For a full list of events visit Parkinson.org/Events.
Find a Moving Day walk in your area! Visit MovingDayWalk.org.

JANUARY 2020
18 Beyond the Diagnosis: Managing Changing Symptoms
Corona Del Mar, CA
Learn more: Parkinson.org/OrangeCounty

21 Expert Briefings Webinar: Optimal Exercise Strategies for Stability, Stamina and Strength
Register: Parkinson.org/ExpertBriefings

FEBRUARY 2020
8 Parkinson's Revolution
Various Cities
Learn more: Parkinson.org/Revolution

12 On the Menu: Nutrition & Parkinson’s
Kansas City, MO
Learn more: Parkinson.org/NutritionKC

22 Better Lives, Together: Fresno Parkinson’s Summit
Fresno, CA
Learn more: Parkinson.org/Fresno

MARCH 2020
3 Mind, Mood & Motion
Omaha, NE
Learn more: Parkinson.org/Omaha

17 Expert Briefings Webinar: Food, Water & Supplements: Does Nutrition Play a Role in PD Symptoms or Progression?
Register: Parkinson.org/ExpertBriefings

21 Gender Differences in Parkinson’s Disease
Phoenix, AZ
Learn more: Parkinson.org/Phoenix

31 New Frontiers in Research: Genetics and PD
Overland Park, KS
Learn more: Parkinson.org/ResearchKC

APRIL 2020
5 Moving Day Fresno
Register: MovingDayFresno.org

14 Expert Briefings Webinar: PD and Medication: What’s New?
Register: Parkinson.org/ExpertBriefings

17 2020 Good Vibrations
Atlanta, GA
Learn more: Parkinson.org/Events

18 Moving Day Omaha
Register: MovingDayOmaha.org

Moving Day South Alabama
Register: MovingDaySouthAlabama.org

Moving Day Ventura County
Register: MovingDayVenturaCounty.org

Moving Day Tampa
Register: MovingDayTampa.org

Moving Day Sacramento
Register: MovingDaySacramento.org

25 Moving Day Little Rock
Register: MovingDayLittleRock.org

Moving Day Baton Rouge
Register: MovingDayBatonRouge.org

Moving Day Lexington
Register: MovingDayLexington.org

26 Big Sur Marathon
Big Sur, CA
Register: Parkinson.org/Champions
A Note From the CEO

Everyone who faces Parkinson’s disease (PD) is a fighter — from the people confronting their symptoms every minute to the advocates raising PD awareness. However, there is one group of people whose fight often goes unnoticed: care partners. We are here for you.

In this issue dedicated to fighters like Tom (page 8), we highlight our Caregiver Checklist, Top 10 Caregiver Resources and check in with how care partners are using collaborative care to make life better.

As we get ready to approach a new year, I am excited to announce our newest campaign “Newly Diagnosed: Building a Better Life with Parkinson’s” with the goal to reach the 60,000 Americans newly diagnosed with Parkinson’s each year (page 4). Find out how we aim to close the gap between a PD diagnosis and the essential resources that can inspire and support those new to our community.

In closing, I want to share a quote from Christina Korines, a young mother of two and Parkinson’s Foundation supporter who inspired us to launch this campaign and do more for our community. “I really feel that anyone who is struggling with their recent diagnosis or life with Parkinson’s can rely on the Parkinson’s Foundation because you will find a home there,” said Christina, who is living with Young-Onset PD.

Tips For Daily Living: Caregiver Checklist

Your caregiver identity will evolve over time. Consider devoting time to implementing these caregiver priorities as part of your life plan.

