

PEDALING FOR PARKINSON'S™

Getting Started Guide //// 🛞



every victory counts®





Thank you for your interest in starting a Pedaling for Parkinson's (PFP) class in your area!

For more than ten years, PFP classes have helped thousands of people with Parkinson's get moving, find community, and feel better. And every single one of those classes has come together thanks to someone like you. PFP relies on community champions who believe in the program and are willing to put in the effort to advocate, create space, and beat the drum to get people riding.

You won't do this alone, however.



PFP has long been led by dedicated volunteers, many of whom live with Parkinson's themselves. When the Davis Phinney Foundation was passed the torch for this program in 2023, we made the commitment to the program's volunteers, researchers, and founders that we would maintain what has always made this program special while amping up support to make it more successful than ever. With dedicated staff, resources, and partnerships, it is our goal to help make sure your efforts result in a lasting and thriving resource for your Parkinson's community.

This guide is just the beginning, but we hope it answers many of the questions you may have as you get your class off the ground. For the questions it doesn't answer, we're here to help.

Thank you again for kicking off the journey to bring this program to your community.

Davis Phinney Foundation staff





ABOUT THE DAVIS PHINNEY FOUNDATION ///

Since 2004, the Davis Phinney Foundation has brought to life essential programs, research, content, and events for those affected by Parkinson's, including people living with Parkinson's and those who love them, physicians, allied health professionals, and others. In addition to PFP, programs of the Foundation include:

- » <u>Every Victory Counts[®] manual and Every Victory Counts[®] Care Partner manual</u>
- » The Victory Summit[®] event series
- » <u>Healthy Parkinson's Communities™ initiative</u>
- » Ambassador Leadership Program
- » Parkinson's webinars and meetups
- » <u>The Parkinson's Podcast</u>
- » <u>Quality of life research program</u>

These programs impact hundreds of thousands of people living with Parkinson's and their families each year. Learn more about the Foundation at <u>dpf.org</u>.





PEDALING FOR PARKINSON'S PROGRAM BACKGROUND ///

Pedaling For Parkinson's was founded by Dr. Jay Alberts, a neuroscientist and researcher at the Cleveland Clinic, and Cathy Frazier, a woman living with Parkinson's. While riding a tandem bike at RAGBRAI in 2003, they discovered that cycling reduced Cathy's symptoms. With Dr. Alberts guiding the bike and Ms. Frazier on the back, she noticed something interesting after the day's ride: She felt like she didn't have Parkinson's anymore!

This experience led Dr. Alberts to study the effects of aerobic exercise (and cycling in particular) on cognitive and motor function through a project funded by the Davis Phinney Foundation in 2009. The results of that research defined a therapeutic protocol that was subsequently deployed in a few cycling studios across the country. Delivering almost immediate results, the test environments were converted to indoor stationary cycling classes that quickly became available to people living with Parkinson's, and thus Pedaling for Parkinson's was born.

Since 2013, Pedaling for Parkinson's has taken hold in YMCAs, gyms, and other community spaces across the country. Taught by local instructors, these accessible classes engage participants in a simple protocol three times a week and are proven both scientifically and anecdotally to help people with Parkinson's feel better and live well today.

In 2023, the founder of Pedaling for Parkinson's, Dr. Jay Alberts, chose the Davis Phinney Foundation to become the stewards of this innovative and effective program. With Davis's roots in cycling and the Foundation's history as an advocate for exercise, this was a natural next step to ensure the sustainability and broad availability of this program for people living with Parkinson's across the country (and, soon, globally).

THE RESEARCH

Dr. Jay Alberts and his colleagues have dedicated 17 years to studying the effects of exercise, primarily forced cycling, on performance in people living with Parkinson's. Each project has inspired the next, and the research continually support anecdotal evidence that forced and high-intensity aerobic exercise improves motor function (and more) in people with Parkinson's.

Learn more about the timeline of this research on the Davis Phinney Foundation website at <u>dpf.org/PFPresearch</u>.



Pedaling for Parkinson's: Getting Started Guide



START HERE ///

The process begins with a commitment to make Pedaling for Parkinson's available in your community. The key to establishing a successful PFP class is a dedicated and committed person to champion the cause. It's also good to have a facility in mind, potential instructor(s), and a good pool of interested people.

