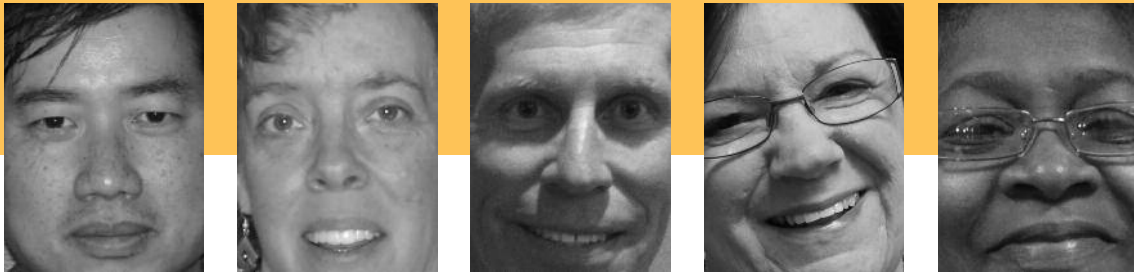


Who is finding the cure for Parkinson's?



They all are.

Parkinson's Advocates in Research

Why PAIR?

Despite promising research, there is neither a cure for Parkinson's nor are there medications that can reverse its course. **But there can be.**

We can bring about better treatments at a faster pace by ensuring that people with Parkinson's are primary partners in research alongside scientists, industry and government.

As a signature program of the Parkinson's Disease Foundation, Parkinson's Advocates in Research (PAIR) is making this partnership a reality. We are bringing together the people who live with Parkinson's and the people who are developing new treatments.

- >> Through in-person trainings and an online course, the PAIR program provides people touched by Parkinson's with the skills needed to pair up with scientists and health professionals.
- >> By collaborating with research institutions, the PAIR program facilitates partnerships between Research Advocates and professionals at the frontlines of research.



"As a doctor and a researcher, I have seen first-hand how the PAIR program can empower people with Parkinson's and care partners. I believe that when we partner with these informed Research Advocates, that is when we will see true change in Parkinson's research."

**Joohi Jimenez-Shahed, M.D., Baylor College of Medicine,
PAIR faculty, Houston, TX**

How PAIR Changes Research

The cornerstone of the PAIR program is a national volunteer network of more than **200 Research Advocates** touched by Parkinson's from **42 states** who are actively changing how research is done by:



Speeding Drug Development

"I represent the urgency of people with Parkinson's, while helping to ensure that potential new drugs are effective and safe."

Rich Hoffman, Pharm.D., PDF Research Advocate, Consumer Representative, US Food and Drug Administration, Hernando, FL

Increasing Trial Participation

"When I ask people with Parkinson's why they are not involved in research studies, many reply, 'Because I have no transportation.' My solution was launching the Clinical Trial Transportation Program (CTTP). By partnering with Beth Israel Deaconess Medical Center in Boston, MA, CTTP has helped 26 volunteers to participate in research studies by transporting them by van from Connecticut to Boston."

Steve DeWitte, PDF Research Advocate, Washington, CT



Informing the PD Community

"This is a hard disease, hard because there is no cure. The only way we are going to speed up the pace of drug development is by getting involved in research. Clinical trials sorely need people with Parkinson's disease and those without it. As PDF Research Advocates, my husband Al and I bring this critical message to support groups, health care professionals and students in our community."

Jane Denmark, PDF Research Advocate, Bay Minette, AL

PDF Research Advocates have brought the latest information on clinical studies to thousands of people touched by Parkinson's, which has led to:

- >> 59 percent of people who have heard a joint presentation by a scientist and a Research Advocate contacting a research site about clinical study participation.
- >> 700+ people enrolling in clinical studies.

How PAIR Works

PDF Research Advocates and professionals are pairing up at all stages of the research process to bring about **better treatments at a faster pace**. Here are specific actions that Research Advocates can take during each phase of **drug development for Parkinson's disease**.

- Discuss with researchers what research is important to the Parkinson's community
- Develop study concept and work as a co-investigator with a movement disorder specialist
- Provide input on study design such as barriers to participation or study endpoints
- Join an Institutional Review Board
- Advise and assist with study recruitment
- Serve as a peer advocate during the informed consent process
- Provide feedback on how the PD community will view study results
- Apply to be a consumer representative to a US Food and Drug Administration (FDA) Advisory Committee
- Attend FDA hearings and provide comment



- Assist in grant writing at local research center
- Serve as a grant reviewer with PDF
- Become a grant reviewer with the Patient Centered Outcomes Research Institute
- Help finalize eligibility criteria within the study protocol
- Assist in creating the informed consent form
- Join a Data Safety Monitoring Board
- Provide recommendations for revising study protocol if changes need to be made
- Write newsletter articles or blog about results
- Co-present results at a conference or support group
- Work with research team to ensure study participants get feedback from study
- Advocate for continued tracking of drugs, devices and therapies
- Work with researchers to integrate patient centered outcomes in research

"I first met Diane as a patient. Then one day she said to me, 'I have participated in so many clinical trials as a subject, I want to do research myself and help others.' She's been an inspiration to others with Parkinson's and to me as a scientist. The roles have changed and I now call her a colleague."