1. **Learn:** Educate yourself about the disease early on, so you can participate in healthcare discussions and make informed decisions, while providing emotional and physical support.
2. **Manage time:** Make realistic daily and weekly to-do lists.
3. **Build in self-care:** Plan quality time for yourself, from exercise to self-care (1–1½ hours a day, if possible), maintain it and protect it.
4. **Find a support team:** Share the care. Explore ways to get physical and emotional help.
5. **Communicate:** Maintain open communication. Express love and appreciation as well as concerns and feelings of frustration.
6. **Plan:** Write out medical, financial and care decisions for the both of you.
7. **Utilize community resources:** Find nearby educational events and exercise classes. Call the Parkinson’s Foundation Helpline 1-800-4PD-INFO (473-4636) for local resources.

Read the full list and more in the Caring and Coping guide at Parkinson.org/Library.
Everyone processes a Parkinson’s disease (PD) diagnosis differently. Navigating a range of emotions — from relief to despair — can feel overwhelming. Built on community, the Parkinson’s Foundation is here to support people newly diagnosed with Parkinson’s and their care partners now and at every stage of their journey.

“Newly Diagnosed: Building a Better Life with Parkinson’s” is the Parkinson’s Foundation campaign working to close the gap between a PD diagnosis and the essential resources that can inspire and support people new to Parkinson’s.

The goal is to help connect those new to the PD community with others living with PD and work toward building a network of support. These five steps can equip people with Parkinson’s with tools that foster well-being while ideally reducing worry and improving day-to-day living.

1. Determine Your Goals
Create an action plan, honor your efforts as you take small steps towards success and don’t be afraid to ask for help. Call the Parkinson’s Foundation Helpline at 1-800-4PD-INFO (473-4636) for answers to all your questions, starting with your diagnosis.

Thinking about what is most meaningful to you, then working it into your daily routine, can be inspiring and empowering. Setting small, clear personal goals — whether designed to boost health or personal connections — and following through, can help you live well. Be sure to reward yourself when you master a goal. This can help inspire you to tackle and conquer your next challenge.

2. Find Someone to Talk to
You are not alone. It’s important to understand how Parkinson’s can impact you physically and how it can impact your mood and emotions. Finding someone to talk to can provide connection, comfort and understanding. A counselor or PD support group can provide opportunities to talk about shared experiences, relieve stress and build new friendships.

Whether you seek out a counselor, support group or connect online through the Parkinson’s Foundation Newly Diagnosed online community, sharing your feelings can help you navigate them and prevent isolation.

3. Create Healthy Habits
Maintaining good health is vital to living well with Parkinson’s. Everyone with PD should strive for good nutrition and ample sleep. Vegetables, fruits, whole grains, milk and dairy products, protein-rich foods and healthy fats, like olive oil and nuts, can improve energy, fight constipation and keep bones strong. Try planning meals in advance to ensure a healthy diet.
Getting enough sleep helps manage mood, health and PD symptoms. Make sure to keep your sleeping area, cool, dark and free from electronics, to ensure plenty of rest.

4. Be Active
Exercise is essential to managing almost every aspect of Parkinson's. Steady physical activity can improve many symptoms and offers a neuroprotective effect. It can also improve mood, coordination, flexibility, working memory and more. Moving Day, A Walk for Parkinson’s, is a great way to get active.

The Parkinson’s Outcomes Project shows that people with PD who start exercising earlier and a minimum of 2.5 hours a week, experience a slowed decline in quality of life compared to those who start later. Establishing early exercise habits is essential to overall disease management.

5. Find a Parkinson’s Expert
Working together with a movement disorder specialist or neurologist who specializes in PD ensures you get the best possible care. Neurologists are doctors who work with brain and central nervous system conditions such as PD. Movement disorder specialists — neurologists with additional training to treat people with Parkinson’s at every stage of the disease — can be a key addition to a quality care team.

Your primary Parkinson’s doctor can recommend other healthcare professionals who can help treat day-to-day challenges. When possible, assembling a holistic, care team can optimize your well-being.

To reach more newly diagnosed people, the Parkinson’s Foundation has launched new resources, compiled expert advice and a new online community for people with Parkinson’s, family members and care partners to build a better life with Parkinson’s.