THE PROGRAM

The Pedaling for Parkinson's program is based on research indicating that forced exercise on a bicycle can reduce symptoms of Parkinson's. The protocol includes a one-hour ride with:

- » a 10-minute warm-up at 60 rotations per minute (RPMs)
- » 40 minutes at 80 RPMs
- » a 10-minute cool down at 60 RPMs.

For convenience, most programs are offered on indoor, stationary bikes and hosted at local YMCAs, gyms, or other community spaces.

Participants who ride three days a week over eight weeks have shown improvement in their Parkinson's-related symptoms by as much as 35%. Classes usually meet on Mondays, Wednesdays, and Fridays or on Tuesdays, Thursdays, and Saturdays.

A typical Pedaling for Parkinson's class includes an instructor and as many participants as bikes are available at each facility. Class sizes range anywhere from three to 30 participants.

- » Participants should be able to secure their feet in or on the pedals and maintain a safe and suitable body position to stay on the bike throughout the duration of the class.
- » Participants are encouraged to wear proper cycling clothing and bring a water bottle.
- » Participants are encouraged to remain seated on the stationary bicycle for the duration of the class.

Learn more about program requirements on page 8.

PFP STARTUP CHECKLIST

Now that you know what the program involves, here's a proven checklist to get your class up and running. Depending on where you live and how many of the program requirements you already have in place, the process typically takes anywhere from one to six months from idea to first class. Ensuring each step is completed and all program requirements are in place is the best recipe to ensure your class will become a staple resource in your community.

- » Download the PFP Getting Started Guide You've taken the first step by downloading this guide!
- » Review Existing Classes in Your Area If you have not done so already, <u>search our</u> <u>exisiting class map and directory</u> to ensure there is not already an existing class in your area. You may also consider expanding your search to see what other classes exist in your state or region. You may find it useful to connect with the with the people leading those classes to learn from them. If you need an introduction, please let us know.
- » Review the Program Requirements You'll want to familiarize yourself with the program requirements listed on page 8 of this guide. Don't worry if you don't have everything on the list figured out just yet, that's why we're here!
- » Submit an Interest Form Once you've read through this guide, including the program requirements, submit the interest form that best aligns with your role found <u>here</u> on our website. Our PFP Program Manager will review this information and then reach out to you with specific questions and resources that can help you start off on the right foot.
- » Put the Pieces Together This is often the trickiest part of starting a new PFP class. Finding the right facility, equipment, and instructor can take time, especially if you live in a more rural or under-resourced area. We're here to support you. You may also find the FAQ on page 10 helpful as you consider what pieces are important for your community.
- » Review and Sign the Licensing Agreement (must be completed by the host facility) Once you have all the requirements in place, your host facility will sign the licensing agreement. This document allows your facility to use the PFP name and opens the door to resources that will help ensure longterm success.
- » Complete the PFP Certificate Course (approx 3 hrs, must be completed by all class instructors) – PFP training is completed online by all instructors and is completely free. It is required by each instructor before they teach their first class and is a valuable resource for anyone leading these classes, especially if they are new to the program and/or the Parkinson's community. Learn more about what makes our certification different in the FAQ on pg 11.

» Promote Your Class – Once ready, your class will be added to the PFP website and online directory. The Foundation will send a geotargeted email to people in your area that are on our mailing list announcing the new class. You will also gain access to our branding and marketing toolkit which can be used to help get the word out about your class!

PFP PROGRAM REQUIREMENTS

Pedaling for Parkinson's is meant to be an accessible program available in any community that wants it. That said, there are certain requirements to ensure classes are safe and instructors and participants are appropriately supported. Don't worry if you don't have everything figured out just yet. While it may take some effort, you *will* be able to bring all the pieces together to start a program in your area just like hundreds of other people like you have done in the last decade.

Location Requirements

Pedaling for Parkinson's classes may be offered at any gym, recreation center, or community center that meets the following requirements:

- » The building and classrooms must be ADA accessible.
- » The location must provide general and professional liability insurance coverage for anyone leading a Pedaling for Parkinson's class.
- » Stationary bicycles should be spaced with at least two feet between bikes for safe mounting and dismounting.
- » The facility must be able to collect class participant information and participant waivers.
- » Safety measures must be in place, including procedures for addressing medical emergencies.

