



Pedaling for Parkinson's®

Indoor Stationary Cycling Program

Start-up Guide

[November 2019]



This document is provided to help you establish a Pedaling for Parkinson's indoor, stationary cycling program in your area. Based on the research performed by Dr. Jay Albert at the Cleveland Clinic®, this guide offers information, suggestions, and best practices. The use of this guide is does not authorize or certify any equipment, instructors; nor any guaranteed results stemming from your specific program; nor does its use constitute an agreement or right to use the program, name, logo or any other trademarked content.

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Introduction

The mission of Pedaling for Parkinson's (PFP) is to help improve the quality of life of people living with Parkinson's disease. In addition, PFP provides information for patients and caregivers, and the general public about the benefits of maintaining an active lifestyle after a Parkinson's diagnosis. Beyond the program, the organization supports research dedicated to prevention and treatment of Parkinson's disease.

Overview and History

The Pedaling for Parkinson's program is a form of "Forced Exercise" on a bicycle. Participants ride for 1 hour — a 10 minute warm up at 60 RPMs, followed by 40 minutes at 80 RPMs, and a 10 minute cool down at 60 RPMs. Programs are offered on indoor, stationary bikes. Participants riding 3 days a week over 8 weeks have shown improvement in their Parkinson's related symptoms by as much as 35%.



Jay Alberts, PhD

In 2003, Dr Jay Alberts (pictured left) and a group of friends participated in the RAGBRAI (*the Des Moines Register's Great Bike Ride Across Iowa*), the oldest multi-day, cross state bike ride in the nation. The group included a woman with Parkinson's disease, Cathy Frazier. Originally, the plan was for Cathy and her husband to ride a tandem. However, having no experience ridding together, Cathy and her husband struggled through the beginning of the ride. Dr. Alberts suggested they switch tandems with Cathy on the back seat of his bike. With this new configuration, Alberts was able to maintain an average cadence of 85-90 rpm for the entire week with Cathy aboard. Surprisingly, at the end of the week-long ride, they noticed her improved penmanship and less severe tremors. "This week, I felt like I didn't have Parkinson's." Cathy commented, leading Dr. Alberts to wonder if there could be a correlation between fast pedaling and a reduction of Parkinson's symptoms. Cathy's observations were later confirmed by Alberts.

Returning to Atlanta, Alberts evaluated Cathy's motor symptoms. Her scores had indeed decreased by nearly 35% from those recorded several months earlier. Improved motor functioning over the course of training for RAGBRAI, and during the event itself, led to Alberts pose that riding on a tandem may have contributed to Cathy's improvements in motor function in the upper and lower extremities.

In the lab, Alberts set up an experiment to see if Cathy's outcomes were coincidental or if there was something happening as a result of the

forced pace cycling. He recruited twelve (12) people with Parkinson's and with similar levels of disability. Each candidate rode a cycle three times a week for one hour, beginning with a 10 minute warm up, 40 minutes of cycling at cadence, and 10 minute cool down. They all kept within 60-80% of their maximum heart rates. Six of the candidates rode on stationary bikes at their own preferred cadence and 6 rode on the back seat of a stationary tandem. The tandem sample rode the 40 minute segment at 80-90 rpm maintained by the captain. At the end of the 8-week trial period, those on stationary bikes were more fit but showed no change in their PD symptoms while those on the tandems experienced an average of 35% reduction of their symptoms. Tested again 4 weeks later, the tandem sample still had a residual positive effect on their PD symptoms.



Following Alberts' research model, several Pedaling for Parkinsons clinical trials were established at facilities around the country. These programs supported 10-week trials designed to confirm results and understand the requirements of managing programs remotely.

Today, PFP is studying the efficacy of altering the disease progression through a community based PFP program. Fifty people living with Parkinsons at 2 sites in Seattle and 3 in the Denver area are participating in the research study to understand the effects of a structured exercise program on the symptoms of Parkinsons disease.

The study aims to determine if individuals participating in a PFP class demonstrate slower rates of progression than the average.

