



Hope through Research • Education • Advocacy

## PDF Today

The Parkinson's Disease Foundation (PDF) is a leading national presence in Parkinson's disease research, patient education, and advocacy for increased federal funding. PDF is working for the nearly one million people in the U.S. living with Parkinson's by funding promising scientific research and supporting people with Parkinson's, their families and caregivers through educational programs and support services.

Since our founding in 1957 by William Black, PDF has funded more than \$50 million worth of scientific research in Parkinson's disease. PDF has corresponding relationships with more than 100,000 Parkinson's families and friends, as well as a range of programs geared to advancing Parkinson's science that includes research awards, training fellowships and the sponsorship of professional and lay conferences.

### **Programs and Activities**

In New York and around the country, PDF runs a variety of programs for research support, patient education and advocacy, including those listed below.

#### *Supporting Research of the Highest Caliber*

PDF currently funds scientific research at three world-class medical centers: Columbia University Medical Center and Cornell-Weill Medical Center in New York City and Rush University Medical Center in Chicago. Through these multi-year commitments to leading Parkinson's research institutions, PDF makes a commitment to creating important programs and keeping them funded.

The other key element is PDF's International Research Grants Program (IRGP), which offers one-year seed grants to help young scientists collect the baseline data necessary to support major proposals to the National Institutes of Health (NIH) and other government funding agencies.

#### *Building the Profession*

Since its founding, PDF has encouraged the best scientific minds to pursue careers in Parkinson's research through postdoctoral and summer fellowship programs. Postdoctoral fellowships enable scientists, fresh from their residencies, to study at major research institution for one or two years. Summer fellowships support medical students and recent medical graduates in the pursuit of Parkinson's-related summer research projects.

### *Advancing Parkinson's Therapies*

In the spirit of collaboration, PDF leads the Advancing Parkinson's Therapies campaign (APT), the umbrella name for a dedicated effort to accelerate the development of new treatments for Parkinson's. A major effort of the campaign is raise awareness and increase participation of the Parkinson's community in clinical trials through a national public awareness campaign. Our work includes publishing a twice-yearly brochure of enrolling clinical trials and the creation and maintenance of a website, [www.PDtrials.org](http://www.PDtrials.org), which also features a constantly-updated list of enrolling trials. Joining PDF in this campaign are the American Parkinson Disease Association, Inc., the Parkinson's Action Network, the Parkinson Alliance, the Michael J. Fox Foundation for Parkinson's Research, the National Parkinson Foundation and WE MOVE.

### *Education and Support for Patients and Families*

PDF encourages queries and requests for information and other assistance from people with Parkinson's and their families, members of the healthcare community, the general public and all others who have an interest in the disease. Our toll-free telephone advice line (800-457-6676) is available Monday through Friday during regular business hours and is staffed by trained healthcare professionals and medical staff. We also feature a web-service, "Ask the Expert," which allows people to submit a question, via email, and receive an answer within 15 working days. Included in our many services are referrals to physicians and other medical professionals who specialize in movement disorders.

A major outlet for PDF's information and education is our website, [www.pdf.org](http://www.pdf.org). Through the website, we supply direct access to user-provided questions, and we maintain an "Expert Resource Center" with medically-approved answers to these questions. We also offer the opportunity to receive our educational materials, including our quarterly newsletter, a booklet of the most common questions asked about PD and their answers, a web resources guide and a booklet for people newly diagnosed with Parkinson's disease.

### *World Parkinson Congress, Inc.*

In 2004, PDF led members of the Parkinson's community in creating the first-ever World Parkinson Congress (WPC). WPC is a nonprofit organization dedicated to providing an international forum for the best scientific discoveries, medical practices and caregiver initiatives related to Parkinson's disease. By bringing physicians, scientists, allied health professionals, caregivers and people with Parkinson's disease together, we hope to create a worldwide dialogue that will help expedite the discovery of a cure and best treatment practices for this devastating disease.

### *Advocacy*

An important goal of PDF is to raise public consciousness among public, professional, patient-support, corporate, foundation and media audiences of the crucial dimensions of

Parkinson's disease, including the costs of the condition to the individual and to society; the promise and potential of current research, both basic and applied; and the need for increased public support to identify the cause and cure of the disease.

We do this through several channels. One is serving as a source of information and scientific interpretations to newspapers, magazines, television and other general news media. Another is advocating for increased support of Parkinson's research through our support of the Parkinson's Action Network (PAN), the unified public policy voice of the Parkinson's community. In fact, PDF uses an important part its contributions to support PAN – \$150,000 in the current year. A third is taking action to promote promising lines of scientific inquiry – such as research involving the study of stem cells.

In the past year, PDF also took a leadership role in organizing a group of New York State-based disease advocacy groups, university research centers and biotech industry leaders to form New Yorkers for the Advancement of Medical Research (NYAMR). This coalition assembled to lead a charge to achieve legislation that would affirm and support scientific research involving embryonic stem cells and other DNA therapies. For more information, visit [www.nyamr.org](http://www.nyamr.org).