Equipment Requirements

Pedaling for Parkinson's requires the use of stationary bicycles with a cadence monitor. Bikes may be upright or recumbent with clip-in or clipless/flat pedals. In addition, classrooms should also provide:

- » A bench or chairs for participants to change shoes or rest when needed
- » A place for participants to put their water bottles, such as a water bottle holder on the bikes
- » Lighting, good acoustics, proper ventilation
- » A sound system, microphone, and reliable Wi-Fi are ideal

Instructor Requirements

In addition to instructor requirements mandated by the facility hosting the classes, it is important that Pedaling for Parkinson's instructors understand:

- » Pedaling for Parkinson's class protocols, including a general understanding of the research behind it
- » The difference between Pedaling for Parkinson's and other indoor cycling classes
- » Basic information about Parkinson's and symptoms, including motor and non-motor symptoms that may impact participants
- » How to keep class participants safe and engaged

Pedaling for Parkinson's instructors do not need to have certifications or training in indoor cycling. However, all instructors (including substitutes) are required to complete our three-hour Pedaling for Parkinson's certificate program. Additional education opportunities for instructors will also be provided, though not required.

Participant Requirements

Pedaling for Parkinson's may not be suitable for every person with Parkinson's. The instructor should make sure candidates can safely mount a stationary bike. Once familiar with getting on and off the bicycle safely, participants should be able to secure their feet in or on the pedals and maintain a safe and suitable body position to stay on the bike throughout the duration of the one-hour class. Participants should also be briefed on proper clothing, shoes, related personal equipment, and strategies to make cycling indoors more comfortable.

Participants should come to class with the following:

- » Comfortable clothing suitable for exercise, which may include padded cycling shorts
- » Closed-toed exercise shoes with a firm sole such as tennis shoes, joggers, or trainers (Cycling-specific shoes are optional but not required.)
- » Water bottle
- » Heart-rate monitor (not required but may be helpful)
- » Portable seat pads, gloves, ear plugs, towel, or other equipment for added comfort
- » Any medications needed before, during, or after class



Below are some of the most common questions we receive from people who are just getting started. Have a question not covered here? Contact us at <u>pedalingforparkinsons@dpf.org</u>.

HOW CAN THE FOUNDATION HELP ME GET STARTED?

Pedaling for Parkinson's classes are community led and, as such, each becomes unique to the community that starts it. Our job is to help you get off the ground and keep moving for years to come. We do this by investing staff time and providing partnerships aimed at:

- » Strategizing resources that can help you get started or solve problems along the way
- » Providing initial and continuing education for instructors
- » Managing agreements with your facility to ensure they meet requirements and can continue to provide space for your class
- » Providing a platform for your class to be discovered by new participants in your area
- » Reducing costs to start or sustain your class

If ever you run into a challenge you can't find a solution for, please contact us at **pedalingforparkinsons@dpf.org** or call 1-866-358-0285. We're here to support you.

HOW DO I FIND A FACILITY?

Finding a supportive facility is a critical part of the process and can be challenging, depending on where you live. If you have a YMCA in your area, we recommend starting there, as YMCAs have historically been very supportive of this program and often have the equipment and staff already in place to make the class happen. The Davis Phinney Foundation is working to build relationships with regional directors of YMCAs to help make this process even easier, so if you run into any friction at the local level, contact us, and we can help.

If you don't have a willing YMCA in your area to partner with, senior centers or community centers tend to be another good place to try. You may also search where other Parkinson's programs such as Rock Steady Boxing, Dance for PD®, LSVT® Big & Loud, PWR® for Parkinson's, and others are happening in your community. Those spaces may also be willing to open their doors to your PFP classes. You may encounter more challenges finding equipment and instructors in these spaces, but they may still be the best option in your area.

On the flip side, gyms that offer indoor cycling classes are worth contacting since they already have the equipment you need. Sometimes, these are a good option as your PFP class might be able to happen during off hours when their equipment isn't being used anyway. A challenge to be aware of is that the gym may require your PFP participants to pay a membership fee, which may be cost-prohibitive. However, some people have been able to negotiate this to allow the use of the space/ equipment without requiring a full membership, so it never hurts to ask!

