Largest Parkinson’s Clinical Study Enrolls 10,000th Participant

Can I Treat Parkinson’s-Related Depression Without Medication?

Moving Day Expands to New States in 2018

9 Ways to Start the PD Conversation

Be Somebody’s Champion
# Events

## April

7 Moving Day Tampa Bay  
Register: [MovingDayTampaBay.org](http://MovingDayTampaBay.org)

11 Celebrate Spring New York  
New York City, NY  
Learn more: [Parkinson.org/Events](http://Parkinson.org/Events)

17 Expert Briefings Webinar: Marijuana and PD: What Do We Really Know?  
Register: [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings)

28 Parkinson’s Unity Walk  
New York City, NY  
Learn more: [UnityWalk.org](http://UnityWalk.org)

29 Big Sur International Marathon  
Big Sur, CA  
Register: [Parkinson.org/Champions](http://Parkinson.org/Champions)

## May

5 Moving Day Twin Cities  
Register: [MovingDayTwinCities.org](http://MovingDayTwinCities.org)

6 Moving Day Broward  
Register: [MovingDayBroward.org](http://MovingDayBroward.org)

Moving Day San Francisco  
Register: [MovingDaySanFrancisco.org](http://MovingDaySanFrancisco.org)

19-20 Tough Mudder Philadelphia  
Register: [Parkinson.org/Champions](http://Parkinson.org/Champions)

## June

2 Moving Day DC  
Register: [MovingDayDC.org](http://MovingDayDC.org)

Rock ‘n’ Roll: San Diego  
Register: [Parkinson.org/Champions](http://Parkinson.org/Champions)

Moving Day Charleston  
Register: [MovingDayCharleston.org](http://MovingDayCharleston.org)

5 Expert Briefings Webinar: Living Alone: Home Safety & Management in PD  
Register: [Parkinson.org/ExpertBriefings](http://Parkinson.org/ExpertBriefings)

9 Moving Day Louisville  
Register: [MovingDayLouisville.org](http://MovingDayLouisville.org)

Moving Day Baltimore  
Register: [MovingDayBaltimore.org](http://MovingDayBaltimore.org)

Moving Day Milwaukee  
Register: [MovingDayMilwaukee.org](http://MovingDayMilwaukee.org)

Moving Day Kansas City  
Register: [MovingDayKansasCity.org](http://MovingDayKansasCity.org)

16 Moving Day San Diego  
Register: [MovingDaySanDiego.org](http://MovingDaySanDiego.org)

For a full list of events visit [Parkinson.org/Events](http://Parkinson.org/Events).

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About our new look: This spring we’re excited to launch the redesigned *Parkinson Report*, the Parkinson’s Foundation newsletter. This newsletter replaces the Parkinson’s Disease Foundation (PDF) *News & Review* newsletter. Thank you for reading!
A NOTE FROM THE CEO

Creating Better Lives Together in 2018

A year into my tenure as Chief Executive Officer of the Parkinson's Foundation, I am continually inspired by the Parkinson’s community and even more committed to the urgency of our mission — to make lives better for people with Parkinson's and advance research toward a cure.

I would like to take a moment to reflect on the progress we have made while acknowledging that there is still much more work to be done.

2017 was a banner year for the Parkinson’s Foundation on all fronts: research, care and education. Here are just a few of our highlights:

• We expanded our Centers of Excellence network to 42 expert care clinics
• We invested in two research fellowship grants and half a million dollars in clinical research studies
• We hosted six professional Parkinson’s health trainings for nurses
• We raised nearly four million dollars for Parkinson’s programs through our signature Moving Day walks across the country
• We provided free resources to the Parkinson’s community through our Helpline, online webinars and redesigned website, Parkinson.org.

As we set our sights on new goals for 2018, we remain grateful for your support in the fight against Parkinson’s. Whether you are a person living with the disease, a caregiver or a loved one, we are here for you and we thank you for helping us create better lives together.

P.S. This April, be sure to #StartAConversation with us. Learn more on page 10.

STAY ENGAGED WITH OUR FREE RESOURCES

Visit the go-to Parkinson’s disease resource, Parkinson.org to check out our free resources that always keep you up to date on the latest Parkinson’s research, news and treatments.

