in detail. An effective intervention will depend on an accurate diagnosis.

Do you recommend other specialists?

Parkinson’s disease involves a broad range of problems, as diverse as difficulty communicating, trouble with activities of daily living, and balance problems. These issues should be maximally treated with medications and different types of therapy, including physical, occupational and speech therapy.

Should I be screened for depression?

Depression and anxiety should be considered and treated if present. Even though they are frequently the most common and disabling conditions in people with PD, they are often overlooked by both physicians and patients. Sleep disorders are also common and can threaten quality of life. Be sure to discuss these conditions with your doctor and aggressively address them if present.

What’s new in Parkinson’s research?

There are numerous opportunities for people with neurological disorders to participate in clinical trials testing new drugs, devices and procedures. Your doctor may be able to offer access to investigational medications that will benefit you. For more information about clinical trials, visit clinicaltrials.gov.

What patient education materials are available to me?

Movement disorder specialists have knowledge of and access to valuable resources such as handouts, pamphlets and websites. These resources can help you manage your care.

If you need additional help preparing for your visit, call NPF’s national Helpline (1-800-4PD-INFO). The NPF Helpline is staffed by nurses and social workers who can answer your questions and provide support.

I have heard that medical marijuana can be beneficial to people with Parkinson’s. What should people with Parkinson’s know about its pros and cons?

Medical marijuana, or cannabis, has been legalized in 23 states and the District of Columbia. Last year, a panel of experts convened by the American Academy of Neurology reviewed the medical literature supporting the use of medical marijuana for treating certain neurological disorders. They found that a pill form of medical marijuana, with the active ingredient tetrahydrocannabinal (THC), was ineffective in treating Parkinson’s-related tremor or levodopa-induced dyskinesias, but there was little information on other symptoms or approaches.

Still, it’s possible to think that marijuana may have the potential to alleviate PD symptoms. Cannabinoid receptors in the brain are concentrated in a region central to PD, known as the basal ganglia. We have reason to think that cannabis, and its derivatives, that act on these receptors, could potentially improve symptoms. Increasingly, people with PD call NPF’s Helpline, reporting positive stories with the use of marijuana.
Eating a healthy diet filled with lots of fruits and vegetables and drinking plenty of water is essential for staying energized throughout the day. But for people with Parkinson's, mealtime can often be a source of stress. Here are some tips to make it more enjoyable.

Plan ahead. It's easier to eat foods you like when it's already on hand and you can get dinner on the table quickly. Stock up on foods that are easy to chew, cut and swallow.

Eat more often. If your appetite is poor, eat small meals frequently throughout the day, rather than forcing yourself to follow the traditional three-meal-a-day plan.

Use adaptive eating utensils. Easy to hold curved utensils, scooper plates and nosey cups with a special cutout rim can make it easier to cut food and drink fluids.

Rethink mealtime. You'll feel better if you choose a comfortable, cheerful setting to serve meals. Play some relaxing music to counteract the ill effects of mealtime stress.

Call NPF's National Helpline. For more information on PD and nutrition, call 1-800-4PD-INFO (473-4636).

The information published in this “Ask the Doctor” Forum is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise. Accordingly, please consult your own professional for all advice concerning medical, legal, or other matters published in connection with this Forum. NPF assumes no liability of any kind for the content of any information transmitted to or received by any individual or entity in connection with their use of the “Ask the Doctor” Forum on the NPF Web site, and NPF does not endorse or recommend any such information.
Family Matters: Senator Cory Booker Raises Awareness

In November, NPF unveiled a new public service announcement (PSA) featuring U.S. Senator Cory Booker (NJ) raising awareness of the early warning signs of Parkinson’s disease (PD) and the important role family and friends play in caring for those affected. The PSA launched during National Family Caregivers Month—a time to thank and celebrate the more than 60 million Americans who deliver care to seniors or people with disabilities or illnesses across the country.

In the 60-second spot, Sen. Booker talks about his father’s battle with PD and the role his mother played as caregiver. Sen. Booker outlines ways to spot the early warning signs and where to seek help. The PSA aired in select markets across the country and is available online.

“Today, approximately one million people in the United States are living with Parkinson’s disease. My dad was one of those people. My mom was his primary caregiver. Know the signs or how to spot them in yourself or someone you love.”

– Senator Cory Booker

Here are ways to spot the early warning signs of PD in someone you love:

- Tremor or shaking
- Small handwriting
- Loss of smell
- Trouble sleeping
- Trouble moving or walking
- Masked face
- Soft or low voice
- Constipation
- Dizziness or fainting
- Stooping or hunching over

The good news: with early detection, treatment and expert care, many people are living longer, more productive lives with PD. Resources are available to help answer questions about the early warning signs—NPF has a community of experts who are available to offer advice and support.

The Social Buzz

@ParkinsonDotOrg

“My mother had this for 19 years. Thank you Senator Booker for raising awareness. It’s through tireless work and raising awareness that we all can beat this disease.”

“The best message about PD I have heard. Thank you Senator Booker – if your message reaches even 1 person you have done a great service for the Awareness of PD.”

“I love this guy anyway... honest, straightforward, man of the people. And now this just makes me love him more. My brother-in-law has Parkinson's so this PSA really hits home. Thank you, Cory.”

For more information, visit www.parkinson.org/10signs.
Have you seen our “Know the Early Signs” video? www.parkinson.org/psa.
Spotlight on Moving Day® DC

The message that comes across loud and clear when speaking to Supereena Kapoor about her battle with Parkinson’s disease (PD) is simple—education is the key to change.