Pedaling for Parkinson's continues to explore ways to expand the fast paced cycling experience for thousands of people with Parkinson's. The result has been the deployment of nearly 150 Pedaling for Parkinson's exercise programs around the United States, serving thousands of people with living with the disease. Through PFP partnerships in existing health and wellness facilities, people with Parkinson's can adopt sustainable lifestyle changes that can significantly mitigate symptoms and improve their overall quality of life.

Program

Pedaling for Parkinson's is among the fastest growing group exercise programs for people living with Parkinson's. That's because it works and, through partnerships with facilities such as yours, helps PFP deliver the therapeutic benefits from cycling.

Start Here The process begins with a commitment to move forward. 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 and a good pool of interested people. With that, it's a simple step-by-step.

1. **Download the PFP Start up Guide** — You've taken the first step by obtaining this guide! But if you need any assistance as you follow the process, contact a Program Coordinator (Appendix A) or PFP staff. Though most of what you need to know is in the guide, a program coordinator can address your specific questions and concerns.
2. **Review your Facility and Equipment** — By the time you've come this far, chances are good you know of a facility and may be familiar with the equipment. Most cycling studios are in a dedicated room in a recreation facility — a YMCA, district or municipal recreation center. You'll want to make sure the facility you would like to use complies with the guidelines outlined in Table 1.
3. **Complete the PFP License Agreement** — An agreement is required to license the use of the program name and logo, protecting the trademarks, and ensuring support from PFP. You can request a license agreement by completing the inquiry form on the web page (www.pedalingforparkinsons.org) or by contacting Nan

Little, 206-321-0200, nan.little@comcast.net. Any questions and concerns regarding the agreement can be addressed to her, also. There is no fee.



Pedaling for Parkinson's at the APEX Center, Arvada CO

4. **Class Leaders** — A class leader is required by PFP and, in most cases, is supplied by the host facility. It is a good idea to cultivate substitutes to ensure classes continue on the regular schedule when the lead instructor is unavailable.
5. **Participants** — Of course, once you've got all the pieces in place, you'll need participants!
6. **Marketing & Promotion** — "If you build it, they will come." But, they do need to know it's there. Marketing and promotion suggestions are provided below.

Documents There are a few important documents you need to review and understand. These are all available on the Pedaling for Parkinson's web site.

- The PFP Start-up Guide — *This document.*
- PFP License Agreement — A license agreement is provided by Pedaling for Parkinson's to protect both the host site and parties associated with Pedaling for Parkinson's.

- PFP Program Protocol — included with the license agreement
- Notes and FAQ — Other documents are included to provide additional information, history and frequently asked questions.

Facilities Pedaling for Parkinson's can be offered in a variety of locations depending on site feasibility, participant population/ demographics and available resources. Potential sites include private athletic clubs, public community centers, and wellness centers.

	Required	Recommended
Facility	Adequate space to accommodate multiple indoor stationary training cycles	Water
	Class leader bike	Towels and bicycle cleaning materials
	Bench or chairs	Rate of Perceived Exertion chart
	Stepstool	
	Adequate lighting, heating, ventilation and air conditioning	
Cycling Equipment	Indoor Stationary training bikes [standard upright or recumbent]	Multi-function bicycle computer
	Bicycle computer to monitor cadence	Clip style pedals
	Water bottle holder	
	Safety mat under each bike	
Participant Equipment	Suitable cycling clothing and shoes	Padded shorts
	Heart rate monitor	Gel-pad seat cover
	Water bottle	Clip style shoes
Class Format	Three (3), 1-hour sessions per week	Warm up / stretching
	10 minute warm up @ 60 RPM	Cool down / stretching
	40 minutes @ 80-90 RPM	
	10 minute cool down @ 60 RPM	

YMCAs, public recreation centers and athletic clubs are a great place to start. If the program fits within their mission and they have an indoor cycling studio, they can generally accommodate a PFP class almost immediately. With equipment and staff already in place, they often need only to advertise to their community and provide training for their spin instructors on the PFP protocols and specific issues that may arise with people with Parkinson's.

As a community service, some public and private facilities offer complementary classes. They may also be associated with local care facilities with a ready group of participants. We encourage you to explore this option to eliminate any fees. We currently have both public and private facilities hosting classes at NO CHARGE.