**Rajeev Kumar, M.D., Director,
CNI Movement Disorders Center, Englewood, CO**



"I realized that I could use my skills and passion for helping people, organizing and solving problems, which I acquired over a lifetime, to help people with Parkinson's disease."

Diane Cook, PDF Research Advocate, Denver, CO

How You Can PAIR Up



As a Person with Parkinson's or a Care Partner

- Your insights can help the professionals who are developing your therapies.
- PAIR Up by taking our online course or applying to one of our trainings.



As a Doctor, Health Care Professional, Scientist or Clinical Trial Coordinator

- Trained PDF Research Advocates are available to provide insights on your studies and increase trial participation.
- PAIR Up by contacting us to find trained Research Advocates in your area.



www.pdf.org/pair



"As a person with Parkinson's, I have been part of 25 clinical trials. But these trials aren't producing the treatments so urgently needed for Parkinson's. The solution? See patients as members of the research team who can offer insights to improve trials. After all, if research is a lottery, it is the patients who are playing to win."

Linda Morgan, R.Ph., M.B.A., PDF Research Advocate, Asheville, NC



Who is PAIRing Up?

PDF Research Advocates have worked with over 400 research professionals and 120 Parkinson's support groups around the US.

AbbVie, Inc.
American Academy of Neurology
American Society on Aging
American Society for Experimental NeuroTherapeutics
Anne Arundel Community College
Arizona State University
Atlantic Neuroscience Institute
Banner Sun Health Research Institute
Bates College
Baylor College of Medicine
Benevilla
Beth Israel Deaconess Medical Center
Beth Israel Medical Center
Boston University Medical Campus
California Institute for Regenerative Medicine
California State University, Long Beach
Capistrano Center for Parkinson's Disease and Movement Disorders at Bethesda Hospital
Cedars-Sinai Medical Center
Center for Information & Study on Clinical Research Participation
Centers for Medicare & Medicaid Services
Chelsea Therapeutics International Ltd.
Clinical Trials Transformation Initiative
Colorado Neurological Institute
Columbia University Medical Center
Critical Path Institute
Dartmouth-Hitchcock Medical Center
Davis Phinney Foundation
Drug Information Association
Duke University Medical Center
Élan
Emory University Udall Center of Excellence for Parkinson's Disease Research
Evercare Hospice & Palliative Care
Faulkner State Community College
Feather River Hospital
Gardner Center for Parkinson's Disease and Movement Disorders

GE Healthcare
Georgetown University School of Medicine
Gladstone Institutes
Health Quest System
Indiana University Health
Institute for Neurodegenerative Disorders
International Parkinson and Movement Disorder Society
JFK Medical Center
The Johns Hopkins University
Lawrence + Memorial Hospital
Massachusetts General Hospital
Mayo Clinic Arizona
Mayo Clinic Jacksonville
The Medical University of South Carolina
Merck & Co., Inc.
Methodist Women's Hospital
Mount Sinai Hospital
Muhammad Ali Parkinson Center at Barrow Neurological Institute
National Institutes of Health/National Institute of Neurological Disorders and Stroke
NewYork-Presbyterian/Weill Cornell Medical Center
North Shore-LIJ Health System
Northwestern University
Norton Neuroscience Institute
NYU Langone Medical Center
Oasis Dementia Care
Ochsner Health System
Olympia Nursing Home
Oregon Health & Science University
Parkinson Study Group
The Parkinson's Institute and Clinical Center
Patient-Centered Outcomes Research Institute
Pen Bay Medical Center
Pennington Biomedical Research Center
Rehabilitation Institute of Chicago
Robert Wood Johnson University Hospital
Rush University Medical Center

Plummer Movement Disorders Center at Scott & White Hospital
St. Joseph's/Candler Movement Disorders Program
The Scripps Research Institute
Spaulding Rehabilitation Hospital
Struthers Parkinson's Center
Teva Neuroscience
Thomas Jefferson University
UCB, Inc.
University of Alabama at Birmingham
University of California, Davis
University of California, Irvine
University of California, Los Angeles
University of California, San Diego
University of California, San Francisco
University of Central Oklahoma
University of Cincinnati
University of Colorado
University of Delaware
University of Denver
University of Kentucky
University of Maryland
University of Miami
University of Michigan
University of Minnesota
University of Missouri
University of Pennsylvania
University of Southern California
University of Southern Indiana
University of Washington
US Food and Drug Administration
Van Andel Institute
Virginia Commonwealth University
Western Washington University
YMCA

The Parkinson's Disease Foundation® (PDF®) is a leading national presence in Parkinson's disease research, education and public advocacy. We are working for the nearly one million people in the US living with Parkinson's by funding promising scientific research and supporting people with Parkinson's, their families and care partners through educational programs and services. Since its founding in 1957, PDF has dedicated over \$100 million to fund the work of leading scientists throughout the world and over \$42 million to support national education and advocacy initiatives.



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