WHAT IS PFP CERTIFICATION LIKE?

Unlike many certificate programs, our Pedaling for Parkinson's certificate is meant to be accessible for anyone interested in teaching a class and qualified to teach at a YMCA, gym, or other facility that meets our requirements. The certificate course takes 2-3 hours to complete and is self-paced and completed online.

The content of our certificate course includes:

- » Background and history about Pedaling for Parkinson's and the research behind it
- » Instruction on how to lead the class and make it safe and interesting for participants
- » Content on Parkinson's symptoms, especially those that may create challenges for participants in the class setting
- » Information on how to anticipate and troubleshoot potential challenges that may come up when teaching the Parkinson's community

WHAT MAKES A GOOD INSTRUCTOR?

You may be surprised to learn that it is not a requirement for PFP instructors to be certified indoor cycling instructors or trainers. The reason for this is the simplicity of the protocol. What is most important is the instructor's connection with the Parkinson's community (or willingness to learn!)

Most gyms and community centers already require certain training or certifications including First Aid and CPR, so if you are working with an existing instructor, you can be sure they have been vetted by your facility. Your focus should be on finding someone who shares your passion for your Parkinson's community members. This is what we've found leads to longevity more than anything else - plus it means they'll put in the work to understand how to create a safe and memorable class!

You may consider inviting a potential instructor to attend another Parkinson's exercise class in your area or attending a support group meeting so they can begin to build connection with the Parkinson's community.

Finally, you may consider asking instructors of other local Parkinson's exercise classes, physical therapists, medical students, or others who have a pre-existing relationship with the Parkinson's community if they'd be interested in becoming a PFP instructor.

WHAT ABOUT SUBSTITUTE TEACHERS?

Once you have your primary instructor in place, it is a good idea to work with them to line up one or two potential substitutes for when they are unable to teach. Substitutes are required to complete our PFP certificate course, so it's important to consider this before you really need them.

WHAT FUNDING WILL I NEED?

Most PFP classes are offered for free in communities and, as mentioned above, many people have been able to negotiate with their facility to reduce or eliminate membership fees for participants. That said, there can be some costs associated with these classes such as:

- » Equipment If you are unable to find a facility with the right equipment for your class, you may need to purchase bikes or other items. This can get expensive. The Davis Phinney Foundation is working to build partnerships with manufacturers of stationary bikes to help reduce this barrier. If you cannot source the equipment you need, please contact us so we can work with you to address this issue.
- » Instructor Fees Ideally, you can source an instructor employed and paid by your facility. If not, consider how you will pay your instructor to teach the class. It is the case in some communities that instructors are volunteers, and that may work for you. However, if you pay your instructor(s), teaching may be more sustainable for them. If you need support solving this issue, contact us.
- » Membership Fees If you are unable to find a space that will reduce or eliminate membership fees for your participants, you may need to offset these costs to make it possible for some people to attend.

WHERE CAN I FIND FUNDING?

Our goal is to eliminate as many costs as possible for your community through our staff support and partnerships so that this does not become an issue. However, we recognize that may only sometimes be possible, and you may need to seek funding to start or sustain your class.

The Davis Phinney Foundation is still working to develop funding and fundraising opportunities for PFP classes. In the meantime, many communities utilize grant funding from the Parkinson's Foundation, local Rotary Clubs, Chambers of Commerce, or other local groups. If you are looking for a funding source, please get in touch with us so we can help you strategize, and we can further understand your needs as we develop more opportunities for PFP leaders.

HOW IS PFP FUNDED?

Pedaling for Parkinson's is funded like all our other programs - by national sponsor partners, individual donors, and fundraisers.





WHAT'S NEXT? ///

CONTACT US

Ready to hit the ground running? Please complete the interest form listed below that most closely aligns with you. We'll use the information provided to help you with your goals. Click on the links below or visit <u>dpf.org/PFPstart</u>.

<u>Click here to fill out our PFP Instructor Interest Form</u> <u>Click here to fill out our PFP Facility Interest Form</u> <u>Click here to fill out our PFP Advocate Interest Form</u>

Have other questions before you start or want to speak with one of our staff members? Contact us at pedalingforparkinsons@dpf.org or by calling 1-866-358-0285

