Calendar of Events
2

Update from Our Parkinson’s Advisory Council Chair
3

FEATURE
PD Conversations: A New Online Parkinson’s Community
4

Top PD Conversations
5

How Denise Went from Newly Diagnosed to Parkinson’s Advocate in Two Years
6

15 Practical Ways to Plan for Parkinson’s
7

Helpful Strategies for Caring for a Person with Dementia
8

Tips for Daily Living: Techniques to Boost Your Brain Power
9

How an Innovative Research Center Studies the Gut–Brain Connection
10

Ellie Rides for Research in Support of Her Dad
11
**Virtual Events**

**APRIL 2020**

14  **PD and Medication: What’s New?**
Fernando Pagan, MD, will discuss Parkinson’s medications. Are they changing the course of Parkinson’s? How do they effect motor and non-motor symptoms?
*Register:* Parkinson.org/ExpertBriefings

30  **Answering Your PD Questions with AARP: From Newly Diagnosed to Caregiver Resources**
This new webinar series in partnership with AARP will provide educational resources and advice for those newly diagnosed. Hosted by Nina Browner, MD, and Amy Goyer, AARP national family and caregiving expert.
*Register:* Parkinson.org/AARPwebinar

**MAY 2020**

9  **Moving Day — A Virtual Walk**
Moving Day events taking place in April and May are going virtual. Join us in moving together at our first-ever Moving Day, A Virtual Walk.
*Register:* MovingDayWalk.org

16  **2020 Care Partner Summit | Cumbre Para Cuidadores**
Calling all care partners! Taking place virtually, engage in our various panels that will answer your questions about cognitive changes, mental health, self-care and more.
*Register:* Parkinson.org/Summit

**JUNE 2020**

9  **Newly Diagnosed: Living Your Best Life with Parkinson’s**
Jenna Iseringhausen, BSN, RN, will highlight strategies for those newly diagnosed with Parkinson’s and care partners.
*Register:* Parkinson.org/ExpertBriefings

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

Find a Moving Day walk in your area! Visit MovingDayWalk.org.

---

**AVAILABLE NOW**

**Ask the Experts: Coronavirus and Parkinson’s,**
Our National Medical Director, Michael S. Okun, MD, and infectious disease expert, Frederick S. Southwick, MD, address your questions about PD and Coronavirus.
*Watch now:* Parkinson.org/Coronavirus

**Substantial Matters: Life and Science of Parkinson’s**
With new episodes every other Tuesday, we interview PD experts about the latest treatments, techniques and cutting-edge research.
*Listen now:* Parkinson.org/Podcast

The Parkinson’s Foundation is devoted to the health and wellbeing of the PD community.

All in-person Foundation events through May 31 are suspended; learn more at Parkinson.org/Events.

If you have questions about Parkinson’s contact our free bilingual Helpline at 1-800-4PD-INFO (1-800-473-4636) or Helpline@parkinson.org.
Robert “Kelly” Sweeney, Chair of the People with Parkinson’s Advisory Council

My primary job as the chair of the People with Parkinson’s Advisory Council (PPAC) is simple: advocate for people with Parkinson’s. As members of this council, some of us have Parkinson’s, like me, and some of us are care partners. Together, not only do we advise the Foundation, we talk things through — from developing new programs to advocating for more research.

Between the monthly calls and advocacy work, sprinkled in between work, family, doctors’ appointments, exercise classes and support groups, as PPAC members we still feel we can do more. I’m excited to be part of a Foundation that sets out to provide more for our community.

Every year I look forward to April, when we can magnify our Parkinson’s awareness to really bring more attention to the one million Americans fighting to live better lives with PD. Help us kick off Parkinson’s Awareness Month! This year our theme is #Plan4PD. We are highlighting the ways we can plan for a better life with Parkinson’s. As PPAC members we aim to accomplish some of these items ourselves, so I encourage you to choose one a week — from writing a letter to the editor to volunteering — to help us bring awareness to a disease that has affected so many we love. Find out how you can #Plan4PD on page 7.

