Calendar of Events
2

Research Update from the Chief Scientific Officer
3

FEATURE
Parkinson’s Foundation Increases Research Investment
4

One Year Later: Catching Up with Parkinson’s Foundation Researchers
5

Ask the Doctor
6

TIPS & TOOLS
Tips for Activities of Daily Living: Is a Clinical Trial Right for You?
7

Marijuana and Parkinson’s: What Do We Really Know?
8

How One Researcher is Helping the Most Vulnerable Parkinson’s Population: Women
9

Parkinson’s Patients Turned Research Advocates
10

Generosity Fuels Life-Changing Parkinson’s Research
11
Events

**SEPTEMBER**

- **6-7** Volunteer Summit
  Orange County, CA
  Learn more: Parkinson.org/Events

- **9** Moving Day Columbus
  Register: MovingDayColumbus.org

- **18** Expert Briefings Webinar:
  Mental Health and PD
  Register: Parkinson.org/ExpertBriefings

- **22** Moving Day Buffalo
  Register: MovingDayBuffalo.org

- **29** Moving Day New Jersey
  Register: MovingDayNewJersey.org

- **30** Moving Day Rochester
  Register: MovingDayRochester.org

For a full list of events visit Parkinson.org/Events.

**OCTOBER**

- **7** Bank of America Chicago Marathon
  Chicago, IL
  Register: Parkinson.org/Champions

- **13** Moving Day Boston
  Register: MovingDayBoston.org

- **14** Moving Day Chicago
  Register: MovingDayChicago.org

- **17-20** Allied Team Training for Parkinson’s Disease
  Atlanta, GA
  Apply: Parkinson.org/ATTP

- **20** Moving Day Las Vegas
  Register: MovingDayLasVegas.org

- **21** Moving Day Los Angeles
  Register: MovingDayLosAngeles.org

- **27** Moving Day Atlanta
  Register: MovingDayAtlanta.org

- **27** Moving Day Dallas/Ft. Worth
  Register: MovingDayDFW.org

- **28** Marine Corps Marathon
  Washington, D.C.
  Register: Parkinson.org/Champions

**NOVEMBER**

- **3** Moving Day NC Triangle
  Register: MovingDayNCTriangle.org

- **4** TCS Marathon
  New York City, NY
  Register: Parkinson.org/Champions

- **10** Moving Day Jacksonville
  Register: MovingDayJacksonville.org

- **18** Philadelphia Marathon
  Philadelphia, PA
  Register: Parkinson.org/Champions

- **27** Expert Briefings Webinar:
  Advanced PD and Palliative Care in the 21st Century
  Register: Parkinson.org/ExpertBriefings
Research Update from the Chief Scientific Officer

Our goal at the Parkinson’s Foundation is to make life better for people living with Parkinson’s disease (PD) by improving care and advancing research toward a cure. As the Chief Scientific Officer, I oversee our research portfolio, which funds: 1) early stage and proven researchers; 2) innovative research; and 3) research networks and convenings on key research topics.

As you will read about in this special issue dedicated to research, the Foundation has made a commitment to increasing the number of researchers funded; expanding our partnerships with patient advocates in research; and creating the first research agenda for women with Parkinson’s.

Since 1957, we have dedicated $330 million to better understanding this disease. To find a cure for Parkinson’s, we must multiply the number of researchers who can make breakthroughs in discovering what causes Parkinson’s, how to treat it and how to prevent it. I am confident that with more research we will make advances toward better therapies and ultimately a cure.

James Beck, PhD, can be reached at jbeck@parkinson.org.

Stay Engaged, Educated and Empowered with These Resources

Visit Parkinson.org, the go-to Parkinson’s disease resource, to stay up-to-date on the latest Parkinson’s research, news and treatments. Check out our free articles, episodes, resources in spanish and educational books.

Call our Helpline 1-800-4PD-INFO (473-4636) to ask our Parkinson’s information specialists about Parkinson’s medications or symptoms, referrals or for emotional support.

Participate or watch our Expert Briefings webinars about Parkinson’s symptoms, treatments and management hosted by Parkinson’s experts.

Order our free Aware in Care kit. Included are the tools and information a person with PD can use to get the best possible care when hospitalized, whether it’s a planned or unplanned visit.
This year, the Parkinson’s Foundation is awarding almost $6 million to Parkinson’s disease (PD) research — funding an additional Movement Disorders Training Award and Postdoctoral Fellowship. These grants bring hope to the Parkinson’s community as each one has the potential to lead to a breakthrough treatment.

Research grant nominees undergo rigorous peer review and explore everything from promising high-impact studies to specialized training. Below we highlight three of the 2018 Parkinson’s Foundation research award recipients leading their own studies.

