

PARKINSON'S DISEASE FOUNDATION

1957-2007

**Fifty Years of Leadership and Commitment
to the Parkinson's Disease Community**





*The mission of the
Parkinson's Disease Foundation
is two-fold: to understand
and find the cure to Parkinson's
disease and related movement
disorders; and, for as long
as this search continues, to
ensure that those individuals
and families who live
with Parkinson's are able
to achieve and maintain
the best possible
quality of life.*

TABLE of Contents

The PDF Story	1
RESEARCH	
Advancing the Science of Parkinson's	
Center Grants Program	5
Fellowships and Career Development Grants	12
International Research Grants Program	14
Collaborative Endeavors	15
EDUCATION	
Educating and Supporting the Parkinson's Community	
Parkinson's Information Service	23
Educational Materials	24
The PDF Website	25
<i>PDtrials</i> : Increasing Parkinson's Clinical Trial Education and Awareness	25
World Parkinson Congress	27
ADVOCACY	
Advocating for the Interests of the PD Community	
Securing Federal Funding for Parkinson's Research	29
The People with Parkinson's Advisory Council	29
The People with Parkinson's Clinical Research Advocacy Initiative	30
The FDA Patient Consultant Program	30
Supporting Research Involving Stem Cells	31
Financial Reports	33
Recognition of Donors	37
Events that Support PDF	43
PDF Grant Recipients	45

Table of Contents



THE PDF Story

For half a century, the Parkinson's Disease Foundation® (PDF®) has been working to solve the mysteries and ease the ravages of Parkinson's disease. Parkinson's affects nearly one million people in the United States. Our mission has been clear: to explore science, to advance treatments, to provide information and support to individuals and families, and to envision a world in which this dreadful and debilitating disease can be consigned decisively to its rightful place in the graveyard of medical history.

PDF was created in 1957 by William Black, founder of Chock full o'Nuts, a successful New York coffee and restaurant business. When Mr. Black's controller and close friend was diagnosed with Parkinson's, he was appalled to learn that no truly effective therapy was available, nor was any basic research being conducted on the disease. With his own money, Mr. Black set up the Parkinson's Disease Foundation with a single goal — to establish a research program aimed at finding effective drug treatment for the disease. He met with Dr. H. Houston Merritt, Chair of Neurology at Columbia University, and Dr. Melvin D. Yahr to help create the first major research center for Parkinson's. Mr. Black made two major gifts to Columbia University: one to help build the research laboratory building that now bears his name and houses one entire floor dedicated to Parkinson's research; the other to endow support for that research. This close relationship between PDF and Columbia University has persisted to this day.



Parkinson's
Disease
Foundation

THE COLUMBIA CONNECTION: BUILDING ON A GREAT FOUNDATION

The importance of Columbia to PDF and to the Parkinson's disease community goes far beyond its role as PDF's scientific authority. Through its programs of post-graduate education and training of physicians and scientists, it has also served as a cradle for the movement disorder community, turning out generations of leaders of other Parkinson's and movement disorder programs in the US and more than a dozen other



PDF founder William Black with his wife, Page Morton Black, PDF's current Board Chairman.

countries. It has been estimated that Columbia has been the source of post-graduate training for most of the current movement disorder

specialists in the New York metropolitan area. In addition, Columbia and two other institutions — Rush University in Chicago and The Institute of Neurology at Queen Square in London — have together been responsible over the last 30 years for training over half of the program directors in movement disorders in the world. Since 1999, Rush has been PDF's other principal grantee.

PDF STORY

Columbia's movement disorder program has been a leading participant at the major milestones in Parkinson's science over the last 50 years — beginning with the university's involvement in the early trials of levodopa, the “miracle drug” that transformed the treatment of Parkinson's in the late 1960s, and continuing through the university's role as one of the world's leading laboratories devoted to studying cell death — the process that is central to understanding

Scientific Director in 1969. Dr. Yahr went on to found the Research Committee on Parkinson's Disease of the World Federation of Neurology and continued providing counsel and direction to the Parkinson's community until his death, at age 90, in 2004.

At the helm of the Columbia program since 1973 has been Dr. Stanley Fahn, a scientist and clinician, who started his career as a neurochemist. Throughout this period, Dr. Fahn has also served as

*“Thank you, PDF, for the great work you have done and continue to do. **After 50 years, the Parkinson's Disease Foundation is still blazing trails and setting an example for others.**”*

– Greg W., Parkinson's advocate
Louisville, KY

the cause of Parkinson's. This success would not have been possible without the involvement of PDF and its thousands of supporters who have contributed a total of almost \$50 million to Columbia's program since 1957.

The creative interplay among PDF, Columbia and the wider Parkinson's world was aptly symbolized a few years ago when scientists at the National Institutes of Health and the Robert Wood Johnson Medical School announced the discovery of the first gene mutation to be associated with Parkinson's disease. The senior scientist on the team, Dr. Roger Duvoisin, by then on the brink of retirement, was the recipient of the very first PDF-funded research fellowship some 35 years earlier.

Another example of this leadership in the field was PDF's association with Dr. Melvin Yahr, the formidable Parkinson's scientist who became PDF's first

Scientific Director of PDF. He currently holds the H. Houston Merritt Professorship of Neurology at Columbia University and directs the university's Center for Parkinson's Disease and Other Movement Disorders. He is a past President of the American Academy of Neurology (AAN) and a co-founder of both the Movement Disorder Society (MDS) and the Parkinson Study Group (PSG). He is widely regarded as the leading figure in the Parkinson's community worldwide.

MEETING THE NEEDS OF PATIENTS AND FAMILIES

In the late 1970s, PDF implemented a new dimension to our programs: using the platform of Columbia's scientific authority as a base for the creation of a program of information and support for patients and their families.

In 1994, PDF staged the first-ever conference on “quality of life” in Parkinson's disease. This event helped pave

the way for a new view of Parkinson's as being not just a disorder of the motor system, but rather a complex disease that affects many parts of the body. This new view, now widely accepted, recognizes that successful management of the disease requires the deployment of a whole new set of therapeutic strategies, from exercise, to lifestyle adjustments, to family support.

CREATING A PARTNERSHIP IN CHICAGO

By the mid-1990s, PDF was ready for new challenges. Among them was arranging a merger with the United Parkinson Foundation in Chicago. One product of this merger was PDF's inheritance of a relationship with Rush University Medical Center, the leading Parkinson's center in the Midwest. Today, PDF annually provides a dollar-for-dollar matching grant of up to \$275,000 towards Rush's exemplary Parkinson's disease research program.