### **Financial Support**

PDF welcomes voluntary contributions from individuals, foundations and corporations. On average, some 80 percent of the revenue we receive as gifts directly supports these efforts. PDF's financial health can be verified by visiting the GuideStar website, [www.guidestar.com](http://www.guidestar.com), the national public information website for charities, or Charity Navigator, [www.charitynavigator.org](http://www.charitynavigator.org), a guide to intelligent giving.

### **Governance**

Our Board of Directors, consisting of accomplished and dedicated citizens from such fields as law, medicine, business, civic leadership and philanthropy, guide us in our efforts. [Click here](#) to see a list of PDF's Board of Directors.

Executive leadership is provided by Robin Elliott, executive director and a [staff](#) in New York and Chicago.

## **A History of the Parkinson's Disease Foundation (PDF)**

### **1957**

Parkinson's Disease Foundation is founded by William Black, creator of Chock Full o' Nuts corporation. Dr. Melvin Yahr is named as executive director and scientific director.

### **1962**

Dr. Roger Duvoisin appointed as PDF's first postdoctoral fellow. (Thirty-five years later, Dr. Duvoisin was senior member of the team that discovered the first gene accounting for some cases of PD.)

Dr. Duvoisin develops the Columbia Rating Scale (the forerunner of the Unified Parkinson's Disease Rating Scale (UPDRS), which in 1987 was developed by Dr. Stanley Fahn and colleagues), for calibrating the severity of Parkinson's disease.

### **1965**

Columbia University opens PDF-funded laboratories on the third floor of the William Black Building at the Columbia Presbyterian Medical Center (CPMC).

### **1967**

Dr. Margaret Hoehn, PDF postdoctoral fellow, and Dr. Yahr publish seminal paper on the natural history of Parkinson's disease. This included the benchmark "Hoehn and Yahr staging system" for identifying the severity of PD.

### **1969**

Dr. Yahr and PDF colleagues publish the results of the first double-blind trial of levodopa, the first medication to relieve the symptoms of Parkinson's disease.

### **1971**

PDF initiates a program of summer fellowships for medical students, to encourage talented young scientists to enter the field of Parkinson's disease research.

### **1973**

Dr Stanley Fahn is named as scientific director of PDF.

### **1981**

PDF and Columbia University sponsor a scientific symposium on experimental therapeutics of Parkinson's disease.

### **1982**

PDF establishes the H. Houston Merritt Sabbatical Fellowships for visiting scientists, named for the renowned neurologist and first president of PDF.

### **1984**

Dr. Fahn, in association with Dr. Ira Shoulson of the University of Rochester, founds the Parkinson Study Group, a consortium of leading research centers assembled to conduct multi-center clinical trials of new drugs.

### **1987**

On our 30<sup>th</sup> anniversary, PDF sponsors a symposium immediately before the annual meeting of the American Academy of Neurology. Dr. Melvin Yahr and Dr. J. William Langston, a discoverer of the neurotoxicity of MPTP, receive the third and fourth James Parkinson awards.

### **1988**

PDF, in association with the United Parkinson Foundation in Chicago, creates a Junior Faculty Award to provide support to young scientists for Parkinson's research.

**1994**

Several Parkinson's organizations, including PDF, team up to create the Parkinson's Unity Walk, a collaborative fundraising effort based in New York City. The proceeds support the research programs of each of the participating organizations.

PDF sponsors the first symposium on the "quality of life" in Parkinson's disease.

**1997**

PDF sponsors "Frontiers in Parkinson's Disease," a symposium celebrating its 40<sup>th</sup> anniversary.

PDF inaugurates the Parkinson's Disease Foundation lectureship at the annual meeting of the American Academy of Neurology. The first honoree is Dr. Fahn.

**1999**

A merger is completed between PDF and the United Parkinson's Foundation, based in Chicago. The merged organization is called the Parkinson's Disease Foundation, Inc.

PDF sponsors *Power Across America*, the first cross-country trek by bike, kayak and hike, to raise visibility and funds for Parkinson's disease research. The PDF budget exceeds \$5 million for the first time.

**2001**

Dr. Stanley Fahn, PDF's scientific director, takes office in May as president of the American Academy of Neurology.

PDF joins with NIH, the Michael J. Fox Foundation for Parkinson's Research and other private foundations to sponsor the R21 program for innovative Parkinson's research projects. This is the first-ever public/private partnership of its kind.

**2002**

The U.S. Food and Drug Administration (FDA) approves Activa Therapy (deep brain stimulation) as a surgical intervention for Parkinson's disease.

**2003**

PDF launches Advancing Parkinson's Therapies (APT), a campaign to increase participation in clinical trials for new Parkinson's therapies.

**2004**

PDF leads other members of the Parkinson's community in creating the first-ever World Parkinson Congress, scheduled for February 2006.