**Figuring Out How the Brain Responds to Visual Cues for Gait Impairment in Parkinson’s**
Samuel Stuart, PhD, from Oregon Health and Science University, a Parkinson’s Foundation Center of Excellence, is one of six Postdoctoral Fellowship awardees this year. The $110,000 Parkinson’s Foundation grant will help his team study which brain regions react to the visual cues that help people with PD with walking impairments.

Walking impairments, like freezing, are common in Parkinson’s and lead to increased risk of falls. Some people experience improvements when they use visual cues, but we don’t know why. Dr. Stuart hopes to find out how the brain responds to visual cues by using a non-invasive device to track walking with and without visual cues, while monitoring gait and brain response. This study can lead to more effective, targeted walking impairment treatments for more people with PD.

**Investigating the Link Between Energy and Brain Glucose Metabolism in Parkinson’s**
Gulcin Pekkurnaz, PhD, from University of California, San Diego, is one of three recipients of the Stanley Fahn Junior Faculty Award. The $300,000 Parkinson’s Foundation grant will aid her study to better understand how the brain’s ability to metabolize blood glucose may impact energy in people with PD.

Parkinson’s develops when the energy factories (mitochondria) start to fail in dopamine neurons. It is still not well understood how we can keep these mitochondria healthy in relation to our dopamine neurons. Dr. Pekkurnaz developed a new way to determine what causes the brain’s energy factories to weaken inside dopamine neurons. Her goal is to identify the vulnerabilities of neurons in PD — before symptoms start.

**Determining if the Alpha-Synuclein Strain Can Predict Cognitive Decline in Parkinson’s**
Liana Rosenthal, MD, from Johns Hopkins University, a Center of Excellence, is one of three Clinical Research Awards recipients. The $200,000 Parkinson’s Foundation grant will fund her study to determine if alpha-synuclein (a protein in the brain tied to Parkinson’s) can predict cognitive decline in people with Parkinson’s.

People with PD who develop dementia experience a significant impact on quality of life and increased caregiver stress. No test can determine who will develop dementia or how quickly it will progress. Dr. Rosenthal will examine if a specific strain of alpha-synuclein can predict slower disease progression. By identifying progression markers for PD-related dementia, she and her team will have the potential to improve the function, health and mortality of people with Parkinson’s.

Learn more about the grants funded by the Parkinson’s Foundation at Parkinson.org/GrantsWeFund.
One Year Later: Catching Up with Parkinson’s Foundation Researchers

The Parkinson’s Foundation Community Choice Research Awards set research priorities based on the insights of people living with Parkinson’s disease (PD). Last year, the Parkinson’s Foundation awarded Community Choice Research grants totaling $500,000. These three researchers are making major strides just one year into their Parkinson’s Foundation grant-funded research.

Using Brain Imaging to Track Fatigue in Parkinson’s Disease

Hengyi Rao, PhD, and his team seek to explain brain function changes underlying PD-related fatigue and explore whether blue light can reduce it and fatigue-related brain dysfunction. The study requires participants to stay in an MRI scanner for up to 100 minutes without head movement. Despite the challenge, Dr. Rao said most participants with PD completed the study because they are dedicated to moving fatigue research forward. Preliminary findings suggest PD fatigue may be associated with altered organization of an interconnected brain network that is normally active when people are at rest and not completing any tasks.

Amy Amara, MD, PhD

Impact of Exercise on Executive Function and Sleep

Amy Amara, MD, PhD, is evaluating exercise’s impact on people with Parkinson’s and PD-related non-motor cognition and sleep symptoms. Not many effective medication treatments for these symptoms exist. Exercise can improve Parkinson’s motor symptoms, so it could improve non-motor symptoms. Participants are randomly assigned a group: exercise or no exercise. The trial compares changes between the two groups through sleep studies. Dr. Amara has seen significant improvements in sleep efficiency and sleep time for the exercise group participants compared to the no-exercise group.

Milton Biagioni, MD

At-Home Brain Stimulation for Fatigue and Cognitive Slowing

Milton Biagioni, MD, is studying whether a portable, non-invasive brain stimulation device can alleviate PD-related fatigue and cognitive slowing — symptoms with no proven effective treatments. Using a specially designed transcranial direct current stimulator (tDCS) device and a new method of remote supervision, the therapy is done in the participant’s home through video conferencing. Preliminary findings suggest an improvement in fatigue with 20 sessions of tDCS, but not with 10 sessions. Ongoing work will aid in determining the ability of this intervention to treat cognition.