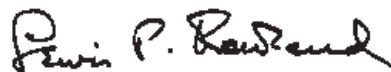
PDF TODAY: VISION, PROGRAMS AND ACTIVITIES

Accompanying these developments has been a significant increase in the number of dollars the organization has been able to raise and direct to research, education and public advocacy. In 1995, the PDF budget was approximately \$2.5 million. By Fiscal Year (FY) 2006, it had grown to more than \$8 million.

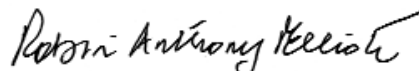
Even with this growth, PDF is able to keep its management and fundraising costs to just 19 percent of annual revenues. This fiscal responsibility has earned PDF a four-star rating from Charity Navigator and the Wise Giving Alliance of the Better Business Bureau (BBB) Charity Seal of Approval — the only national Parkinson's organization that currently enjoys both ratings.

Today, PDF builds on a tradition of scientific authority and a commitment to patients and families to create a vision for the future that is rooted in good science and propelled by a deeply-held perception of human need in the Parkinson's disease community. We aim not for a "second half-century" of life but for something shorter and more intense: a vigorous decade or two of battle, at the end of which PDF will proudly draw the curtains on Parkinson's disease.

In this new chapter of our institutional life, PDF draws on its traditional resources and commitments and invests them in programs to meet the needs of today and tomorrow. To accomplish this, we tap three rich veins of our culture: the scientific imagination and medical excellence of great medical institutions; the needs, interests and concerns of the patients, families and friends who make up the Parkinson's disease community; and the resources of a diverse group of not-for-profit Parkinson's organizations, each working in its own way to assist, and in the long run to render redundant, a Parkinson's community that none of its members volunteered to join, and that all, in a heartbeat, would joyfully exit.



Lewis P. Rowland
President, Board of Directors



Robin Anthony Elliott
Executive Director

PDF STORY

RESEARCH

designed to advance the understanding of Parkinson's disease and to find the cure by funding science of the highest caliber. We pursue this goal through a combination of Center Grants, individual investigator grants, training initiatives and collaborative efforts with other organizations.



ADVANCING the Science of Parkinson's

Researchers today are reporting unprecedented excitement in the science of Parkinson's disease (PD). Among the most interesting questions being addressed are how cells die in Parkinson's; how gene therapy involving growth factors can slow or stop the development of parkinsonism; what might be an agent for an anti-PD vaccine; which environmental toxins may be implicated in Parkinson's; and what are the number of genes (12 and counting) that play a role in at least some cases of Parkinson's disease.

At PDF, we assist in this process — with the help of our donors — in four distinct ways. One of these is through a series of Center Grants at major universities. Another is encouraging promising young investigators to devote their talents to the study of Parkinson's through mentored fellowships, training opportunities and career development grants. A third is funding talented independent investigators through our International Research Grants Program (IRGP). And through the fourth, PDF is collaborating with other organizations on innovative joint projects.

Throughout these diverse activities, there is a single underlying objective: to identify the best scientific investments and match them to PDF's unique traditions and capacities. To ensure that we are funding the best science with the most potential, our investments are guided by a Scientific Advisory Committee of leading Parkinson's scientists, headed by Dr. Stanley Fahn, PDF's Scientific Director.

CENTER GRANTS PROGRAM

The science of Parkinson's, as in other disease areas, takes shape in three sequential phases: basic, translational and clinical. Basic science, sometimes

called "bench" science, takes place in the laboratory. Translational science, which also takes place in the lab, seeks to verify, in settings where the focus is a specific disease, the laboratory-tested hypotheses that emerge from basic science. This phase of investigation typically involves experiments with small animals such as rats and mice. The final phase, clinical science, is where the potential of promising molecules, compounds and surgical interventions is examined in human volunteers.

Through our Center Grants program, PDF supports science in all three phases of Parkinson's research. Center Grants are awarded to select research groups that specialize in unlocking the mysteries in PD and related disorders. The concept behind funding these Parkinson's research centers is that "the whole is greater than the sum of its parts." Our Center Grants allow a strong group of talented scientists, each working on different but complementary Parkinson's projects, to tie their work together. This long-term investment in a group of researchers provides the flexibility needed to ensure the kind of innovative, pioneer-



RESEARCH

ing work that will advance the understanding and treatment of Parkinson's.

Currently, we award Center Grants to the movement disorder centers at three prestigious institutions: Columbia University Medical Center in New York

In June 2005, when the Columbia program was last evaluated by PDF's Scientific Advisory Committee, the program was described as "... an outstanding research endeavor in Parkinson's disease" and "... a national asset." Early in

"The Parkinson's Disease Foundation has been enormously helpful in coordinating activities across the whole spectrum of advocacy groups, and it has been ... among the most enlightened in funding highly innovative studies that are difficult to fund by the usual NIH methodology of peer review. There are not only terrific laypersons involved, but the scientists who are affiliated with the foundation have been among the most helpful to the planning efforts of the NIH."

– Gerald Fischbach, M.D., Former Director
National Institute of Neurological Disorders
and Stroke

City; Rush University Medical Center in Chicago; and Weill Cornell Medical Center in New York City.

All three of these programs are of the highest scientific quality, and all are peer-reviewed periodically by an independent group of renowned Parkinson's disease scientists who make up our Scientific Advisory Committee.

the following year, the committee performed a similar review of the Rush center. Its conclusion: "The Rush group is highly integrated ... This group has a clinical emphasis, especially in translational research and this ... program is a major strength."

COLUMBIA UNIVERSITY MEDICAL CENTER

PDF's largest grant — amounting to a record \$2.4 million in 2006 — goes to the Center for Parkinson's Disease and Other Movement Disorders at Columbia University. The center comprises six main laboratories, and a variety of clinical studies and training programs. The 15 scientists at the core of the center all have M.D. or Ph.D. degrees (and some have both). With these resources, the Columbia center represents the largest — and certainly one of the most productive — multidisciplinary Parkinson's research teams in the world.

SCIENTIFIC ADVISORY COMMITTEE

J. Timothy Greenamyre, M.D., Ph.D.
University of Pittsburgh

Oleh Hornykiewicz, M.D.
University of Vienna

J. William Langston, M.D.
The Parkinson's Institute

G. Frederick Wooten, M.D.
University of Virginia

Anne B. Young, M.D., Ph.D.
Massachusetts General Hospital

The following are examples of some recent accomplishments of the Columbia University team.

Role of Cell Death in Parkinson's Disease

Dr. Serge Przedborski, the Page and William Black Professor of Neurology, heads one of the world's most productive laboratories in the pathogenesis and treatment of Parkinson's disease. Its focus is on the role of cell death in Parkinson's, using experimental animal models of PD to understand more about the mechanisms of cell death and the pathology of the disease.