Visit Parkinson.org/NewlyDiagnosed to order or download Newly Diagnosed resources.
Newest Center of Excellence Brings Unique Parkinson’s Programs to Network

The Movement Disorders Center at the University of Colorado School of Medicine treats more than 7,000 people who are living with a movement disorder. Of those, 3,281 have Parkinson’s disease (PD) or parkinsonism, and all are treated by one of the center’s 10 movement disorder specialists.

Providing expert PD care through an interdisciplinary care team, unique programs and innovative research are just three of the reasons the University of Colorado School of Medicine was designated as a Parkinson’s Foundation Center of Excellence. A Center of Excellence is a medical center with a specialized team who is up to date on the latest Parkinson’s medications, therapies and research to provide the best care.

“We belong to the Parkinson’s Foundation Center of Excellence network is a great honor and a testament to the exemplary expertise and care provided by our Movement Disorders Center at the University of Colorado,” said Victoria S. Pelak, MD, Professor of Neurology and Ophthalmology at the University of Colorado School of Medicine.

Multidisciplinary Visual Care Clinic
As the only Center of Excellence with a multi-disciplinary vision clinic for people with Parkinson’s, the clinic’s team addresses the vision symptoms of people with PD. An optometrist, ophthalmologist, movement disorder specialist, occupational therapist and fellows all work in the clinic.

“We built the program to address the unique visual problems experienced by people with Parkinson’s, and we do so in a specialized clinic because patients often cannot get the answers or care necessary at routine eye appointments,” Dr. Pelak said.

Research
In 2018, the center invested $3.6 million into 39 different movement disorders studies. Devoted to furthering PD research, the center has a specialist on staff who recruits for clinical studies.

While a hot topic, studying medical marijuana as it relates to PD brings many challenges. However, the center has completed numerous studies on the topic and plans to complete more. “We’re finding that cannabis is likely to be safe for people with PD, and we’re still trying to determine if it’s effective for certain symptoms of Parkinson’s,” said Lauren Seeberger, MD, Associate Professor and Director at the Movement Disorders Center.

Neuropalliative Care Program
The center also houses a neuropalliative (symptom relief management for people with neurological conditions) care program. The goal of the program is to improve quality of life, while also teaching fellows the importance of neuropalliative care. Uniquely, the program has its own interdisciplinary team that incorporates patient-care advocates who volunteer and are all family members of people who have or had Parkinson’s.

Community Outreach Helping the Hispanic Population
In addition to the 55 educational talks the center completed in 2018, the center will soon launch an educational program to promote Parkinson’s education in the Hispanic community. It will also work to break down the barriers that prevent Hispanics from participating in PD research.

“We want to engage with the population to see how we may better understand unique perspectives and deliver care,” Dr. Seeberger said.

Learn more about the Center of Excellence network at Parkinson.org/ExpertCare.
Parkinson’s Foundation Researchers Pursue Next Breakthrough

Every day, potentially groundbreaking Parkinson’s disease (PD) research ideas are explored in labs across the country. This year, the Parkinson’s Foundation funded $12.2 million in designated Research Center awards and research grants. The below researchers were awarded the Stanley Fahn Junior Faculty Award, which helps ensure promising early career scientists stay in the Parkinson’s research field, helping us solve, treat and end this disease. Award recipients receive $300,000 in total costs to cover three years of research.

**Roy N. Alcalay, MD, MS**

**Investigating the Role of Lipids in Parkinson’s**

The most common genetic changes linked to Parkinson’s occur in a gene called GBA. The role of GBA is to break down complex lipids (like fats and oils) in the cell’s “recycling bin.”