Podcast
With a different Parkinson’s expert on every episode, our podcast is designed exclusively for the PD community. Parkinson.org/Podcast

Expert Briefings Webinars
Participate live or watch one of our more than 40 recorded webinars about Parkinson’s symptoms, treatments and management. Parkinson.org/ExpertBriefings

Educational Books
Find an abundance of free Parkinson’s-tailored resources in our PD Library — from books, fact sheets, videos and more! Parkinson.org/Library
The Parkinson’s Foundation has enrolled the 10,000th person with Parkinson’s disease (PD) in the largest-ever clinical study of Parkinson’s. The Foundation’s ongoing Parkinson’s Outcomes Project has already led to the discovery of critical new learnings in the Parkinson’s field. We look forward to sharing more findings from the study in the years to come.

“When the Foundation launched the Parkinson’s Outcomes Project nine years ago, our goal was to understand the impact of Parkinson’s on everyone living with the disease,” said Peter Schmidt, PhD, Senior Vice President, Chief Research and Clinical Officer of the Parkinson’s Foundation, who leads the study. “The Foundation and the numerous researchers we fund can utilize the study’s wealth of information. The data we are collecting is informing trials to deliver new and better therapies.”

Launched in 2009, the study has grown from a small pilot program to 29 expert clinics across five countries. It now serves as a platform for clinical studies to improve the lives of everyone with Parkinson’s.

What exactly does the Parkinson’s Outcomes Project evaluate? In a clinical setting, specialists track a range of Parkinson’s-specific factors such as: medications, other treatments, motor symptoms, cognition, anxiety, depression and caregiver burden. The study has recorded more than 25,000 clinical visits and data from more than 6,000 caregivers.
The study has already led to life-changing discoveries that have helped Parkinson’s health practitioners provide better treatment to people with Parkinson’s. Study findings include:

- **Regular neurologist care** could save thousands of lives every year.
- **Increasing exercise and general movement** to at least 2.5 hours per week may slow the decline in quality of life.
- **People with Parkinson’s should be screened for depression.** Depression and anxiety are leading factors determining the overall health status of people with PD.
- **Women are at a disadvantage when it comes to receiving care, when compared to men.** Women with PD are more likely to have a paid caregiver than men at the same stage, unlike men who are more likely to rely on their spouses and family members for support with everything from daily care to doctor visits.

“We’re working to ensure that every patient receives the best possible care, no matter where they’re seen,” Dr. Davis said.

The Parkinson’s Foundation partners with its vast Centers of Excellence network, leading academic and medical institutions around the world, to determine which Parkinson’s care teams achieve the best results and why. The 42 medical centers that comprise the network deliver care to more than 100,000 people with Parkinson’s every year. Parkinson’s Foundation Center of Excellence status is the most respected and sought-after designation in the field of movement disorders, with each center required to meet rigorous clinical, research, professional education and patient service criteria.

“My goal is to help identify the best care and disseminate that information widely.”

The Parkinson’s Foundation Prevalence Project found that nearly 800,000 people are currently living with Parkinson’s in the United States. This number will rise to nearly 1 million in less than two years.

This new estimate is nearly double the original 1978 study count. “In the past 40 years, our knowledge of Parkinson’s has evolved significantly and so should our understanding of the population that has this disease,” said James Beck, PhD, Parkinson’s Foundation Chief Scientific Officer. “This study will help the Parkinson’s Foundation attract the attention of federal and state government as well as the pharmaceutical industry to the growing need and urgency in addressing PD.” This new estimate will help us better serve the Parkinson’s community and advocate for their needs. The entire study is available and was recently published in the Parkinson’s Foundation scientific journal, *npj Parkinson’s Disease*.

Learn more about the Parkinson’s Outcomes Project at Parkinson.org/Outcomes.

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**Parkinson’s Foundation Prevalence Project Finds Number of People With Parkinson’s Severely Underestimated**

The last time a scientific study counted the total number of people with Parkinson’s disease (PD) living in the United States, “Grease” was still in theaters and a gallon of gas was 79 cents. To fix this, the Parkinson’s Foundation set out to determine a more accurate representation of people living with PD today.

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Read more about the study and what it means for the Parkinson’s community at Parkinson.org/Statistics.
My sister has Parkinson’s. Knowing that exercise can improve mood, motor function and symptom management, how can she overcome the typical barriers to exercise for people with Parkinson’s?