Thank you for helping us raise awareness!

-Kelly

Join Us

2020 Care Partner Summit

May 16, 2020

Taking place virtually from noon to 3:30 p.m. ET, engage and ask your questions online to our various panels that will address cognitive changes, mental health, self-care, planning and more.

Register to attend virtually at Parkinson.org/Summit.

Made possible by Presenting Partner ACADIA Pharmaceuticals Inc.
PD Conversations: A New Online Parkinson’s Community

When Parkinson’s disease (PD) symptoms become more obvious or troublesome, many people with Parkinson’s avoid leaving the house. Unfortunately, isolation can lead to depression. The value of a social support team cannot be overstated. Having friends, family and professionals around you can help you stay engaged and remain part of a community.

In January 2020, the Parkinson’s Foundation launched PD Conversations, an online community where people can find a network of support and answers to their PD-related questions.

“This is an online space created just for the Parkinson’s community,” said Adolfo Diaz, Parkinson’s Foundation Senior Director of Patient Services. “Whether you are a person living with Parkinson’s, a care partner, an adult child living far from your parent with PD, sometimes you just need to find answers or simply find solace in the fact that other people are experiencing your new normal.”

As part of PD Conversations, Parkinson’s Foundation Helpline specialists will answer questions and offer support on the online forum. When joining a discussion group, participants will connect with other people who share the same interests, challenges and hopes. From diagnosis to caregiving, PD Conversations has a place for everyone.

PD Conversations includes eight lively Discussion Groups:
1. Newly Diagnosed
2. Symptoms of PD
3. Treating PD
4. Tips for Daily Living
5. Caregiving
6. Young Onset
7. Español
8. General Discussion

The Parkinson’s Foundation is built on community. Building a support system may seem daunting at first, so take one step at a time. PD Conversations is a safe space to find a shared connection and understanding among a community. The site also features a “What’s Trending” section, where anyone can get a quick pulse on the most pressing topics to the PD community right now.

Join the Conversation

2. Choose a username and password.
3. Join a Discussion Group.
4. Visit weekly to explore trending PD topics.
Top PD Conversations

Our new, interactive “PD Conversations” online community gives everyone in the Parkinson’s community a platform to ask their most pressing Parkinson’s questions. The below are some of our top PD Conversations.

Q: My friend was diagnosed with PD last summer, but he still hasn’t accepted the diagnosis. It took me a good year to accept the diagnosis. What helped you accept your diagnosis?

A: “I’ve been fortunate to have a good movement specialist, medicine that works and recent DBS surgery, which has had a positive impact on my life. I hope you can find some solutions.”

-Sara

A: “Doing my own online research on PD and experiencing the symptoms have made it slowly hit home for me.”

-Chris

A: “Took me a year to accept it. I cope by doing what I can now, who knows what will happen in the future? Unforeseen circumstances befall us all. There are so many videos now to help deal with this illness.”

-Beryl

From PD Conversations Discussion Group: Newly Diagnosed. For more information visit Parkinson.org/NewlyDiagnosed.

Q: My name is Patrick and I was diagnosed with PD in 2015. My biggest challenges are stiffness and tremor (mainly during off time), depression/anxiety and fatigue. I used to enjoy running but find it difficult these days. What is everyone’s exercise of choice to stay fit and fight this disease?

A: “All exercise is good. The most important thing is to do something you enjoy. If you can do it with others with PD and involve your spouse, that’s a plus. I coach Rock Steady Boxing, do PWR!Moves®, take dance classes with my husband, hike and everything in between!”

-LAD

A: “The best exercise for you is the one that you enjoy and actually do. I have tried many forms of exercise and Rock Steady Boxing works for me. Have you tried it?”

-MK

A: “I walk a minimum of 12,000 steps a day and do Shotokan karate. Just keep moving!”