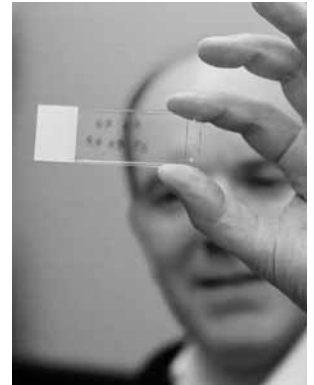
In the June 22, 2004 edition of the *Proceedings of the National Academy of Sciences*, Dr. Przedborski, along with colleagues from the University of Nebraska Medical Center, revealed their discovery of a vaccine that protects brain cells in a mouse model of Parkinson's disease. Their study aimed to test whether a protein called Copaxone®, used by patients with multiple sclerosis, could be used to prevent or reduce cell death in Parkinson's disease. The result could help to slow disease progression and improve the quality of life for people living with Parkinson's. Clinical trials ultimately will determine if the observations seen in mice can be translated into humans.

One of the recent findings of Dr. Przedborski and his team is that the gas nitric oxide does not, on its own, cause direct damage to dopaminergic neurons, but must react with other species to cause cell death. Because of such a discovery, the research team believes that the process of neurodegeneration is triggered by not one but several factors.

Studies of How Growth Factors May Help Brain Cells Regenerate

One of the most promising approaches to combating Parkinson's disease is the study of so-called growth factors — naturally occurring substances that can protect, or even help regenerate, the brain cells that die in Parkinson's. The best-known of these is a molecule called glial cell line derived neurotrophic factor (GDNF). GDNF has been shown to protect and restore dopamine neurons in animal models of parkinsonism, and it is now being assessed for its potential to treat Parkinson's in people.

Dr. Robert Burke, the Alfred and Minnie Bressler Professor of Neurology and Pathology and Director of Laboratory Research in Parkinson's Disease and Related Disorders, and his colleagues are busy learning more about GDNF and its potential. Their progress was reported in a paper published in the *Journal of Neuroscience* showing that GDNF plays a critical role in the regulation of the development of dopamine neurons. In fact, they showed that GDNF actually suppresses natural cell death. These studies provide the first evidence as to how naturally-occurring GDNF behaves in the neurobiology of dopamine neurons in the living brain.



RESEARCH

With his staff of fellows and research assistants, Dr. Burke spends much of his time these days studying Parkinson's disease in the rodent brain to better under-

oration with Dr. Ana Maria Cuervo at the Albert Einstein College of Medicine, showed how alpha-synuclein is normally broken down, and why this does not

*"To find a way to cure or prevent Parkinson's disease, **you need to attract first-rate, talented young scientists to the laboratory, something we thankfully have done successfully. You require **laboratory equipment** to perform the research — this can become more expensive and difficult to obtain as we develop a deeper understanding of the details of the disease. Finally, **research is full of surprises, and you need the flexibility to follow promising new leads as they arrive.** PDF's Center Grant provides us with all of these, so that we can continue the work to locate the causes and find the cure for Parkinson's."***

– David Sulzer, Ph.D., Associate Professor,
Departments of Neurology and Psychiatry
Columbia University

stand why and how dopamine neurons are slowly destroyed. His team is currently studying the effects of another growth factor, BDNF, in the rodent brain on dopamine neuron development.

Understanding How Parkinson's Develops

In a paper published in *Science*, Dr. David Sulzer, Associate Professor in the Departments of Neurology and Psychiatry, and his colleagues

suggested a possible explanation for the development of some forms of Parkinson's disease that may be found in mutations of a brain protein called alpha-synuclein.

Alpha-synuclein is a normal protein in the brain that mutates in certain cases of Parkinson's. Dr. Sulzer's team, in collab-

occur among the mutant forms that are found in Parkinson's. Their recent work is indicating why normal alpha-synuclein breakdown does not occur in the most common forms of Parkinson's disease, which appears to result from a reaction between the protein and dopamine.

Armed with this information, Dr. Sulzer's lab now is working to determine how the non-degraded alpha-synuclein then goes on to damage neurons. The team is currently experimenting with a viral vector in an animal model of Parkinson's to package and deliver dopamine to these neurons in a way that will prevent the damaging reaction between alpha-synuclein and dopamine.

The Biology of Alpha-Synuclein

Dr. William T. Dauer, Assistant Professor of Neurology, and his research team are working to unravel the molecular and cellular mechanisms of diseases



that disrupt the motor system. Their primary focus is on Parkinson's disease and DYT1 dystonia. For each of these projects, the team studies disease genes that cause these disorders, employing a range of molecular, cellular and whole animal studies to dissect what is the normal role of disease proteins, and how pathogenic mutations lead to disease. The team's Parkinson's disease-related work initially centered on the biology of alpha-synuclein. Dr. Dauer's team has generated an

lumbia's Sergievsky Institute published a paper in *Movement Disorders* that showed that a gene mutation seen almost exclusively in the Ashkenazi Jewish population is associated with Parkinson's disease. When a "double dose" of the gene (beta-glucocerebrosidase N370S allele) mutation is present (that is, one gene inherited from each parent, a pattern that is known as autosomal recessive), there is a metabolic condition known as Gaucher disease. But when only a single

It is a measure of PDF's worldwide scientific leadership that Dr. Stanley Fahn, H. Houston Merritt Professor of Neurology and Director of the Center for Parkinson's Disease and Other Movement Disorders at Columbia University, was chosen by the Annemarie Opprecht Foundation to receive its prestigious Parkinson Award for 2005. The foundation, which is based in Switzerland, presents its award every three years to the authors of the two most outstanding papers published in Parkinson's disease research.

Dr. Fahn received the award for his paper on the ELLDOPA project, a study that discovered that levodopa — the gold-standard treatment for Parkinson's for more than three decades — does not hasten the clinical progression of the disease, as some scientists had feared, and may actually slow it down. The paper was published in *The New England Journal of Medicine* in December 2004.

alpha-synuclein mouse model and demonstrated that they are strikingly resistant to the parkinsonian neurotoxin MPTP. More recently, Dr. Dauer and his team have been working on the most common genetic cause of Parkinson's disease, LRRK2, and have identified a novel effect of PD mutations in that gene.

Analyzing the Genetic Risk Factors in Parkinson's

In January 2005, geneticist Dr. Lorraine Clark, Assistant Professor of Clinical Pathology, and her colleagues at Co-

mutation is inherited from just one parent, the result is a higher risk of developing Parkinson's disease. On the basis of these pilot studies that were funded through the PDF grant, Dr. Clark expects to proceed to a larger study that will be eligible for funding from the National Institutes of Health.

