

“I sit on an IRB at Georgetown University, along with researchers and doctors. I review 15-20 clinical trials a month and **advise on research design** and study outcomes from the patient/community perspective.”

*Paul N. Zimmet, D.D.S.*  
PDF Research Advocate

“As a Learning Institute faculty member, I realized that people with Parkinson's have an important role to play in **informing the research process**. Their 'take' on the process offers valuable insight that is often so different from that of scientists and doctors.”

*Claire Henchcliffe, M.D., D.Phil.*  
Director of the Parkinson's and  
Movement Disorders Institute,  
Weill Cornell Medical College

“There is a real community need for information on clinical trials and guidance on making informed decisions as study participants. After attending the Learning Institute, I decided to bring **clinical research presentations** to all 50 of the Michigan Parkinson Foundation support groups.”

*Carolyn Weaver*  
PDF Research Advocate

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 our founding in 1957, PDF has dedicated over \$85 million to fund the research of leading scientists throughout the world and over \$34 million to support national education and advocacy initiatives.



## Parkinson's Advocates in Research

Community Voices  
Advancing Science



## Engaging Community Voices in Research

People with Parkinson's disease have the most at stake when it comes to the success of clinical studies, yet there are few opportunities for their voices to be heard within the research process. The Parkinson's Disease Foundation's (PDF) Parkinson's Advocates in Research (PAIR) program is dedicated to bringing educated community voices to important issues in research. Research Advocates work to:

- Expand understanding of and support for research;
- Increase participation in clinical studies; and
- Bring the perspective of people with Parkinson's to all levels of the research process.

## Building a Network of Research Advocates

Research Advocates attend a three-day Clinical Research Learning Institute where they:

- Learn from leading clinical research experts and former Learning Institute graduates;
- Become familiar with the science of Parkinson's disease and the clinical research process;
- Gain leadership and advocacy skills to confidently interact with the scientific community.

Graduates of the Learning Institute work closely with PDF staff and fellow Research Advocates through ongoing education, resource sharing and networking opportunities to strengthen the role that people with Parkinson's play in the research process.

## Advancing Parkinson's Research

Involving Research Advocates in the research process helps advance science. Whether you are a person living with Parkinson's interested in research advocacy or a professional working in Parkinson's research, you can pair up with PDF's network of Research Advocates around the country who are available to:

- Speak at educational conferences and support groups on the importance of clinical research and study participation;
- Serve on scientific review committees and clinical research advisory boards; and
- Review and comment on clinical research study design and protocol, the informed consent process and enrollment strategies.

To learn more about the PAIR program, the Clinical Research Learning Institute or how to contact a Research Advocate in your area, please visit our website at [www.pdf.org/PAIR](http://www.pdf.org/PAIR), call us at (800) 457-6676 or email us at [info@pdf.org](mailto:info@pdf.org).

Advocate

Educate

Collaborate