Exercise, including activities like walking, swimming or yoga, is vital to living well with Parkinson’s and can help with balance and mobility issues. A 2017 study conducted by Northwestern University, a Parkinson’s Foundation Center of Excellence, and the University of Colorado showed that intense exercise may improve the symptoms of Parkinson’s.

Additionally, the Parkinson’s Outcomes Project has shown that activities that provide symptomatic benefits, such as exercise, may possibly affect disease progression.

How to help someone overcome exercise barriers:

- Work with a Parkinson’s-trained physical therapist to address concerns and limitations.
- Find a local Parkinson’s exercise class led by a person experienced with Parkinson’s.
- Work with a specialist to create a tailored exercise program that includes aerobic exercise, such as walking and weighted resistance training.

California just legalized recreational marijuana and medical marijuana is legal in 29 states. Do you have any advice on using medical marijuana to treat Parkinson’s?

There are no guidelines for using medical marijuana in Parkinson’s therapy. We need more studies to define which patients and which Parkinson’s symptoms have the greatest potential to improve with cannabis. There is currently no evidence that it can change or slow disease progression, though many experts believe patients can experience positive effects, and many of our Centers of Excellence have been reporting powerful anti-anxiety benefits. It’s important to know some of the benefits and risks associated with the use of cannabis for people with PD:

- **Potential benefits:** While not proven through Parkinson’s-specific studies, benefits can include possible improvement in pain management, sleep dysfunction, weight loss and nausea.
- **Risks:** Impaired cognition, dizziness, blurring of vision, mood and behavioral changes, loss of balance and hallucinations. Chronic use can increase risk of mood disorders and lung cancer.

Your first step should be to talk to your doctor about medical marijuana. Be careful if you and your doctor decide it is right for you and never drive under the influence. Finally, remember that smoking may be harmful to the lungs.

Read Dr. Okun’s monthly What’s Hot in PD? column at Parkinson.org/Blog.
My husband has Parkinson’s and he has lost a great deal of weight. I make good, nutritional meals, but the weight keeps coming off. He was diagnosed 10 years ago and has trouble with his mobility. As his primary caregiver, how worried should I be?

Slow, steady weight loss can occur in Parkinson’s. Because Parkinson’s affects brain systems important to weight, it can sometimes be hard to put pounds back on, even by increasing calories. A 2017 Neurology study found people with Parkinson’s or atypical parkinsonism had lower body weights and lost weight faster compared to people who did not have Parkinson’s.

Your doctor should track your husband’s weight at each visit and suggest dietary changes that can minimize weight loss. You and your doctor should decide together if gaining weight is more of a priority than eating a healthy diet. Atypical forms of parkinsonism may require more aggressive treatment.

These tips can help with weight gain:
• Eat small, frequent meals every two to three hours.
• Eat foods you enjoy.
• Keep easy-to-prepare foods on hand.
• Season food with herbs, spices and sauces to stimulate appetite.
• Add high-calorie foods, like cream and butter, to your diet. Ask your doctor before doing so.
• Increase consumption of whole grains, like rice and breads.

If you have Parkinson’s disease (PD) and you live alone, utilizing dependable local resources can be a game-changer. These tips can help you stay independent:

1. **Build a Team.** Ask your healthcare provider for a referral to a social worker, therapist and physical therapist, among others, who can address medical issues as they arise.

2. **Find a Support Group.** The right group can nurture friendship, community and provide advice. Call our free Helpline at 1-800-4PD-INFO (473-4636) to find one near you.

3. **Research Transportation.** Many areas offer low-cost or free transportation. Some community centers or religious organizations offer shuttle services.

4. **Minimize Home Risks.** Our safety checklist can help create a safe and easily accessible home. Request a home safety evaluation from your doctor. Then, consider purchasing a wearable medical alert system in case of an emergency.

5. **Know Who to Call.** Whether it’s for gardening or groceries, keep a list of people who can help when you need it.

Can I Treat Parkinson’s-Related Depression Without Medication?

The following article is based on a Parkinson’s Foundation Expert Briefings webinar about depression presented by Roseanne D. Dobkin, PhD, from Rutgers, The State University of New Jersey. View all past Expert Briefings at Parkinson.org/ExpertBriefings.