RESEARCH

RUSH UNIVERSITY MEDICAL CENTER

Since 1999, when the Parkinson's Disease Foundation merged with the United Parkinson Foundation, PDF has made annual grants to support the investigations of Rush University Medical Center (formerly Rush Presbyterian-St. Luke's Medical Center) in Chicago. Through FY 2004, the annual grants were \$450,000. Beginning in FY 2005, total funding of the Parkinson's center — the PDF grant plus matching gifts — was \$500,000. One-half of this was contributed by PDF and the other half was provided as matching funds by Rush donors. In FY 2007, the total funding was \$550,000.

PDF's support provides stability to the Rush Movement Disorders Center. The clinical program is directed by Dr. Christopher Goetz, and the basic science program is directed by Dr. Jeffrey Kordower.

As with all PDF Center Grants, scientists at Rush work together closely and apply their decoding skills across various aspects of Parkinson's disease, including the following.

Clinical Studies of Hallucinations in PD

Dr. Christopher Goetz is one of the few nationally-recognized scientists to focus on hallucinations, which affect one-third of people with Parkinson's disease. Working with his colleagues in neuroimaging, Dr. Goetz has used new brain-scan techniques to define the regions of the brain that are over-active or under-active in patients who hallucinate. He continues this research to learn more about the anatomical layout of hallucina-

tions in people with PD and the brain activity changes that occur when medications are used to treat hallucinations.

In addition, Dr. Goetz is directing a grant from the National Institutes of Health to analyze how the so-called "placebo effect" impacts patients with Parkinson's disease. The placebo effect is the improvement that regularly occurs when patients enter into a clinical trial for a new treatment, even when they are assigned to the control group and receive an inert substance (such as a sugar pill). More than any other neurological disease group, Parkinson's disease patients respond positively to treatment with placebos in both surgical and pharmacological clinical trials. Placebo-related improvements are thought to occur at least in part from increases in dopamine function that are induced by novelty, positive anticipation and motivation. The findings from this study will have important implications for the design of future Parkinson's disease clinical trials.

Clinical Trials of Potential Neuroprotective Therapies

In the growing field of testing possible therapies that may potentially slow the development of Parkinson's disease, Dr. Kathleen Shannon has served as Site Principal Investigator at Rush on the Neuroprotection Exploratory Trials in Parkinson's Disease (NET-PD), sponsored by the National Institute of Neurological Disorders and Stroke (NINDS). Dr. Shannon, Associate Professor in the Department of Neurological Sciences, has made important contributions to the finding that two potential treatments — creatine and minocycline — are worthy of further study. As a member of the steering committee for this multi-center research effort, Dr. Shannon is helping to



determine if these agents have the potential to delay clinical decline in patients with Parkinson's disease. Whereas neuroprotection trials have previously been limited to patients with very early Parkinson's disease, the planned upcoming trial will allow patients already on treatments to participate in the program.

Sleep-Related Disorders in PD

Dr. Cynthia L. Comella, Professor of Neurological Sciences and Clinic Director, heads the sleep research programs on Parkinson's disease at Rush. Most recently, Dr. Comella has been involved with clinical trials that test an adenosine A_{2A} receptor antagonist, the combination of levodopa/carbidopa and entacapone for nocturnal sleep disruption and newly-developed drugs traditionally used to treat hallucinations in PD. Her other work includes in-depth investigations of the treatment of dystonia with botulinum toxins.

Gender Differences in Parkinson's Disease

As an extension of her laboratory work with non-human primates, Dr. Katie Kompoliti, Associate Professor of Neurological Sciences, is studying gender differences in clinical phenomenology and drug safety among PD patients. As part of this effort, Dr. Kompoliti has investigated the effects of estrogen on women's clinical responses to levodopa in order to develop practical recommendations for post-menopausal women with Parkinson's disease who are faced with the dilemma of whether or not to take hormonal replacement therapy.

Neurotransplantation and Gene Therapy

Dr. Jeffrey Kordower, head of basic research studies at Rush and Director of the Research Center for Brain Repair, bridges the three phases of research

(basic, translational and clinical) by studying cellular replacement and gene therapy strategies in rodent and non-human primate models of PD — and now, in humans. Over the past several years, Dr. Kordower has investigated the efficacy of gene delivery of a trophic factor, called neurotrophin, in non-primate models of PD. He also continues his work in neurotransplantation, including testing the potential of stem-cell transplants in non-human primates. All of Dr. Kordower's studies, many of which are done in collaboration with other scientists at Rush, are designed and executed to ensure that the positive findings of basic science can be examined for possible integration into the clinical program.

Neurosurgical Studies

Dr. Leo Verhagen, Associate Professor of Neurological Sciences, and Dr. Roy Bakay, Professor of Neurosurgery, have developed one of the largest surgery programs internationally for people with Parkinson's disease and other movement disorders. Deep brain stimulation, cellular transplantation and most recently, gene therapy are all conducted under this program. This effort directly interfaces



RESEARCH

with Dr. Kordower's laboratory program, as it provides a direct line for laboratory discoveries of potential new therapies to be brought to people with Parkinson's disease.

Cognitive Issues: Studies of Intellectual Function

For people living with Parkinson's disease and their families, intellectual decline is among the most feared aspects of the disease. Dr. Jennifer Goldman, Assistant Professor of Neurological Sciences, has focused her research efforts on defining the different types of problems experienced by Parkinson's disease patients and is conducting neuroimaging studies to examine the brain changes responsible for intellectual declines. Her goal is to separate two primary forms of cognitive problems, clinically termed "cortical" and "subcortical" with ana-



tomical precision and to detect very early changes in the brain that are associated with mild cognitive impairment. These studies build on research related to Alzheimer's disease

and demonstrate the utility of collaborations among Parkinson's disease experts and specialists in other areas of neurological study.

WEILL CORNELL MEDICAL CENTER

For the past four years, PDF has committed a third Center Grant — this one for \$100,000, to Weill Cornell Medical Center in New York City. Headed by Dr. M. Flint Beal, the Cornell grant has made notable contributions in several

areas of Parkinson's research. Two examples follow.

Coenzyme Q10

Cornell played an important role in an exploratory study to test the potential of Coenzyme Q10, a common over-the-counter dietary supplement, in slowing the progression of Parkinson's disease. Scientists noted a significant slowing in the progression of the disease among the trial participants who received higher doses of Coenzyme Q10, compared with those who took lower doses or were in the placebo group. What is more, the substance appeared to cause so few side effects that none of the patients in the study needed to adjust their dosages of Parkinson's medications.