Learn more about Parkinson’s Foundation grant opportunities at Parkinson.org/Grants.
Ask the Doctor

Authors: (top to bottom) Michael S. Okun, MD; Kelly D. Foote, MD; Adolfo Ramirez-Zamora, MD.

What is the current medical opinion of stem cell research in relation to Parkinson’s disease (PD)?

There are two types of stem cell research: lab and human-based. Lab-based stem cell research can help us better understand PD and identify potential new treatments. Stem cells administered to people have not shown any evidence of halting PD, but it might help ease motor symptoms when implanted into the brain (not spinal cord). However, research will have to prove it as efficient as dopamine pumps or deep brain stimulation. Few human-based clinical trials are underway. If you decide to participate in a stem cell clinical study, keep the following in mind:

- Confirm that the study has been approved by an Institutional Review Board (IRB), which is responsible for protecting study participants by ensuring that research follows ethical and regulatory guidelines.

- Ask for a copy of the stamped and dated study protocol and informed consent form and share them with your doctor. Walk away if these documents cannot be provided.

- Be aware of the practice of “stem cell tourism” where individuals travel and pay thousands of dollars for unproven stem cell treatments that are not part of an approved clinical study.

- Know that stem cell transplants for PD are classified as research and are not an FDA-approved therapy.

Stem cells are not a cure for Parkinson’s. Always talk to your doctor before you participate in a clinical study.

I am in my 60s and was recently diagnosed with Parkinson’s. My doctor suggested I consider signing up for a clinical medication trial. Should I participate?

Clinical trials help us to discover new drugs and new uses for drugs. Clinical trials have been crucial to developing currently available Parkinson’s medications. A good trial must fit the patient’s needs and the patient must be willing to participate.

While the most notable benefits include access to leading healthcare professionals and a cutting-edge potential treatment, participants also usually gain more insight into their PD symptoms and treatment. Clinical trial treatments can involve risks, such as undesirable side effects or seeing no effects. In a clinical trial you have the right to quit any time. However, discuss the pros and cons of any clinical trial with your PD specialists prior to participation.

Read Dr. Okun’s monthly What’s Hot in PD? column at Parkinson.org/Blog.
I've read that the “placebo effect” may benefit some people with Parkinson’s. Is this true?

To measure the effectiveness of potential PD treatments, scientists compare the experiences of a group taking a treatment to a group taking a placebo — an inactive substance, such as a sugar pill.

Before starting a double-blinded trial (when neither participants nor researchers know who is receiving the real treatment) participants are told they may receive the placebo. Researchers often find that some people taking a placebo will report improvement in their symptoms. This is called the “placebo effect.” Unlike a drug or treatment, the placebo effect usually does not last.

PD-related studies show that the placebo effect is more than imagination; biochemical changes occur in the brain. Dopamine, which is reduced or lost in Parkinson’s, also plays a role in the placebo effect. Researchers are working to understand how the placebo effect changes the brain and how it affects clinical trial results. This information may help us better evaluate therapies.
The following article is based on a Parkinson’s Foundation Expert Briefings webinar about marijuana presented by Benzi M. Kluger, MD, MS, from the University of Colorado. View all past Expert Briefings at Parkinson.org/ExpertBriefings.

People with Parkinson’s disease (PD) and their physicians want to know if medical marijuana can help manage Parkinson’s symptoms. Researchers have barely scratched the surface on the topic and studies are inconclusive, but many people with Parkinson’s remain curious. Here is what you need to know:

**About Marijuana**

Marijuana comes from the plant genus Cannabis. Cannabis chemicals — cannabinoids — affect the nervous system. The plant contains more than 100 different psychoactive chemicals, which have complex effects. The best-known chemicals are:

- **THC (D9-tetrahydrocannabinol):** generally makes a person feel “high.”
- **CBD (cannabidiol):** generally helps calm the nervous system.

Endocannabinoids are the brain’s naturally occurring cannabinoids. Marijuana’s cannabinoids can bind to and activate or block endocannabinoid receptors. Two main brain receptors respond to marijuana: CB1 (primarily in the central nervous system) and CB2 (in the immune system).

Preliminary studies suggest that activation of CB1 receptors can improve dyskinesias and involuntary movements. Although unknown, the antioxidant and anti-inflammatory effects of cannabinoids may also foster neuroprotective activity.

**Marijuana risks and side effects**

- slow movement, cognitive slowness, decreased motivation, memory problems and low blood pressure that can lead to dizziness and an increased fall risk.

**Clinical Studies**

There is currently no conclusive scientific research supporting the benefits of cannabis for any aspect of Parkinson’s. In less rigorous studies, some people with PD reported that cannabis helped with tremor, slowness and non-motor symptoms including pain, sleep difficulties, anxiety and appetite loss.