-PM

From PD Conversations Discussion Group: Young Onset. For more information visit Parkinson.org/YOPD.

Q: My husband was diagnosed with PD two years ago and his anxiety has gotten worse. He has crazy dreams with punching and tremors, but his anxiety is a huge social barrier. We have not gone on vacation in two years. Any suggestions?

A: “This all sounds familiar. My wife’s first symptom was severe anxiety and tremor started soon after. She couldn’t stay by herself and we had to cancel trips. She was better after she was on her PD meds. Anxiety is still a problem, but not as severe... As far as dreams go, we have to sleep in separate beds. It is called REM sleep disorder. She just started on CBD oil, that may make a difference, but I doubt it.”

-COACH T

A: “My hubby has the same issues with REM sleep disorder... It’s not every night, but when it happens, he acts out his dreams, punching and kicking and usually screaming. We see a sleep disorder specialist at Emory University, a Center of Excellence. He is on a mild sleeping medication and at night he takes a carbidopa/levodopa extended release.”

-GA Carepartner

From PD Conversations Discussion Group: Caregiving. For more information visit Parkinson.org/Caregiving.

Become a part of the community at Parkinson.org/PDConversations.

Top PD Conversations is not intended to replace and should not be relied upon as professional or medical advice. Always consult your doctor for medical matters. The Parkinson’s Foundation assumes no liability for any content. The Foundation does not endorse or recommend any information.
Denise Coley thought her tremors and muscle fatigue were from her marathon training, but her concern escalated when her children noticed she was shaking during Thanksgiving dinner. In January 2018, minutes before receiving her Parkinson’s disease (PD) diagnosis, she read an article about how exercise helps with PD symptoms in her neurologist’s waiting room.

“I immediately began Rock Steady Boxing classes, where you not only exercise, but you also get a gigantic support group,” Denise said. “It was a solid place to start and look for what else is out there.”

During her career in the technology industry, Denise thrived on project planning, so she created her own PD plan. “I gave myself a six-week pity party and moved on,” Denise said.

Her first step was to get informed. “I went to all the PD websites, I signed up for emails, read the blog and newsletter to learn anything new,” she said. “I then started finding ways I could get connected.”

Within months, Denise was boxing and participating in Tai Chi classes, attending a support group and trying complimentary therapies, like acupuncture, “but the most fabulous thing was when I went to the Parkinson’s Foundation educational event for women and found a Parkinson’s Women Support Group,” Denise said.

Denise called the Parkinson’s Foundation Helpline to find out how she could get more involved. Soon after, Denise and her husband, Bernard, became Parkinson’s Advocates in Research (PAIR). “PAIR allows us to be more engaged and share new perspectives when it comes to Parkinson’s research.”

Next, Denise joined the Parkinson’s Foundation People with Parkinson’s Advisory Council (PPAC) in August of 2019. “The Parkinson’s Foundation is absolutely the best place to be to be an advocate to help, give insight, learn and have hope and knowledge,” Denise said.

Since that day in the waiting room, Denise now participates in support groups, Moving Day, A Walk for Parkinson’s, clinical studies and serves on two Parkinson’s Foundation committees.

She also speaks at local Parkinson’s Foundation events and helps the underserved. In February 2020, she joined the World Parkinson Coalition’s working group “Reaching the Underserved.”

“I want to have the most impact and help with policies and reach the underserved communities,” Denise said. “I want everyone to know that they can have a better quality of life.”

To help those newly diagnosed, like Denise, the Parkinson’s Foundation launched Newly Diagnosed: Building a Better Life with Parkinson’s to close the gap between a PD diagnosis and the essential resources that can inspire and support people new to Parkinson’s.

If you are newly diagnosed, you are not alone. Learn more at Parkinson.org/NewlyDiagnosed.

How Denise Went from Newly Diagnosed to Parkinson’s Advocate in Two Years

Denise Coley with son and grandchildren at an autumn outing.