Dr. Alcalay will work to identify the parts of lipid metabolism that are most affected by Parkinson’s and to find potential drug targets to correct them. With cutting-edge technology, he will measure lipids in blood samples, analyzing 600 people with Parkinson’s and 400 without PD, testing for genetic changes in 32 genes involved with lipid metabolism. In people who carry PD-related genes, he will test if altered lipid levels are linked to a PD diagnosis. He will also test whether lipid concentrations are related to the activity of certain enzymes (the part of a cell that helps speed up chemical reactions).

We hope that this research can identify new drug targets and Parkinson’s biomarkers that will improve diagnosis and treatment.

*Dr. Alcalay, Columbia University Medical Center, a Parkinson’s Foundation Center of Excellence and Research Center.*

**Tim Bartels, MSc, PhD**

**Protein May Hold Clues to Development of Parkinson’s**

Alpha-synuclein is a protein in the brain associated with the development of PD. It also helps control lipids and fatty acids that help prevent disease-associated changes in the brain.

Dr. Bartels is working to better understand alpha-synuclein in PD. His team will analyze the interactions of lipids with different forms of alpha-synuclein in human brain samples, trying to find which ones prevent and which ones promote the clustering of alpha-synuclein. He will also work to identify the specific lipids and fatty acids that are associated with PD. Together, this research could lead to the development of drugs that stabilize alpha-synuclein.

We hope that this research could lead to our first PD biomarker — a biological molecule that is a sign of disease. A biomarker could lead to earlier diagnosis and can improve outcomes for people living with PD.

*Dr. Bartels, University College London.*

**Gulcin Pekkurnaz, PhD**

**Understanding How Aging Affects Dopamine in Parkinson’s**

People with PD have low levels of dopamine in the brain due to dopamine neurons dying. Parkinson’s develops when the cell’s energy factories, called mitochondria, start to fail in dopamine neurons. Researchers also believe aging-associated changes play a role in developing PD.

Dr. Pekkurnaz is studying the mitochondria from dopamine nerve fibers in animals. Her goal is to identify what happens to mitochondria in dopamine neurons before Parkinson’s symptoms start. To accomplish this, she will develop new technology that will allow them to analyze unique features of mitochondria in dopamine neurons as a part of aging.

We hope to gain important insights into how the dopamine neuron energy supply works and how it starts to fail. These findings can lead to potential drug targets for Parkinson’s.

*Dr. Pekkurnaz, University of California San Diego, a Parkinson’s Foundation Center of Excellence.*

Learn more about Parkinson’s Foundation research at Parkinson.org/Research.
From Choir to Care: Navigating Parkinson’s Together

Just as Parkinson’s disease (PD) changes over time, so does a care partner’s role. Tom Manak has evolved with those changes — aided by both his healthcare background and the Parkinson’s Foundation — since 1990 when his wife Rosemary, or “Ro”, was diagnosed at 36 with the progressive disease.

The couple met nearly 45 years ago, as Marquette University chorus members. The songbirds, a bass and an alto, have since performed in venues across the county, including Carnegie Hall and the Kennedy Center, with the First Congregational Church of Glen Ellyn choir. They’ve spent nearly as long navigating Parkinson’s challenges together.

Since Ro’s diagnosis, she’s weathered a failed deep brain stimulation (DBS) implant surgery, a stroke, permanent DBS device deactivation, knee surgery, along with acute care and rehabilitative hospital stays. Tom’s 40-year healthcare strategy, business development and finance career helped guide her care, in addition to Parkinson’s Foundation resources.

The Aware in Care hospital kit helps Tom successfully manage Ro’s medications during hospital stays and he’s re-read the Caring and Coping guide, to help him care for Ro, as well as himself. His gratitude for those and other resources is why he’s now “paying it forward.”

He recently joined the Parkinson’s Foundation People with Parkinson’s Advisory Council (PPAC) and serves as a 2020 Care Partner Summit committee member. He also volunteers and serves as a board member for a local Rock Steady Boxing affiliate, assists staff and attendees of the Loud Crowd PD speech therapy and remains active in church — always alongside Ro.