Instructors Class leaders may also be refereed to as instructors, facilitators, coaches or other similar designations and should be employees or approved volunteer staff of the host facility. In any case, instructors must be protected under the host facility's liability insurance. Lead instructors should develop substitutes to ensure classes continue on the regular schedule when the lead instructor is unavailable.

Pedaling for Parkinson's requires instructors and substitutes to know about both indoor cycling and Parkinson's disease. Instructors should have ample experience leading indoor cycling classes, and though no specific indoor stationary cycling certification is required, it is recommended and encouraged. In addition, instructors should be familiar with body mechanics and fitness, cycle adjustments, fitting the cycle to the rider, and how to ensure a challenging workout for the class.

Instructors should also have current American Red Cross First Aid and CPR/AED certifications. Most recreation facilities require these and can help facilitate safety training.

All instructors are required to watch both the PD For Spinning Webinar and the Pedaling for Parkinsons Program Facilitator Training videos available on the Pedaling for Parkinsons Colorado webpage. The videos are designed to help people understand what it feels like to have Parkinson's and the limitations caused by the disease.

Participants Pedaling for Parkinson's may not be suitable for every person with PD. The instructor should make sure candidates are able to board a stationary bike without assistance. Once familiar, participants should then be able to secure their feet in the pedals and maintain a safe and suitable body position to stay on the bike. Candidates should also be briefed on proper clothing, shoes and related personal equipment and should understand the potential seating discomfort and strategies to mitigate it. To ensure the safety of the participants, instructors are encouraged to review the program and protocol with candidates and address any questions or concerns.

Pre-Screening Questions:	Yes:	No:
Have you taken any heart medications?		
Have you ever had a heart attack?		
Have you ever had heart surgery?		
Have you ever had heart failure?		
Have you ever had pacemaker/ implantable cardiac defibrillator/ rhythm disturbance?		
Have you ever had cardiac catheterization?		
Have you ever had coronary angioplasty?		
Have you ever had heart valve disease?		
Have you ever had congenital heart disease?		
Have you had a close blood relative who had a heart attack before age 55 (father or brother) or 65 (mother or sister)?		
Have you experienced unreasonable breathlessness?		
Do you take blood pressure medication?		
Are you a diabetic or take medicine to control blood sugar?		
Is your blood cholesterol >240 mg/dL?		
Females: Have you had a hysterectomy or are you postmenopausal?		
Have you experienced dizziness, fainting or blackouts?		
Do you smoke?		

Participant Pre Screening Form

Candidates are required to complete the application and screening forms, provide emergency contact information, and return a physician's release.

If a candidate answers "Yes" to any questions on the Pre-Screening form, the candidate's physician must address the concern(s) and provide written clearance/permission for the candidate prior to participation.

Pedaling for Parkinsons does not affect the doctor/patient relationship nor does it impact medications. It has, however, been shown to temporarily relieve some symptoms. Though it does not stop the progression of Parkinson's Disease, it provides an opportunity for patients to take advantage of and participate in ongoing research that proves that pedaling at a fast rate can temporarily reduce some Parkinson's symptoms.

First Time Participants

Following your trial class, participants are asked to return completed Registration documents to the instructor. Plan to arrive up to 20 minutes early for initial cycle fitting and any potential facility registration requirements.

Appropriate cycling attire is strongly encouraged. Padded Cycling shorts to which some may wish to add a bicycle seat gel pad will help tremendously. Clip in cycling shoes are helpful as more bikes are available. All participants should have a full water bottle. Though Heart Rate Monitors may not be required, they provide the best metrics to show improvement.

Participants MUST bring any medications they may need before, during, or after the class. Some facilities may offer locker room and showering opportunities. Check with your instructor before use.

Registration

Participants are required to register for all PFP programs. Information collected includes release of liability and use waivers for both the host facility and PFP, health permission, emergency contacts and other important details.

The standard registration package is available online at the Pedaling for Parkinsons web page. This includes required information to be provided to the instructor by all participants. Completed registration materials are required at the beginning of the second session.