At least 50 percent of people living with Parkinson’s disease (PD) experience depression at some time. The Parkinson’s Foundation Parkinson’s Outcomes Project found that mood, depression and anxiety together impact health even more than PD-associated motor impairments.

While depression can amplify PD challenges, it’s a controllable symptom. Though no one chooses Parkinson’s, they can choose how to cope with it. Cognitive behavioral therapy (CBT) skills are proven to help.

Behavioral Intervention
PD-related brain changes and other factors can contribute to depression. Our outlook and behaviors influence how we feel. But behavioral intervention can lift moods. Cognitive behavioral therapy is a non-drug approach to developing the skills and actions that change patterns of thought and behavior related to depression.

Changing Behavior
Learn to let activities guide you when feeling depressed or anxious. Prioritize meaningful pursuits. Set small, realistic goals. Focus on three areas when setting goals:

- **Exercise.** Pursue a safe, doable daily exercise goal, whether running a 5K or completing a seated exercise class.
- **Socialize.** Aim for small social goals, like answering the phone or saying hi to a cashier.
- **Self-soothe.** Plan a satisfying, positive daily activity — take a bath or listen to your favorite album.

Reintroduce or modify activities that may have taken a backseat with your PD diagnosis, or discover new ones. Plan around physical limitations and “off” time by pacing yourself and staying flexible — if you can’t walk for 30 minutes, start with 15.

Using Thoughts to Achieve Balance
When depressed or anxious, thoughts often include negative predictions. Predicting things will not go right can influence our actions. Remember, healthy thoughts help you cope with PD, but destructive ones derail your efforts. Try to fight worst-case thinking with this activity:

- **Write down negative thoughts.** For example, “My PD makes my friends uncomfortable.”
- **Share the thought with a loved one.** Do others share your perception? Is there evidence against it?
- **Revise your thought** to help you objectively cope with PD challenges.

Managing Depression
Caregivers are essential in helping loved ones cope with depression. Research shows people with Parkinson’s using CBT have longer, greater depression improvement when care partners receive CBT educational sessions.

Taking action is hard when struggling with depression. A surprising CBT benefit is that it’s self-reinforcing. A glimmer of success gives you enthusiasm to do more. Talk to your friends, family and doctor if you feel sad or hopeless. You and your care team may consider antidepressant medication or an effective, non-drug treatment, available alone or in combination with drug therapies.

For more information about depression and anxiety, order a free copy of Mood: A Mind Guide to Parkinson’s Disease or call our Helpline at 1-800-4PD-INFO (473-4636).
“When you have Parkinson’s disease (PD) you have the choice to get involved and try to make a difference or let others do the work,” Scott Rider said. “For me, the best way to do that was to help the Parkinson’s Foundation through Moving Day, A Walk for Parkinson’s.”

Scott has walked in Moving Day Columbus to help fund PD research, which has motivated him to manage the top fundraising team three years in a row. This year, he’s ready to do it all again in Charleston, SC, where the Parkinson’s Foundation will host one of its 39 Moving Day walks in 2018. Sixteen of these walks will be held in new states, like New Jersey.

John Kolaya was introduced to Moving Day when his son, Tim Kolaya, joined the Moving Day Miami committee and named his team after John — “Team Grampy.” After attending Moving Day Miami, John set out to bring the walk home to New Jersey. John, now a Rock Steady Boxing instructor, found hope in exercise after his Parkinson’s diagnosis.

“Moving Day shows you what other exercises are available that can change your life,” John said. Moving Day promotes movement, as each event features a Movement Pavilion where participants can try new exercises like non-contact boxing, yoga, Zumba and more.

The 2017 Moving Day season reached major milestones by raising $3.9 million dollars and bringing together 14,500 participants. With a new website and logo created to celebrate the Parkinson’s community, the Parkinson’s Foundation continues the fight to beat the disease by hosting a record number of walks in 2018.

“Parkinson’s can be isolating, but Moving Day is an incredible event that brings the entire Parkinson’s community together to move,” said Kayln Henkel, Parkinson’s Foundation Vice President of Field Development. “This year, we want to reach even more people.”

Every walk supports Parkinson’s Foundation efforts to fund cutting-edge Parkinson’s research and improve PD treatment and care in order to help people with Parkinson’s live better lives. Since its 2011 inception, Moving Day has raised more than $17 million for Parkinson’s research and programs.