The couple has a strong community of support in their choir. They’ve also found one in the Parkinson’s Foundation.

“People need not to be afraid to go talk to someone.”

Visit Parkinson.org/Caregiving to discover more caregiver resources.

Rosemary “Ro” Manak, who is living with Parkinson’s, with her husband, care partner and choirmate, Tom.
Care partners share a common thread — they are unsung heroes whose lives have veered from the path they envisioned. “You’ve had to readjust your expectations and look at what life is today and not what life will be,” said caregiver Caryn Balaban, who moderated the 2018 Parkinson’s Foundation Caregiver Summit Collaborative Caregiving session. “And if you are very lucky, you have learned how to celebrate life in your new normal.”

The Parkinson’s Foundation is gearing up for its 2020 Care Partner Summit, but the words of Caryn and her panel peers continue to inspire hope. Though every person’s Parkinson’s disease (PD) journey is unique, some successful caregiving strategies are nearly universal, as are some frustrations.

“Caregiving is indeed about the balance of power — about navigating the ethics of constantly shifting rights and responsibilities,” said L. Addison Diehl, who’s is in his eighth year of caregiving for his mother.

Finding the fragile balance between giving a loved one independence and knowing when to intervene is key. “Be patient with your loved one,” said panelist Lisa Seghetti, Parkinson’s Foundation research advocate who was her father’s caregiver. “Resist the urge to intervene or take over a task because your loved one is struggling.”

During the Collaborative Care panel, Dean Clarke Taylor, care partner to Bill Sabatino, diagnosed with PD almost four years ago, said the couple meets monthly with each other. They meet in their living room without distractions — no pets or electronic devices — to communicate what’s going right, before talking about challenges. They choose one or two things to work on, checking back on progress at the next meeting. “For us it has been terrific,” Dean said. “It’s been a journey of 13 years together. I say to him, ‘I love you more every day.’”

Respect and collaboration benefit both the person with Parkinson’s and their care partner. A care partner must first care for their own health and well-being.

Panelist Leslie Peters, Parkinson’s Foundation People with Parkinson’s Advisory Council member, began her PD caregiving with her mother-in-law. Now she’s a care partner to her husband Steve, who was diagnosed in 2012. The couple initially isolated themselves until Leslie, urged on by her family, became a PD advocate.

“This may not be the life we planned, but we are all in this together,” Leslie said. “I get great comfort knowing how hard the Parkinson’s Foundation is working to make life better for people with Parkinson’s disease and their caregivers.”

The 2020 Parkinson’s Foundation Care Partner Summit will take place in May. Learn more at Parkinson.org/Summit.

Join Us
2020 Care Partner Summit
May 16, 2020

Planning for the Unpredictable Path of Parkinson’s Caregiving is the theme for the 2020 bilingual, international event. This free event is created for care partners of someone living with Parkinson’s.

Register to attend virtually or in-person starting November 1 at Parkinson.org/Summit.

Made possible by Presenting Partner ACADIA Pharmaceuticals Inc.
Navigating Parkinson’s disease (PD) is a life-long process for caregivers, but you don’t have to do it alone. We’re here for you with these top 10 caregiver resources:

1. **Helpline**
   Our PD specialists answer all Parkinson’s and caregiver questions, provide emotional support, direct callers to nearby resources and provide referrals to healthcare professionals.
   → Call 1-800-4PD-INFO (473-4636) or email Helpline@parkinson.org.

2. **Caring and Coping + Parkinson’s Library**
   This comprehensive guidebook is for caregivers at every stage of PD. It contains tips and tools to make the caregiving journey as productive as possible. Visit our PD Library for our vast collection of free publications and fact sheets.
   → Read or order your free copy at Parkinson.org/Library.

3. **Resource Finder**
   With so many resources, where do you begin? Answer two questions and we will personalize a list of free caregiver resources you can check out right away.
   → Visit Parkinson.org/Keys.