Marketing and Promotion Marketing and promotional materials are available from Pedaling for Parkinson's and with the help of local PFP Coordinators. Promotional materials include logo sign, large and small info placards, brochures and note cards. Contact PFP staff for details.



PEDALING FOR PARKINSON'S

FREE with annual pass

This innovative class is based on studies that show that "forced exercise" on a stationary bike – riding at a set speed three times a week – can reduce Parkinson's disease symptoms by as much as 35%.

- Starting November 7, M/W/F, 10:30 am in the Apex Center Cycle Burn Studio

SEE GUEST SERVICES FOR DETAILS

APEX CENTER
13150 West 72nd Ave., Arvada, CO 80005
303-424-2739, apexprd.org
guestservices@apexprd.org

CYCLE BURN

APEX
PARK & RECREATION DISTRICT

In the Cycling Studio

Pedaling for Parkinson's is a high-intensity, forced exercise cycling program conducted on a stationary bicycle. Classes are typically offered three (3) times per week, with a day of rest in between (i.e. Monday, Wednesday, Friday,) and last approximately one hour.

A class consists of a 5-10 minute warm-up followed by 40 minutes of aerobic exercise, and concludes with a 5-10 minute cool down. Pedaling rate, measured in revolutions per minute (RPM), should be 60 RPM during warm up and cool down periods, and within the recommended range of 80-90 RPM during the 40 minute aerobic phase.

Participants are encouraged to stretch prior to and after exercising, during the warm up and cool down periods. Stretching the upper body can be done on the bike though participants with balance issues can refrain to keep their hands on the bike.

Instructors should encourage participants to remain seated, using alternate methods to relieve seat pain. Paying close attention to participants is recommended to observe individual performance, struggles and possible health issues.

Metrics Measuring effectiveness is typically done by assessing a participants performance per the basic UPDRS exam. However, many students notice improvements in very specific symptom areas. Official results may be measured by Cleveland Clinic/PFP clinicians.

Tips for Instructors Instructors are encouraged to customize class presentation to maintain interest, challenge performance, and increase benefit within the parameters of the prescribed program. While its important to follow the class protocol to achieve symptomatic relief, it's as important to improve fitness and maintain good health. Aging with Parkinson's is more challenging than normal and as people with PD encounter health issues both related to and in addition to Parkinsons, being in better health can provide a significant advantage in recovery.

Classes behave differently and instructors are encouraged to be creative with media to enhance the experience. Music is typically a staple in a cycling studio. So, in addition and leveraging established infrastructure, interesting playlists help riders keep pace and enjoy the time. Other options include reviewing current and recent PD news, stories of victory, latest research and events. These can be found in podcasts and related resources on the internet.

Challenges Designed to mimic a racing bicycle, adjusting to a stationary indoor bike can be challenging for people. Padded cycling shorts are highly recommended. Gel seat pads are also quite common and used separately or in conjunction with padded shorts. Participants are encouraged to wear appropriate, comfortable cycling clothing.

Clip-in cycling shoes are very helpful and comfortable, and offer greater stability when pedaling. Participants should consider walkable clip-in shoes and should avoid shoes with laces.

Dystonia is a common side effect from PD medication, causing abnormal muscle tone and tightening spasms. Relieving such cramps may require the cyclist stand up on the bike pedals to put pressure on the bottom of the feet, adding pressure to the foot, and potentially easing the cramp. Or, the cyclist should dismount and walk around to relieve the cramping discomfort, resuming if tolerated.

Orthostatic hypotension (low blood pressure or dizziness) is another common symptom of PD. A full 10 minute cool down is encouraged to help bring blood pressure back down before getting off the bike. If symptoms persists, the instructor should seek first aide assistance.

Administration

Pedaling for Parkinson's is headquartered in Cleveland, OH. While research continues at the Cleveland Clinic, the PFP program operates independently. Occasionally, researchers visit and observe classes in action and commission studies at existing locations.

Roles Dr Alberts continues to lead both the non-profit indoor cycling program along with his research responsibilities. Along with a few staff in Cleveland, there are currently three Program Coordinators — Nan Little (Seattle), John Carlin (Denver) and Tom Palizzi (Denver). Nan is the Program Administrator while John and Tom focus on promotion and marketing.

