



# Peer-to-Peer Clinical Research Outreach and Education: A Model for Increasing Clinical Study Awareness, Inquiry and Enrollment among People with Parkinson's

Robin Elliott, Veronica Todaro, New York, NY, Maureen Cook, New Orleans, LA, Christine Hunter, Houston, TX, Joohi Jimenez Shahed, Houston, TX, Patricia Kavanagh, Brooklyn, NY, Cathi Ann Thomas, Boston, MA, Mickie Welsh, Los Angeles, CA, Lin Zhang, Sacramento, CA

Parkinson's Disease Foundation

## Abstract

**Background:** The Parkinson's Disease Foundation's (PDF) Clinical Research Learning Institute (CRLI) annual multi-day training provides people with Parkinson's disease (PD) with the information and tools they need to be advocates within the clinical research enterprise. This training includes sessions taught by experts on topics such as the clinical research process, participant protections, bioethics, and study evaluation and analysis. After the completion of the training, PDF Research Advocates engage in such activities as educating other people with PD about clinical research and study participation; serving on review boards; and providing research sponsors and investigators with input on trial design, implementation and evaluation.

**Objective:** To determine if peer-to-peer clinical research outreach and education leads to an increase in: knowledge about clinical research; inquiries to study sites about participation; and study enrollment among people with Parkinson's.

**Methods:** Analysis of the results of an online survey administered to identify the type and number of education and outreach activities conducted. Analysis of the results of a survey administered to individuals who had contact with a Research Advocate to determine if the individual experienced an increase in knowledge about clinical research, contacted a study site, and/or enrolled in a clinical study.

**Discussion:** PDF Research Advocates have initiated both a range and volume of outreach and education activities aimed at increasing awareness and participation in clinical research among people with PD. These activities have resulted in an increased likelihood that people with PD will seek out information about Parkinson's clinical research, inquire about participating in studies and when eligible, enroll in a trial. This engagement of people with PD as Research Advocates can assist in addressing the issue of lack of clinical research awareness and low clinical study enrollment among the PD community.

## Introduction

- Increasing the role of people with PD in clinical research is a critical variable in building awareness of and engagement in the research process.
- The PDF Clinical Research Learning Institute provides people with PD with the knowledge and skills to effectively serve as advocates within many aspects of the clinical research process.
- People with PD most often learn about clinical studies from support groups (40 percent) and other people with PD (27 percent).\*
- One of the roles of PDF Research Advocates is to increase awareness and education about clinical studies among peers through presentations and one-on-one communication.
- There are over 100 Research Advocates in 36 states throughout the US.

## Methods

**Method 1:** Research Advocates who participated in the 2008, 2009 and 2010 Clinical Research Learning Institutes complete an online activity survey on a quarterly basis. The last survey period ended February 2011.

**Method 2:** Research Advocate presenter evaluation forms (n=90) were collected and analyzed to determine if attendees experienced : a) an increase in awareness about and b) an increased likelihood of seeking more information about Parkinson's clinical research.

## Results

**Results from the education and outreach activities survey found that PDF Research Advocates have:**

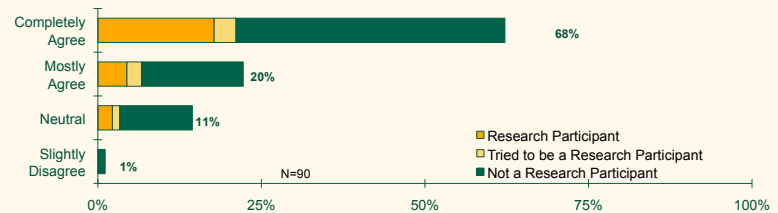
- Spoken with over 8,500 people living with PD about clinical research participation through support group meetings and conferences (over 350 presentations total) as well as one-on-one outreach.
- Initiated close to 1,000 media contacts (website promotion, newsletter articles, letters to the editor, radio, television, blogs and message boards).
- Facilitated the inquiry into a clinical study by close to 800 people with PD, with an estimate that close to half enrolled in a clinical study. (One Research Advocate organized a Clinical Research Fair that led to close to 50 individuals being screened on-site for one study.)

**Results from the PDF Clinical Research Liaison presenter evaluations found that:**

- 88% of people with PD attending a presentation by a PDF Research Advocate learned at least one new piece of information about clinical research.
- 96% of people with PD attending a presentation by a PDF Research Advocate stated that they will seek out further information about Parkinson's clinical studies.

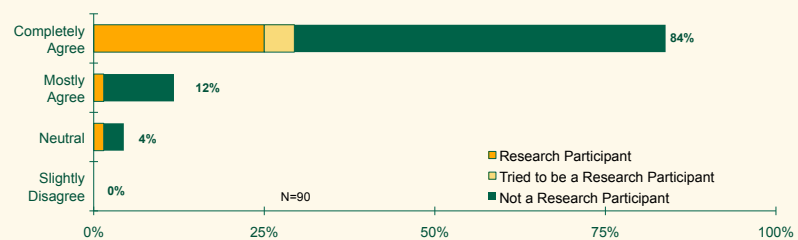
## Areas of Impact

"I acquired new knowledge about clinical research"



## Areas of Impact

"I would seek out further information about clinical studies"



## Conclusions & Next Steps

Findings indicate that peer-to-peer Parkinson's clinical research information and education efforts conducted by PDF Research Advocates increase awareness of clinical research and the likelihood of seeking out information about Parkinson's clinical studies. PDF has developed and is piloting an online support group survey to determine if individuals who have met with a Research Advocate contact a study site and, if eligible, enroll in a trial. The results of this survey will be available in Summer 2011.

\*March 2005 Harris Interactive Survey commissioned by the Michael J. Fox Foundation for Parkinson Research on behalf of the PDtrials clinical research education and awareness coalition initiative led by PDF.

[www.pdf.org](http://www.pdf.org) | (800) 457-6676