DENISE’S PD PLAN:

- Gather information from Parkinson.org
- Call the Helpline at 1-800-4PD-INFO (473-4636)
- Maintain exercise program
- Join PD support groups
- Create care team
- Define PD goals and quality of life
- Become a research advocate
- Participate in clinical trials
- Become a PD advocate
- Speak and advocate for underserved communities
15 Practical Ways to Plan for Parkinson’s

April is Parkinson’s Awareness Month and this year we want to help you plan for Parkinson’s disease (PD). Visit Parkinson.org/Awareness to print our #Plan4PD calendar and follow along with a family member or friend.

Start a Conversation
- Ask questions and explore trending topics in our PD Conversations online community! Visit PDConversations.org.
- Help make life better for people with PD. Start an awareness month Facebook fundraiser at Parkinson.org/FB.
- Spread PD awareness with a letter to the editor of your local paper. Use our template at Parkinson.org/Awareness.

Research
- Follow us on Facebook, Twitter, Instagram and YouTube @ParkinsonDotOrg and never miss a research update.
- Learn more about genetics and join our genetics research initiative, PD GENEration, at Parkinson.org/Genetics.
- Listen to experts discuss PD research on our podcast at Parkinson.org/Podcast.

Prepare
- Save our bilingual Helpline number in your phone as a contact so you can reach out to us with PD questions! 1-800-4PD-INFO (473-4636).
- Always be prepared for a planned or unplanned hospital stay. Order your free Aware in Care kit today at Parkinson.org/Store.
- Calling all care partners! Join us at a watch party or online for our 2020 Care Partner Summit/Cumbre Para Cuidadores on May 16. Register at Parkinson.org/Summit.

Get Involved
- Stay social. Schedule a phone call with a loved one you haven’t reached out to in a while.
- Get involved and utilize local resources, support groups, health and wellness classes through your local Parkinson’s Foundation chapter. Visit Parkinson.org/Chapters.
- Join your community at one of our Moving Day walks! Register today at MovingDayWalk.org.

Build A Care Team
- Are you receiving expert PD care? Find your nearest center at Parkinson.org/Search.
- Learn how to build your care team at Parkinson.org/ExpertCare.
- Always be prepared. Make a list of everyone in your care team and keep it with your medical documents. Call our Helpline for referrals.

To view all 30 ways to #Plan4PD visit Parkinson.org/Awareness.
Helpful Strategies for Caring for a Person with Dementia

Cognitive changes are common, but less recognized Parkinson’s disease (PD) non-movement symptoms. The following healthy management strategies help people living with cognitive PD changes and their care partners.

Dementia types
Lewy body dementia (LBD) is a term that includes two different types of related dementias, distinguished by which symptoms start when:
- Parkinson’s disease dementia (PDD) – diagnosed when a person living with PD experiences significant cognitive decline after a year or more of motor symptoms (most typically, after many years of experiencing motor symptoms).
- Lewy Body Dementia (LBD) – diagnosed when cognitive decline is the earliest symptom or when cognitive decline and motor symptoms begin and progress together. Can also be referred to as Dementia with Lewy Bodies (DLB).

1. Confirm your diagnosis.
Medication and health issues can look like dementia. Your Parkinson’s doctor should look at all factors before possibly providing a PDD or LBD diagnosis.

2. Find a doctor familiar with PDD and LBD. A clinical diagnosis – rather than a single test – determines Parkinson’s-associated dementia. Find a physician familiar with dementia or geriatric medicine.

3. Get Parkinson’s dementia education, including: expert medical and legal advice, safety education from expert resources — call the Parkinson’s Foundation Helpline 1-800-4PD-INFO (473-4636) or visit Parkinson.org, or visit the Alzheimer’s Association online, www.alz.org, and learn appropriate communication techniques.