The Cornell team, working with NINDS, is now preparing for a larger clinical trial of the potential treatment.

Developing a New Animal Model

The Cornell group has been working on developing what Parkinson's scientists have long needed: a good animal model of the disease that truly reflects how the disease occurs in humans. They hope that such a model would make it possible, finally, to make a definite diagnosis, rather than one based primarily on identification of symptoms. Such a development could reduce the rate of "false-positive" diagnoses of Parkinson's, which is estimated at 10 percent even at the best clinics and much higher elsewhere.

FELLOWSHIPS AND CAREER DEVELOPMENT GRANTS

PDF offers a diverse portfolio of awards to generate interest in Parkinson's research and patient care among younger scientists and clinicians. In this category are post-doctoral fellowships for neurologists, post-doctoral research

fellowships and summer fellowships for high school and college students who are interested in neuroscience and program-specific mentored training grants.

Post-doctoral fellowships for neurologists are used to support doctors who wish to train in movement disorders as well as those who have finished their

(PSG), the leading consortium of university centers that run clinical trials in Parkinson's disease. The impact of the award is already apparent — one of the first recipients of PDF's Mentored Clinical Research Award is now overseeing Parkinson's clinical trials at the National Institute of Neurological Disorders and

PDF's influence on the Parkinson's disease community is vividly demonstrated by the number of scientists who started their careers under our mentorship programs. For the past 30 years, PDF's financial support of these scientists and their projects gave them the training they needed to lead some of the largest Parkinson's disease research centers in the world (see map on page 18). In this way, the impact of PDF's support extends beyond the current generation of Parkinson's scientists to touch those who will be leading the field in the future.

This imprint is highlighted in the work of Nir Giladi, M.D., a well-known Parkinson's researcher and recipient of two PDF fellowships and an International Research Grant. Dr. Giladi is a Senior Lecturer at Tel Aviv University, Sackler School of Medicine in Neurology and Physical Therapy and is founder of the Movement Disorders Unit (MDU) at Tel Aviv Sourasky Medical Center in Tel Aviv, Israel. This center is a model of a multidisciplinary team approach to the treatment of Parkinson's disease.

movement disorders training and wish to complete advanced research and clinical training. Most of the graduates of this program return to their home states and continue to lead — in many cases, to create — exemplary programs in movement disorders. PDF also grants post-doctoral research fellowships to young scientists who have a Ph.D. or M.D.

One of PDF's newest initiatives in this area is the creation of prestigious mentored fellowships in collaboration with two leading professional associations. One is the Parkinson Study Group

Stroke, the world's leading source of funding for research into Parkinson's and other brain disorders.

The other is the Parkinson's Disease Foundation/American Academy of Neurology Foundation Clinician Scientist Development Award, presented through the American Academy of Neurology (AAN), the world's premier professional

RESEARCH

society of physicians specializing in brain disorders. PDF and AAN hope that by working together, this award will attract outstanding young scientists to the field of clinical research.

Finally, for younger aspirants who are interested in pursuing careers in Parkinson's science, PDF runs a program of summer fellowships for high school seniors, undergraduates and medical stu-



dents to support Parkinson's disease-related research projects. Typically, PDF awards 20 summer fellowships each year. These fellows undertake 10

weeks of laboratory work overseen by a sponsor. Several of our summer fellows have gone on and presented their work at professional medical meetings.

INTERNATIONAL RESEARCH GRANTS PROGRAM

The Parkinson's Disease Foundation fosters Parkinson's science through a competitive, investigator-initiated program of one-year "seed grants" known as the International Research Grants Program (IRGP). These funds are granted by PDF's Scientific Awards Committee to talented investigators from around the world, most of them at an early stage in their careers. Investigators are testing novel ideas and building data that will later qualify them to apply for larger and longer-term grants (typically, from the NIH and other government funding agencies) to support their projects.

The goal of IRGP is a natural complement to PDF's research strategy: to support the investigation of innovative approaches to better understanding Parkinson's disease and finding new treatments. The competition is tough — in fact, it continues to get tougher, as dem-

An International Research Grants Program (IRGP) evaluation study, completed in the spring of 2003, showed that of the 49 scientists who received awards from PDF between 1999 and 2002, 18 have since received multi-year awards from the National Institutes of Health (NIH) or another private foundation. An additional 16 were either preparing proposals for submission to the NIH or had already submitted proposals to NIH and were waiting to hear if they had been successful. Typically, the work the scientist had done under the PDF grant supported his or her application to a government agency for a major extension of the work.

The total amount of money granted by other agencies to the 18 IRGP awardees during the period covered by this review was almost \$20 million — 10 times the total amount of IRGP funding to these same scientists from 1999 through 2002! PDF is proud to have been a major factor in fostering these research projects.

onstrated by the near-doubling of the applications that were submitted to PDF in 2005 compared to 2004.

In FY 2007, total spending for IRGP awards was \$667,000 (to 17 recipients).

Michael J. Fox Foundation for Parkinson's Research on a project to help accelerate the development of an effective biomarker, or diagnostic test, for Parkinson's disease. Development of a valid

*"The PDF funding was **essentially the seed money we needed to prepare for the NIH-funded project of \$1.2 million over five years. This later work would not have been possible without PDF's early investment.**"*

– Un Jung Kang, M.D., Associate Professor of Neurology, Pharmacology & Physiology
University of Chicago — IRGP grant recipient

PDF is aware that competition is keen and has increased its cap on IRGP awards from \$40,000 in FY 2007 to \$50,000 in FY 2008. We have also streamlined our applications submission process by requiring that all proposals be submitted online.

IRGP recipients for the last four years are listed on pages 45 – 48, and their locations in the world are shown on the map on page 18.

COLLABORATIVE ENDEAVORS

PDF pursues additional collaborations with other organizations that fund Parkinson's research to sponsor programs larger and broader-based than either of the organizations could manage alone. One example of this kind of collaboration was joint funding of a "fast-track" program run by the NIH. The goal of this program, known as the R21 series, was to speed up the commitment of funds for innovative, high-impact projects targeting Parkinson's and other diseases. PDF, joined by several other Parkinson's organizations, contributed funding to the program in 2001 and 2002.

Recently, PDF collaborated with The

biomarker would greatly increase scientists' ability to test the efficacy of new therapies for PD and possibly help with early detection of the disease. The pilot program was concluded in the summer of 2005 and the Fox Foundation is working on a follow-up program.

PDF also collaborates with the Fox Foundation on an initiative called the Parkinson's Community Research Advisory Council (PCRAC), an endeavor to collect data from US-based funding organizations to determine the scientific areas to which Parkinson's research money — government as well as



RESEARCH

private — is being directed. Dr. Stanley Fahn, PDF's Scientific Director, has been leading this initiative.