4. **Parkinson.org/Caregiving**
   From beginning your caregiver journey to caring for someone with advanced PD, our caregiving articles can help you at every stage.
   → Check out Parkinson.org/Caregiving.

5. **Podcast**
   With more than 60 episodes on various topics, listen to PD experts discuss the latest in PD research, treatments, exercise and nutrition.
   → Listen at Parkinson.org/Podcast.

6. **Aware in Care Kit**
   Care partners can order and use this free hospitalization kit to organize a loved one’s medical needs in the event of a planned or unplanned hospital stay.
   → Visit Parkinson.org/AwareInCare.

7. **Caregiver Summit Videos**
   Collaborative caregiving, intimacy and PD and building stronger caregiving partnerships through communication are just some Caregiver Summit sessions you can watch online.
   → Watch videos at Parkinson.org/Summit.

8. **Educational Webinars**
   Find out what leading PD doctors and other experts have to say through our free Expert Briefings webinar series. Check out our newest topics and dates.
   → Visit Parkinson.org/ExpertBriefings.

9. **Moving Day**
   With 46 events taking place across the nation, help us fight PD and celebrate movement — proven to help manage Parkinson’s symptoms.
   → Sign up at MovingDayWalk.org.

10. **Follow us on Facebook**
   Like us on Facebook and join our global community. We post the latest PD articles about research and managing Parkinson’s, along with links to our free resources.
   → Visit Facebook.com/parkinsondotorg.

Edna Culp, pictured with her Aware in Care kit, is a nurse and care partner for her husband who has had Parkinson’s for almost 20 years.
Join the Parkinson’s Revolution

The Parkinson’s Foundation is launching a new way for people to join our Parkinson’s community. Parkinson’s Revolution is an indoor cycling experience that combines passion, determination and community to generate awareness and funds to help us advance research toward a cure for Parkinson’s disease (PD).

The first-ever Revolution cycle event will take place on February 8, 2020 in the following cities:
- Boston, MA
- Chicago, IL
- Dallas, TX
- Miami, FL
- New York, NY
- San Francisco, CA
- Washington, D.C.

Not only will riders work up a sweat, they will also generate dollars with their ride. The Parkinson’s Foundation will provide all the tools needed to exceed fundraising and fitness goals, while helping make life better for people living with Parkinson’s.

Riders of all abilities are invited to attend and can choose between a 90-minute or 45-minute high-energy ride with a motivating instructor and fast-paced music. Those who cannot make it in person can join us as a virtual rider.

Exercise, like cycling and indoor cycling, can improve quality of life for people with Parkinson’s. The Parkinson’s Revolution will give participants an opportunity to perspire while being inspired! What are you waiting for? The movement begins with YOU.

Join the Revolution at Parkinson.org/Revolution.

Brenna DeVincentis and Mark Zak ran the Chicago Marathon as Parkinson’s Champions for Brenna’s father, who has had Parkinson’s for 10 years, and Mark’s grandfather, diagnosed four years ago. “Seeing our loved ones affected by this progressive disease is not easy, which is why we are raising money together, to support the fight against Parkinson’s.” They have raised more than $6,000.

Caitlin Nevins is a Boston-based Parkinson’s Champion who combined her two passions, spin class and baking! “I love indoor cycling because when the lights go down and they turn the music up, we all get to ride together,” said Caitlin. After the ride she celebrated with her teammates and homemade Funfetti cupcakes.

Become somebody’s Champion at Parkinson.org/Champions.

SUPPORT THE FIGHT AGAINST 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. For more information please contact Sean Kramer at SKramer@Parkinson.org.

PARKINSON.ORG/PLANNEDGIVING

GIVE ONLINE TODAY
Help is just a click away.
Get the resources and information you need. Our free educational books, hospitalization kit, podcast, fact sheets and webinars are made for everyone in our community. Parkinson.org/Library

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.