4. Schedule a family meeting to cover ways to support the primary care partner.

5. Include the person with dementia in early decision-making, giving them a chance to express their preferences. Know when safety concerns should limit decision-making.

6. Consider and monitor safety issues. Is your loved one still driving? Change driving privileges before...
safety is a concern. Your doctor can make a driving evaluation referral. Ensure financial safety from scams and fraud. Limit prescription risks. If the person is in dementia’s early stages and capable, fill their weekly pill box together and monitor use.

7. **Address financial and legal issues with an elder law attorney, including:**
   - An advance directive to ensure your healthcare preferences are carried out.
   - Healthcare and financial power of attorney (POA) documents naming who you want making related decisions.
   - Physician orders for life sustaining care (POLST).

8. **Seek out care partner support.**
   Find someone to rely on for support and regular breaks.

9. **Provide a medical alert ID bracelet.**
   Include a phone number should the person with PD dementia wander or get lost, even briefly.

10. **Focus on the primary care partner’s needs.**
    - You must first care for yourself to care for others.
    - Have an emergency care plan to ease transitions should others need to unexpectedly take over care duties.
    - Attend a support group or talk to someone.
    - Build in weekly time for yourself.
    - Get adequate sleep.
    - Remember your sense of humor.
    - Sustain supportive friendships.
    - Value yourself.

**Care Partner Self-Care**
Care partners for those living with dementia face increased health risks. Studies show caring for your heart can benefit your brain. Embrace the American Heart Association’s “Life’s Simple 7” checklist that includes:

1. Aerobic exercise
2. Control cholesterol
3. Eat according to Heart Association guidelines
4. Manage blood pressure
5. Manage weight
6. Reduce blood sugar
7. Quit smoking

Learn more about Parkinson’s and dementia by calling our free Helpline at 1-800-4PD-INFO (473-4636).

**Tips for Daily Living:**
Techniques to Boost Your Brain Power

Do you ever walk into a room and forget why? Next time try closing your eyes to jog your memory. Memory, language and learning changes can be common in Parkinson’s disease (PD). Here are some ways to enhance your cognitive function, starting now:

- **Keep learning.** Choose activities that keep your brain working, like watching a new video or setting a complex goal.
- **Eat a healthy diet.** Following the Mediterranean diet can help people with Parkinson’s slow levodopa absorption into the brain.
- **Carry a book with you.** Reading can improve memory and cause positive neurological changes.
- **Meditate.** Stress can temporarily worsen PD symptoms. Meditating just 15 minutes a day can bring a sense of calm and the ability to see things more clearly.
- **Be creative.** Stimulate your brain by varying your mental activity. Try drawing, painting or writing.
- **Exercise.** Intense exercise can improve efficiency of your brain cells using dopamine and lessen PD symptoms.
- **Drink caffeine.** Research shows that a cup a day may help motor symptoms, boost memory and lower the risk of depression.

For more Tips for Daily Living visit Parkinson.org/Blog.
How an Innovative Research Center Studies the Gut–Brain Connection

“Parkinson’s disease (PD) is not only happening in the brain,” said Malú Tansey, PhD, Director of the Center for Translational Research in Neurodegenerative Disease at the University of Florida (UF), a Parkinson’s Foundation Center of Excellence. “It’s a multisystem disease with many non-motor symptoms that manifest in the gastrointestinal system.”

UF in collaboration with Emory University is a newly designated Parkinson’s Foundation Research Center — a medical or academic institution that receives Foundation funding to strengthen its PD research efforts. UF will receive $2 million to conduct three unique, PD-specific studies led by Dr. Tansey, an endowed chair of the Norman Fixel Institute for Neurological Diseases at UF Health, that seek to establish key connections between the gut and Parkinson’s:

**Study 1: Connecting Gut Bacteria to PD**
Researchers suspect that alpha-synuclein (a key protein involved in the development of PD) levels change depending on the microbes and pathogens present in the gut. This study will seek to find if this connection is a two-way street by assessing protein changes in the microbiome (the body’s storage of bacteria) and how it responds to inflammation in the gut. In short, can balancing your gut bacteria with a probiotic or diet help control alpha-synuclein levels and how the protein travels from the gut to the brain?