ENGAGING THE COMMUNITY IN SYSTEMS CHANGE

PDF recognizes that there are core structural and cultural barriers that delay the movement of Parkinson's disease treatments and therapies from "bench to bedside." In response, PDF has estab-



lished the Advancing Parkinson's Treatments Innovations Grant. This grant is part of a multi-pronged effort by PDF to fund

new and innovative programs that facilitate the clinical research process so that treatments and therapies move at an accelerated rate from "bench to bedside." The Parkinson Study Group is a recent grant recipient.

co-founded by Ira Shoulson, M.D., of the University of Rochester and Dr. Stanley Fahn. Drs. Shoulson and Fahn served respectively as chair and co-chair of the consortium until the spring of 2006, when leadership was transferred to Dr. Karl Kieburtz of the University of Rochester and Dr. Karen Marder of Columbia University.

The program, now in its fourth year, has been used to advance clinical research in several ways. One of these has been to foster efficiencies in Parkinson's database management by funding the inventory, assessment and integration of PD study databases among all the research projects that are managed by PSG. The focus of this integration has been to take the databases of PSG studies that were sponsored by the NIH and other organizations over the last 20 years and put them into a format that is usable for retrospective analyses. These retrospective analyses or "data mining" efforts allow the matchless resource that is

"The PSG is particularly appreciative of PDF's support. This unique kind of collaboration provides the energy to launch new careers, new projects and to bring new collaborators to the field of PD research."

– Karl Kieburtz, M.D., Chair
Parkinson Study Group

Parkinson Study Group

Founded in 1985, the Parkinson Study Group (PSG) is a non-profit, cooperative group of Parkinson's disease experts from medical centers in the US and Canada who are dedicated to improving treatment for people living with Parkinson's disease, primarily by coordinating and managing clinical trials of promising new treatments. PSG was

represented by a large clinical trial database to be used for secondary analyses that go far beyond the purpose of the original trials.

PDF has taken the lead in funding another data-building initiative by supporting a PSG project known as FOUND (Follow-up of Persons with Neurologic Diseases) that is run by Dr. Caroline Tanner at The Parkinson's Institute in

Sunnyvale, CA. The primary objective of this study is to gather long-term data on Parkinson's disease progression, treatment response, complications and outcomes. The FOUND study acquires this information by following up with clinical trial participants after the end of a trial through questionnaires that are mailed three times a year. This type of project is especially important in chronic diseases such as Parkinson's, as the data can help provide scientists with a more complete picture of the disease and how it develops over time. Studies such as this can also help clinical investigators gather information about non-motor aspects of PD, which are often the most troublesome to people living with Parkinson's.

In the same spirit of encouraging young investigators to pursue careers in Parkinson's, PDF has provided resources to PSG for training new investigators who may not yet have had experience in developing and managing clinical trials. This training focuses on such areas as good clinical practices and ethics in research; standardized training on the Unified Parkinson's Disease Rating Scale; standardized training on "non-motor" aspects of Parkinson's, including those involving mood and cognition; and use of electronic data capture systems. The main objective is to train and increase the number of researchers who are able to conduct clinical trials, with the intent of widening the pool of qualified Parkinson's investigators — thereby accelerating the pace of clinical studies and the development of new treatments.

Since 2002, PDF has committed close to \$1 million to this essential component of the research equation.