Research suggests CBD may calm people with Parkinson’s-related Lewy body dementia, however people with dementia should avoid marijuana and THC products.

**Warning: Synthetic Marijuana**

Synthetic marijuana can cause severe and deadly side effects. Also known as K2 and Spice, it is unregulated and not a plant-based marijuana substitute.

**Medical Marijuana and Parkinson’s Guidelines**

As of May 2018, medical marijuana is legal in 29 states. Trying it for PD symptoms? Consider it a complementary therapy — never a medication substitute — and read these tips:

- Always work with a doctor. Potential drug interactions include entacapone (Comtan®) and citalopram (Celexa®).
- Know that cannabis is unregulated and fluctuates. While two products can be labeled as the same strain, they can have different effects.
- Stay consistent. Use the same product from the same source.
- Start with a low dose. Observe the effects and only increase the dose gradually.
- Avoid smoking. Smoking increases lung cancer and pulmonary risks.
- Know that edible cannabis absorbs less predictably. It can cause uneasiness.
- Try patches for localized pain. Use a cannabis cream or a patch for large areas.

For more information about medical marijuana and Parkinson’s visit Parkinson.org/Marijuana or call our Helpline at 1-800-4PD-INFO (473-4636).
How One Researcher is Helping the Most Vulnerable Parkinson’s Population: Women

In addition to being a movement disorder specialist, Allison Willis, MD, at the University of Pennsylvania Movement Disorder Center, a Parkinson’s Foundation Center of Excellence, is one of the few researchers to conduct Parkinson’s disease (PD) research on one of the most vulnerable populations within the Parkinson’s community: women.

The definition of vulnerable is an underserved population that is not accessing or cannot access healthcare services for their disease. “We know that people with Parkinson’s are physically, psychologically and socially vulnerable,” Dr. Willis said. What researchers, including Dr. Willis, are discovering is that women with Parkinson’s are uniquely vulnerable because they do not receive the same advocacy or care as other vulnerable populations with Parkinson’s.

Dr. Willis conducts her research using a wide range of data. One of her primary sources is the Parkinson’s Foundation Parkinson’s Outcomes Project, the largest clinical study of PD that tracks more than 10,000 people with Parkinson’s.

In general, women have an overall lower risk of being diagnosed with Parkinson’s than men. Researchers believe this could be due to the natural protection estrogen provides in the brain or by another hormone not yet known. However, the total number of women living with PD is not far behind that of men, because, on average, women live longer.

Studies show that women who are diagnosed with Parkinson’s face more struggles throughout the course of their disease than their male counterparts.

Women with PD are more likely to:
• Have side effects from their Parkinson’s medications.
• Not receive social support.
• Have overwhelmed care partners, requiring outside, paid caregiving.

“We really need to think carefully about why we have so few women involved in research when there are actually a lot of women who are being diagnosed with Parkinson’s; they’re just not being directed to our centers for research,” Dr. Willis said.

In addition to her research, Dr. Willis treats patients with PD at her center and co-leads the Parkinson’s Foundation Women and PD Teams to Advance Learning and Knowledge (Women and PD TALK) program. The program has received a Patient-Centered Outcomes Research Institute (PCORI) award to improve the health of women living with Parkinson’s research and care.

Women and PD TALK has hosted 10 forums across the nation, engaging local communities to identify women’s needs and prioritize solutions. Next, the Parkinson’s Foundation, along with leadership teams, will use these combined insights to develop and implement an action plan to change the landscape of Parkinson’s research care.

Learn more about how the Parkinson’s Foundation is addressing the needs of women living with PD at Parkinson.org/WomenandPD.
Every year, the Parkinson’s Foundation hosts an event that transforms people with Parkinson’s disease (PD) into research advocates.

After a competitive application process, the Parkinson’s Foundation invites select applicants to attend a unique training called the Learning Institute that teaches people with Parkinson’s how to help further clinical studies.

This year, the Learning Institute took place in Atlanta, GA, from March 4 to 7 in collaboration with Emory University’s Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors (DREAMS). The event brought together 29 people with PD from across the nation and introduced them to researchers and the research process.

“Ultimately we are preparing people to work with research teams so pharmaceutical companies, academic centers, major research institutions and government can use their feedback to design and implement more efficient Parkinson’s clinical trials,” said Karlin Schroeder, MA, Parkinson’s Foundation director of community engagement and Learning Institute lead.

Once the training is complete, attendees become research advocates with the Parkinson’s Foundation Parkinson’s Advocates in Research (PAIR) program. Through in-person trainings and an online course, the PAIR program provides advocates with the knowledge and skills needed to help scientists and health professionals.