“The best way I can give back is to educate people about this disease. If people knew more about all that is involved in this disease and how it really affects people, they would be more willing to give money to Parkinson’s research, and they would be more tolerant of people they encounter with the disease,” Supereena said.

On June 7, Supereena and the team she started—Team Supereena Kapoor—will take part in Moving Day® DC. She is gathering over 100 friends, neighbors and community members to walk alongside her at the event and to help her reach her fundraising goal.

This year, Moving Day® DC will take place at the National Mall. The festive, family event will spotlight PD and give participants a chance to speak out about the disease in the nation’s capital. The money generated through Moving Day® helps fund local outreach and education and advancement of clinical care for people living with PD.

In addition to the one-mile or 5K walk, the event will feature a Movement Pavilion with stations offering yoga, Tai Chi, dancing and Pilates, as well as food, fitness and medical vendors. The theme of the day—movement is the body’s way of celebrating life—is a message that brings people together.

Supereena was only 33 when she was diagnosed with Young-Onset Parkinson’s disease. At the time, she knew very little about the disease, even though she was working as a pharmacist. In the ensuing years, her health declined drastically. As a result, she had deep brain stimulation, which improved her life dramatically. Today, 15 years after her diagnosis, the single mother of two is passionate about raising awareness of PD.

“It’s important for people to talk about their disease. Many people are ashamed that they are experiencing these symptoms and won’t talk about it. They hide and don’t socialize. I did the opposite. I told everyone, everywhere I would go. I think the more open you are, the more willing people are to help,” Supereena said.

Besides raising money and awareness at Moving Day® DC, Supereena also hopes to lift some spirits.

For people who don’t have Parkinson’s, I’m hoping that this event will help them truly begin to understand the depth of how disastrous this disease is to people. And for people with Parkinson’s, I’m hoping they will come away from Moving Day® re-energized. I want them to feel that they have power over this disease, and that they can live very happy, productive lives with modifications, Supereena said.

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

Come join us at Moving Day® DC on Sunday, June 7, 2015. The event will take place at the National Sylvan Theatre (Washington Monument Grounds). For more information, visit www.movingdaydc.org.

The National Parkinson Foundation Helpline
1-800-4PD-INFO
1-800-473-4636
Help is just a phone call away.

…we speak English and Spanish
2015 NPF Spring Event Calendar

APRIL

4/8: Free Webinar: “The Path to the Next Breakthrough in Parkinson’s Disease”
Register online: www.parkinson.org/webinars

4/11: Moving Day® Tampa Bay, FL
Register online: www.movingdaytampabay.org

4/12: Moving Day® Tucson, AZ
Register online: www.movingdaytucson.org

4/12: Team Hope for Parkinson’s™, Hapalua Hawaii’s Half-Marathon
Learn more: www.parkinson.org/marathon

4/19: Moving Day® San Francisco, CA
Register online: www.movingdaysanfrancisco.org

4/25: Visit the NPF Booth at the Parkinson’s Unity Walk, Central Park, New York City—Presented by the Parkinson Alliance
Register online: www.unitywalk.org

4/25: Moving Day® Silicon Valley, CA
Register online: www.movingdaysiliconvalley.org

MAY

5/2: Moving Day® Twin Cities
Register online: www.movingdaytwincities.org

5/16: Moving Day® Tallahassee
Register online: www.movingdaytallahassee.org

JUNE

6/7: Moving Day® Washington, DC
Register online: www.movingdaydc.org

6/13: Moving Day® Kansas City, MO
Register online: www.movingdaykansascity.org

6/14-18: NPF Wellness Retreat, Stockbridge, MA—Kripalu Center for Yoga and Health
Learn more: www.parkinson.org/retreat

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

The National Parkinson Foundation’s 2014 Annual Report, “Expert Care for a Better Today, Research for a Better Tomorrow” is now available to view online:

www.parkinson.org/annualreport
Run to Beat Parkinson’s

Have you always wanted to run in one of the most memorable races in the country? You can now run with Team Hope™ for Parkinson’s in the Marine Corps Marathon on 10/25/15 or the TCS New York City Marathon on 11/1/15 to support the brave people who battle Parkinson’s every day. You will make the personal achievement of running a long-distance race even more memorable by helping NPF improve care and change lives for people with Parkinson’s.

Sign up to run with Team Hope™ and you will receive a guaranteed race entry! Don’t wait – spots are limited. Reserve yours before it’s too late!

For more information about participating in the Marine Corps Marathon or TCS New York City Marathon, please contact Sara Teeter at teamhope@parkinson.org or 305-537-9951.

Help Is At Your Fingertips

Join One of Our Free Online “Ask the Expert” Forums

For detailed, step-by-step instructions for registering and logging into the forums, visit www.parkinson.org/forums.

ASK THE DOCTOR:
A team of Parkinson’s specialists answer medical questions about Parkinson’s disease.

ASK THE SPEECH CLINICIAN:
A team of experts answers questions regarding speech and swallowing.

ASK THE PHARMACIST:
Mark Comes, RPh, fields questions about medication management.

PREGÚNTELE AL MÉDICO:
Ramon L. Rodriguez, MD contesta preguntas con respecto a la enfermedad de Parkinson y materias relacionadas.
WHATEVER IT TAKES
to Beat Parkinson’s
Support NPF and learn how to beat Parkinson’s with our new line of merchandise

SHOP THE COLLECTION
www.parkinson.org/store

Please recycle this newsletter.