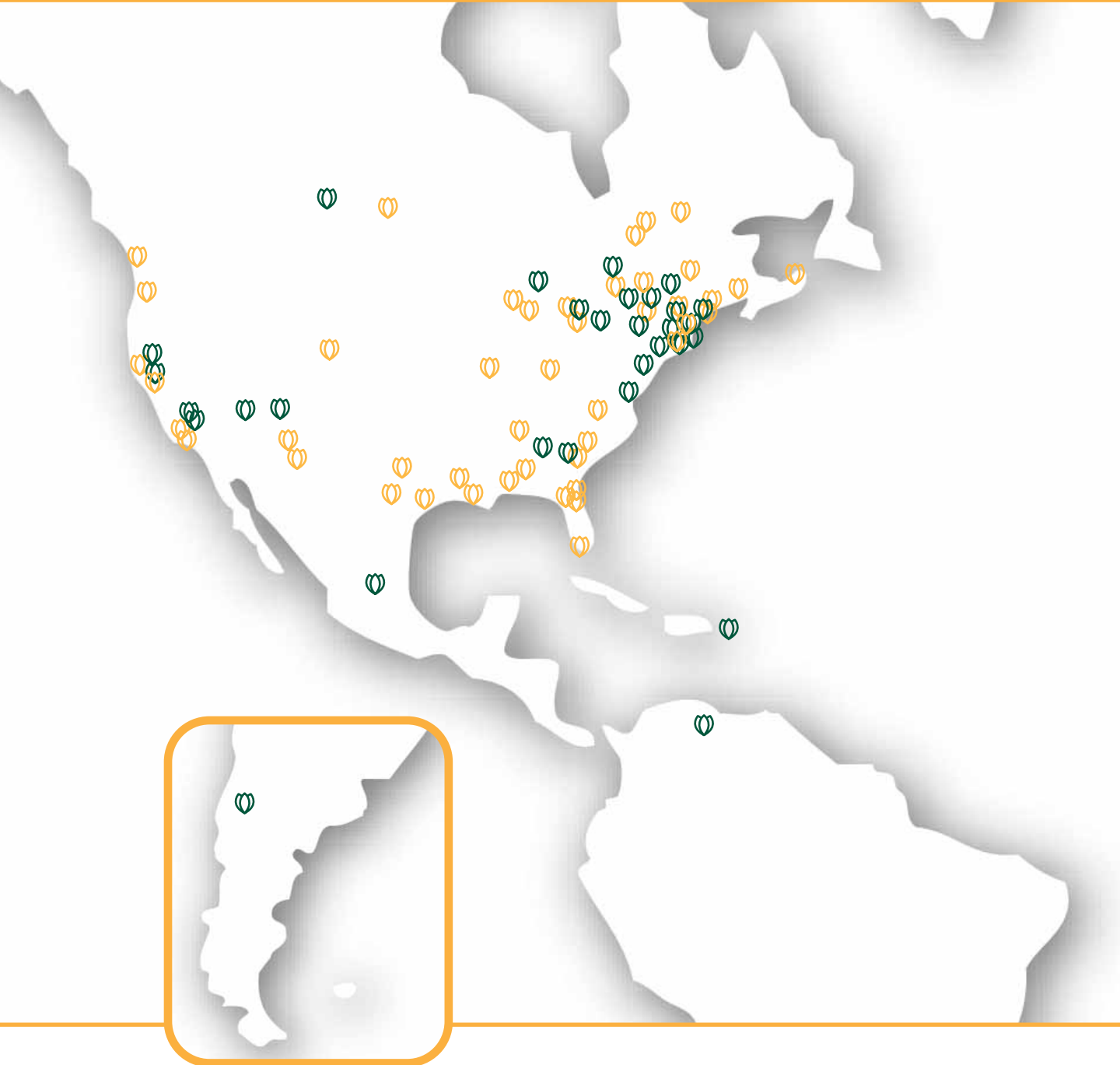
FOCUS on PDF Programs RESEARCH

- Directing Center Grants to major universities to fund a group of investigators who have a proven record of high-quality research in Parkinson's disease.
- Encouraging promising young investigators to devote their talents to the study of Parkinson's disease through mentored post-doctoral fellowships, training opportunities, career development grants and summer fellowships.
- Funding talented investigators through the International Research Grants Program, which helps scientists collect data to support larger proposals.
- Collaborating with other organizations on innovative joint projects to move the community closer to a cure.

RESEARCH

PDF, the Nation and the World

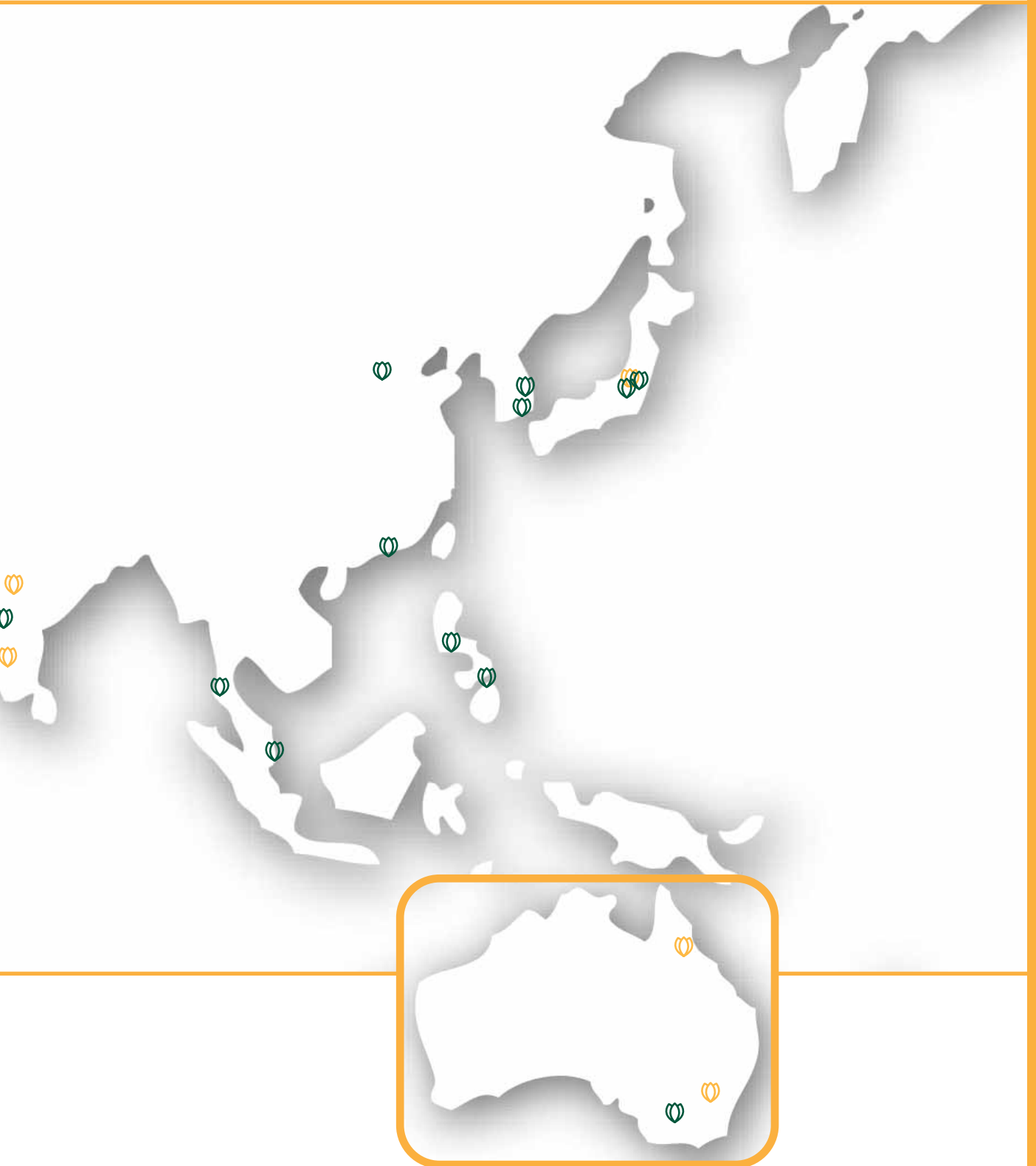
For 50 years, the Parkinson's Disease Foundation has supported leading scientists in their cutting edge Parkinson's research endeavors. Today, the impact of PDF's funding on Parkinson's disease research can be seen around the globe.