“Over time, as a Foundation we realized that we had to find a way to facilitate more successful Parkinson’s trials for people with Parkinson’s,” Karlin said. “We created an in-person education model to engage people with Parkinson’s and scientists to address these challenges.”

This year’s Learning Institute addressed the need for diversity in clinical Parkinson’s research. When trials are conducted within a limited demographic, results may overlook varying side effects from populations not reflected in the study, such as women. This year’s Learning Institute included attendees from different racial and ethnic backgrounds, a mix of urban and rural populations and varied socioeconomic status. The Foundation covers travel, meals and housing for each attendee.

Session topics included: upcoming PD clinical research studies, better understanding the clinical research process and how to effectively advocate within the clinical research process.

“My wife and I learned a lot about Parkinson’s, its treatment and clinical research during the PAIR Learning Institute. It also opened the door for my appointment to the FDA’s Peripheral and Central Nervous System Drugs Advisory Committee, where I will be directly involved in the approval process for new PD drugs,” said Rich Hoffman, caregiver and Learning Institute attendee.

There are currently 300 designated Parkinson’s research advocates across 42 states who help educate their communities about clinical trials, and actively address and design clinical trial protocol.

The Foundation is currently planning the 2019 Learning Institute and will announce the location and research themes later this year.

Find out how you can become a research advocate or work with our research advocates at Parkinson.org/PAIR.
Generosity Fuels Life-Changing Parkinson’s Foundation Research

When it comes to causes he cares deeply about, North Carolina’s Tom Trussler, 80, has a knack for “getting out with people and raising money.” Faith plays a significant role in all his efforts. As the former planned giving officer and president of ministry funding for the Baptist Bible Foundation, he has raised millions of dollars.

Living with Parkinson’s disease (PD) for the last nine years, Tom stays active. His faith led him to recently offer his fundraising experience to the Parkinson’s Foundation.

“I worked in fundraising for 30 years,” Tom said. “I want my donation to the Parkinson’s Foundation to be part of my legacy.”

He and his wife, Barbara, have both donated to the Foundation and have included it in their estate plan.

Tom feels blessed to be able to function with his Parkinson’s, have the ability to spend time with his family and be able to make life better for people with Parkinson’s through his legacy.

For more information on including the Parkinson’s Foundation in your estate plans, please contact Sean Kramer at skramer@parkinson.org or 305-537-9904.

SUPPORT THE FIGHT AGAINST PARKINSON’S DISEASE

Make a difference in people’s lives and create a meaningful legacy through planned giving.

Are you looking for a way to make a significant gift to help further the work of the Parkinson’s Foundation? A bequest is a gift made through your will or trust. It is one of the most popular and flexible ways you can make a difference in the Parkinson’s community.

PARKINSON.ORG/PLANNEDGIVING

The Parkinson’s Foundation makes life better for people with Parkinson’s disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson’s community.

HELPLINE
1-800-4PD-INFO (473-4636)
Get your PD questions answered
Mon-Fri, 9 a.m. – 6 p.m. Eastern
English / Español

E-NEWSLETTER
Parkinson.org/Register
Get all the latest headlines.

BECOME A MEMBER
Parkinson.org/Donate
For just $25 a year, become a member
and continue receiving issues of the
Parkinson Report.

Get the latest on social media
Facebook, Twitter, Instagram
/ParkinsonDotOrg

200 SE 1ST STREET, SUITE 800
MIAMI, FLORIDA 33131
1359 BROADWAY, SUITE 1509
NEW YORK, NEW YORK 10018

CHIEF EXECUTIVE OFFICER: John L. Lehr
CHAIRMAN: Howard Morgan
MEDICAL DIRECTOR: Michael S. Okun, MD
EDITOR: Leilani Pearl
WRITERS: Kristy Pomes,
Jennifer Clayton
DESIGN: Gretchen Heim, Ultravirgo

Although we attempt to ensure accuracy,
the publisher cannot accept responsibility
for the correctness of the information in
this publication. Published articles may be
edited at the editors’ discretion. Information
provided in regard to medical diagnosis,
treatment and research reflect the views
of the authors and should not be taken as
endorsements by the Parkinson’s Foundation.
In the event of medical issues, please seek
advice from your physician.

Every effort is made to avoid duplication of
mailing labels. If you receive an extra copy,
please pass it to a friend. If you do not wish
to receive further issues please contact us via
the information listed below.

Comments or Questions? Contact us.
contact@parkinson.org
toll-free: 1-800-4PD-INFO (473-4636)
Parkinson.org