



Parkinson's Advocates in Research: A Parkinson's Disease Foundation cutting edge program in patient engagement in research

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Introduction

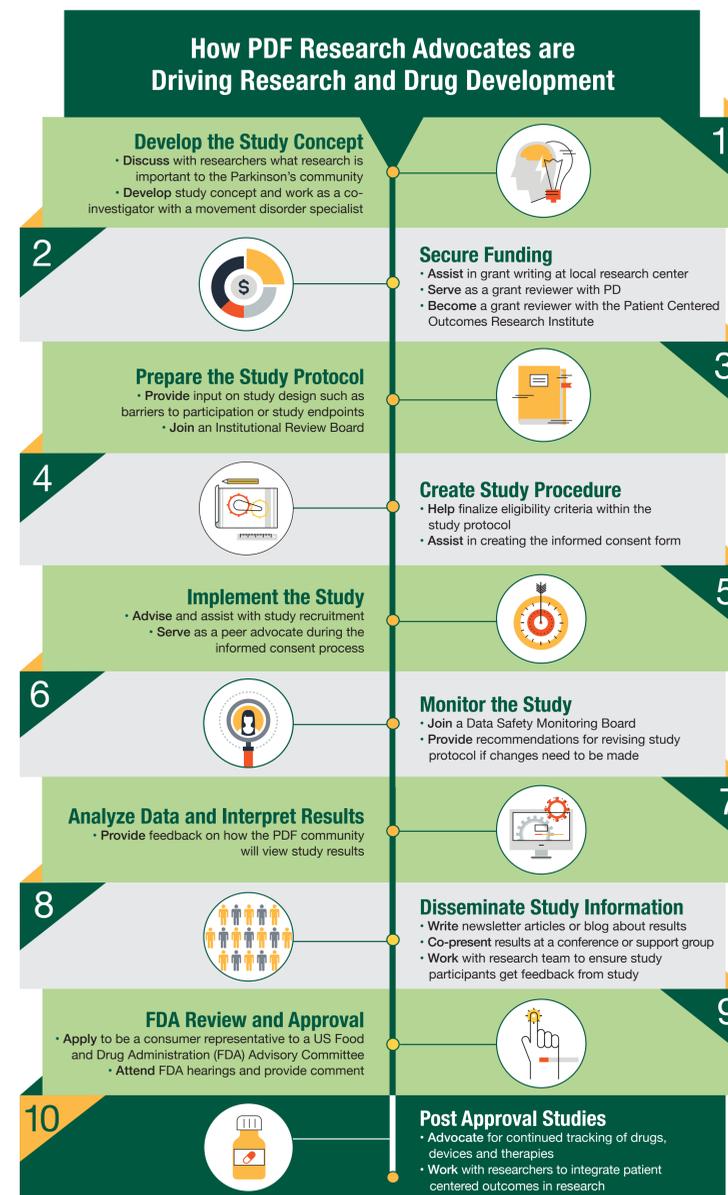
In 2008 the Parkinson's Disease Foundation (PDF) held the first Parkinson's Advocates in Research (PAIR) Learning Institute. This innovative program builds partnerships between people with Parkinson's disease (PD), care partners and research teams to ensure research incorporates the needs and priorities of the PD community. The PAIR program has improved the community's understanding of research advocacy and has trained 280 PDF Research Advocates (people with PD and care partners) in how to work collaboratively in the clinical research process, develop best practices for patient engagement and work with academia, government and industry to ensure the expertise and perspective of people touched by Parkinson's is incorporated into research decision making.

Methods

The PAIR Learning Institute trains people with PD and care partners at the three-day PAIR Learning Institute. PDF staff mentor and consult research teams on collaboration by providing tools, resources, additional training and best practices. The PDF PAIR Leadership Awards provide funding for collaboration between researchers and PDF Research Advocates on studies that focus on unmet needs or barriers to moving research forward.

Conclusions

PDF has a proven track record in leading a cutting edge patient engagement in research program (PAIR). Through the PAIR program, PDF has improved the community's understanding of research advocacy, increased the likelihood of researchers collaborating with patients in their work and aligned research with community needs and priorities.



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A Parkinson's Advocates in Research (PAIR) infographic that has been repurposed and disseminated nationally and internationally by such organizations as the Clinical Trials Transformation Initiative.

Results

Improve the community understanding of research advocacy –

- PDF recently held its 10th Parkinson's Advocates in Research Learning Institute in which 96 percent of attendees reported the Learning Institute changed the understanding of research advocacy either “moderately” or “very much.”

Increase the likelihood of collaboration between researchers and PDF Research Advocates –

- PDF partnered with UCB, Inc. on the creation of their corporate framework for partnering patient organizations.
- PDF Research Advocate interactions at the Community Choice Research Award meetings on dystonia, fatigue and cognition, led 78 percent of researchers to say they were more likely to include patients in scientific conversations.
- The collaboration between a PDF Research Advocate and researcher, with the assistance of a PDF Leadership Award, laid the groundwork for a \$1.9 million grant on palliative care research from the Patient Centered Outcomes Research Institute (PCORI).

Align research with community needs and priorities –

- PCORI awarded a PDF Research Advocate \$90,000 to create a comparative effectiveness research network in Wyoming, a state which currently does not participate in PD research.

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