Both John and Scott will attend Moving Day walks this year. In South Carolina, Scott is revving up the PD community, while John serves as Moving Day New Jersey event co-chair and is ready to get in the ring come event day.

See all 2018 Moving Day events at MovingDayWalk.org.
April is Parkinson’s Awareness Month. Here are nine ways you can help the Parkinson’s Foundation spread Parkinson’s disease (PD) awareness and start the conversation:

1. **Advocate with Us.** We’re looking for people in the PD community to champion our mission. Join us in advocating for research, addressing women’s specific needs relating to PD and help legislating change. Visit Parkinson.org/GetInvolved.

2. **Walk for Parkinson’s.** This year, we are hosting a record 39 Moving Day events across the nation. Join the conversation by moving with us! Find your nearest walk at MovingDayWalk.org.

3. **Tell Your Story.** While Parkinson.org provides millions of people with vital information each year, sometimes the most life-changing advice comes from you! Submit your Parkinson’s story and you just may inspire someone. Visit Parkinson.org/MyPDSStory.

4. **Host a Do-It-Yourself Fundraiser.** Start the conversation among your own social group. Host an event — from a brunch to a hike — where all proceeds help make life better for people with Parkinson’s. We’ll help you every step of the way! Visit Parkinson.org/Champions.

5. **Start a Support Group.** Leslie Peters and her husband couldn’t find a support group for people with young-onset PD that fit their needs. She now manages a support group that meets over dinner. Start a support group that works for you. Download our Support Group Guide at Parkinson.org/Library.

6. **Call our Helpline at 1-800-4PD-INFO (473-4636).** Start a new conversation with one of our Helpline information specialists. Staffed by nurses, social workers and therapists, the Helpline is here to support you in any way. You can also email the Helpline at helpline@parkinson.org.

7. **Try a New Class.** Strengthen your PD community through our local networks. The Parkinson’s Foundation provides people with PD and caregivers access to local exercise classes and education programs. Find your next class at Parkinson.org/Search.

8. **Write a Letter to the Editor.** Represent your local PD community and educate your city about Parkinson’s in your local newspaper. Visit Parkinson.org/Statistics to give your letter some strong talking points.

9. **Find us on Facebook and Twitter.** Follow us to read daily Parkinson’s updates when it comes to treatments, research and news. Tell us how you are starting the PD conversation this month at Facebook.com/ParkinsonDotOrg and Twitter.com/ParkinsonDotOrg.

By raising awareness about Parkinson’s disease, we can do more together to improve the lives of people with Parkinson’s and their families. Take our online pledge and keep the conversation going at Parkinson.org/Awareness.

#StartAConversation
Be Somebody’s Champion

Parkinson’s Champions is a community-driven fundraising program that allows people to raise funds and awareness for Parkinson’s however they like. Make this the year you run that half-marathon, and do it as a Parkinson’s Champion. Parkinson’s Champions get race entry into prestigious races around the nation. You can plan your own event and turn it into a Parkinson’s Champions fundraiser!

Why Join Parkinson’s Champions?
- Funds raised through Parkinson’s Champions support our mission to improve care and advance research toward a cure.
- Get unlimited access to our Parkinson’s Champions team, who provide fundraising support, and use our free customizable webpage to track your donations and progress.
- Fundraise in honor of a loved while making life better for the one million Americans living with Parkinson’s.

What Is a Parkinson’s Champions Event?
Take part in an endurance race — like the TCS NYC Marathon or Marine Corps Marathon, join a local Tough Mudder or Rock ‘n’ Roll Marathon, or run a race that’s right for you as a Parkinson’s Champion. You don’t have to run; host your own unique event like a golf tournament or a theme party!

Parkinson’s disease is a marathon, not a sprint. Be somebody’s champion. Join our team at Parkinson.org/Champions.

SUPPORT THE FIGHT AGAINST PARKINSON’S DISEASE

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

When you share your commitment to the Parkinson’s Foundation in your estate or financial plan, you become a member of our Legacy Society. These honored members are recognized in our Annual Report, receive special updates from the CEO, but most importantly, help us make life better for people with Parkinson’s.

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

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contact@parkinson.org
Toll-Free: 1-800-4PD-INFO (473-4636)
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Find Parkinson’s-tailored exercise classes, support groups and programs in your area by calling our Helpline at 1-800-4PD-INFO (473-4636).