**Study 2: What Is a PD Genetic Mutation Doing in the Gut?**
LRRK2 is a common gene mutation linked to Parkinson’s. This study will help us understand the role LRRK2 plays in the gut-brain highway. In order to find out, researchers will use mouse models that have LRRK2 mutations to track if these mutations change the gut and how they affect the brain. Then, they will put the gut microbiota from the PD models in healthy mice to see how the gut is triggered. From there, researchers can figure out which parts of the system bring proteins to pathology (the potential effect and cause of a disease).

**Study 3: Creating a PD-Colitis Molecular Signature**
This study will cross-reference those with the inflammation of the gut (such as irritable bowel syndrome) and those living with Parkinson’s. Through analyzing samples of 120 participants, researchers seek to find relationships between inflammatory molecular signatures in the gut and Parkinson’s progression. Interestingly, should a person with Parkinson’s know they have the LRRK2 genetic mutation, through the Parkinson’s Foundation genetic initiative for instance, they would be able to sign up for a study like this.

“Receiving Research Center funding is a way for me to say that the Parkinson’s Foundation believes in providing us the opportunity to become a truly interdisciplinary multi-center and reach out to experts in the GI, neurology, gut-immunobiology and immunology fields to help us understand the mechanisms of Parkinson’s in order to better develop new treatments,” Dr. Tansey said.

Research gives Dr. Tansey hope. “What is most exciting for me is that by understanding the gut-brain connection and how we can alter the microbiome through things that are in your control — from probiotics, diet, exercise or lifestyle — we may one day be able to delay the onset of Parkinson’s,” Dr. Tansey said.

Learn more about Parkinson’s Foundation Research Centers at Parkinson.org/Research.
Ellie Rides for Research in Support of Her Dad

New York-based Ellie Cornell and her team "Corncycle" rode to victory in Boston, MA, on February 8, 2020 in the inaugural Parkinson’s Revolution indoor cycling experience that took place in seven locations across the U.S. and select locations in Canada and the United Kingdom. Ellie’s father (and fellow teammate), James, was diagnosed with Parkinson’s disease (PD) in late 2019. Like James, Ellie immediately dove into learning as much about the disease as possible, while discovering ways to fight it.

“My dad and I are very, very close and I wanted to be more active in handling this new information,” Ellie said. “Having worked with several nonprofits in my professional life, the Foundation’s commitment to funding breakthrough research really resonates with me.”

Ellie emailed her family and a few close friends to tell them about her father’s diagnosis, and her plans to ride in his honor. “The donations just started pouring in,” Ellie said. “People were so incredibly generous.”

Relatives across the country also made Parkinson’s Revolution a family affair, with a cousin, Julia, riding in San Francisco, CA, and another cousin, Henry, and aunt, Katie, spinning in Washington, D.C., “Everyone joined in!” Ellie added.

Join the Parkinson’s Revolution or become somebody’s Champion at Parkinson.org/Revolution.

Will, Tim and Peter ran as Parkinson’s Champions in the 2019 Philadelphia Marathon Weekend 8K. The triplets led their family team of seven in honor of their beloved grandfather, Papa Gus, raising $3,750 for Parkinson’s research.

“The Crozet Jam Band” played a tribute concert at Starr Hill Brewery in Virginia to celebrate singer Linda Ronstadt who is living with Parkinson’s. The band and their fans raised awareness and $605 to fight Parkinson’s.

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
We have expanded our Helpline hours!
Call our free Helpline at 1-800-4PD-INFO (473-4636) Monday through Friday from 9 a.m. to 8 p.m. ET to get your Parkinson’s questions answered in English or Spanish.