Class Leaders or Instructors are typically associated with one location though they may be available to fill-in for other instructors as needed. Each location is encouraged to recruit substitutes to ensure uninterrupted program delivery. Class instructors are also responsible for leading the program at their location; addressing questions and concerns; and building awareness for the program within their area.

Staffing While it is possible for one person to run a program, many facilities have assistants to help people get on and off the cycle; ensure participants are properly fit to their bike and in case of emergencies. Class leaders are typically provided by the host facility and can be recruited from both the host's existing staff or other sources. Some class participants may be completely capable of leading the class, as well.

Budget Pedaling for Parkinson's is provided free of charge — there is no cost to license the name, protocol or routine. Though PFP works hard with host facilities to provide the room, cycles and instructors, some hosts may charge facility access fees to use the facility. Your budget may depend on several factors, including the availability of grant resources, cooperation from the host facility, sponsors and other local resources. Contact PFP staff for details on starting a class in your area with little to no money.

Appendix A — Program Coordinators

Local Program Coordinators are available to help you with every step of the start-up process and thereafter. They can answer questions, address concerns and help you plan and organize your program.

Nan Little	(206) 321-0200
Seattle, Washington	nan.little@comcast.net

Tom Palizzi	(303) 883-6801
Denver, Colorado	tom@pedalingforparkinsons.org

John Carlin	(720) 369-4940
Denver, Colorado	doublehaul3@comcast.net

We are looking for more Local Area Coordinators. If you would like to help assist in the development of Pedaling for Parkinsons programs in your area, please let us know.

Appendix B – Start-up Checklist

Local Program Coordinators are available to help you with every step of the start-up process and thereafter.

- ☐ Download the PFP Start-up Guide. This resource will help you establish and operate a PFP program in your area.
- ☐ Complete the on-line form to request the License Agreement. Review, sign, and return the agreement. The License Agreement is required.
- ☐ Ensure your facility meets the minimum recommendations outlined in Appendix C and on pages 7 & 8 of the Start-up Guide.
- ☐ Both Instructors and substitutes have watched the Instructor Training Videos. These are found on the PFP website.
- ☐ Download and familiarize yourself with the PFP participant registration materials. These are found on the PFP website.
- ☐ Visit the website for ideas on how to announce and promote your class to potential participants in your area.
- ☐ Visit the website for ideas on how to make your class fun and interesting for your participants.
- ☐ Be sure to return to the website often to see what others are doing to make PFP useful and fun.

Appendix C — Facility & Equipment Reference Guide

To help ensure the effectiveness and safety of the program, certain protocols are encouraged. The following

	Required	Recommended
Facility	Adequate space to accommodate multiple indoor stationary training cycles	Water
	Class leader bike	Towels and bicycle cleaning materials
	Bench or chairs	Rate of Perceived Exertion chart
	Stepstool	
	Adequate lighting, heating, ventilation and air conditioning	
Cycling Equipment	Indoor Stationary training bikes [standard upright or recumbent]	Multi-function bicycle computer
	Bicycle computer to monitor cadence	Clip style pedals
	Water bottle holder	
	Safety mat under each bike	
Participant Equipment	Suitable cycling clothing and shoes	Padded shorts
	Heart rate monitor	Gel-pad seat cover
	Water bottle	Clip style shoes

Appendix D — Class Protocol Reference Guide

To help ensure the effectiveness and safety of the program, the following protocols are encouraged

	Required	Recommended
Time	Three (3), 1-hour sessions per week	Warm up / stretching
	10 minute warm up @ 60 RPM	Cool down / stretching
	40 minutes @ 80-90 RPM	
	10 minute cool down @ 60 RPM	
Heart Rate	Participants should maintain their heart rate between 60 to 80% of their max	Target heart rate is calculated at 220 minus the participant's age
	Heart rate is measured using a monitor device.	
Cadence	Participants should maintain 80 to 90 RPM for a full 40 minutes duration	Cadence can be carried between 80 — 90 RPM per the instructors guidance