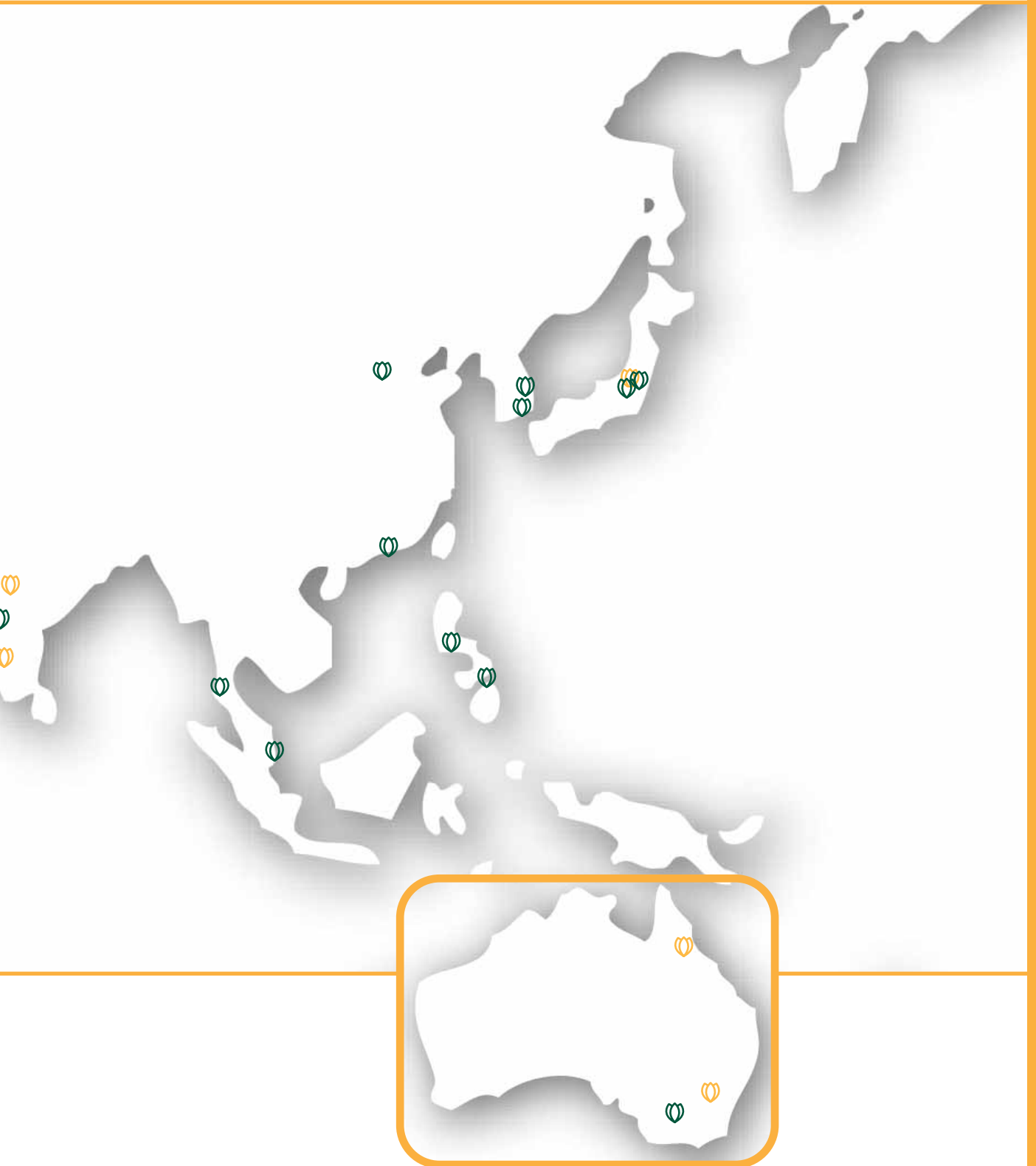


Location of recipients of IRGP grants, 1998-2007



Current locations of post-doctoral fellows funded by PDF and what was formerly UPF, 1980-2007





The impact of the Parkinson's Disease Foundation on the Parkinson's community is demonstrated by the number of scientists who started their careers with PDF funding. PDF's financial support of these scientists and their projects has given them the training they needed to lead some of the world's most important Parkinson's research and clinical centers.

EDUCATION

and support for the Parkinson's disease community through extensive informational materials, a dedicated toll-free helpline and a comprehensive website.



EDUCATING and Supporting the Parkinson's Community

The mission of the Parkinson's Disease Foundation is not only to pursue the cure for Parkinson's but also to provide assistance to the people who live with the disease. This means offering accurate, accessible information to the people who need it. It means serving the needs of the people who are directly touched by Parkinson's and it also means helping the doctors and other health professionals who provide treatment. To meet this challenge, PDF brings an authority based on a half century of creative contact and collaboration with people who live with Parkinson's disease, with the doctors who treat the disease, and with the scientists who work to understand it and solve it.

We are guided in our efforts by a Medical Advisory Committee of top Parkinson's scientists and clinicians, and by a People with Parkinson's Advisory Council (PPAC), made up of people with Parkinson's and caregivers who lend their invaluable perspective and insight to shape our work (see page 29).

PARKINSON'S INFORMATION SERVICE

At PDF, we understand that people often have specific questions that need answers. That is why we take great pride in our Parkinson's Information Service (PINS), a multi-faceted approach to responding to the needs and questions of the community. One of the main features of the service is a US toll-free number, (800) 457-6676, which is available from 10 AM to 5 PM EST. This line is staffed by a team of Parkinson's information specialists who are trained to answer general questions about Parkin-

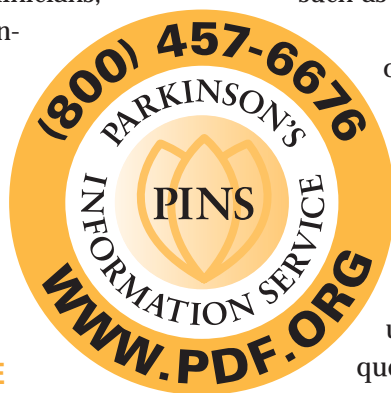
son's disease, its treatments and therapies, the progress of research and coping strategies. If a question turns out to be beyond their training, the counselors refer it to one of a dedicated group of experts in such fields as medicine, healthcare, finance and social work, who stand by to help us in this



important work. Our staff also maintains referral lists of experienced neurologists that cover most areas of the United States and major cities abroad. In addition, we are often able to direct callers to other resources in their area, such as support groups.

After speaking with one of our specialists, callers can request a custom-tailored package of print and audiovisual materials on Parkinson's disease. The package covers a wide range of topics and can be used as a reference for future questions as they arise. PDF is seeing a marked return on its increased investment in PINS. In April 2006, our Parkinson's information specialists reported that the number of calls to our helpline has nearly doubled in just one year!

For people who feel more comfortable asking questions by email, access to



EDUCATION

our services is available through “Ask the Expert,” a section of the PDF website, www.pdf.org. Visitors can submit a ques-

available to the Parkinson's community.

The list also includes updates of popular existing publications, such as *Deep*

*“Thank you for the helpline. Unless you have been a Parkinson's patient or the spouse of one, it is hard to imagine **how important PDF's helpline is**. I have spoken to your [information specialists] when I needed information ... and oh how they have helped and alleviated much stress.”*

– Renee W., person living with Parkinson's
New York, NY

tion or review answers to more than 750 commonly-asked questions that are in our archive. Newly submitted questions are

answered by PDF's team of physicians and Parkinson's information specialists — usually within eight to 10 business days.

The goal of PINS is simple:

to serve as a “one-stop shop” for finding answers to questions about Parkinson's disease.

EDUCATIONAL MATERIALS

PDF has published and distributed patient-education materials, including a quarterly newsletter, since 1980. In recent years, we have expanded and refined this program. Among the recent products is a video and print package designed for the newly-diagnosed patient, entitled *Diagnosis Parkinson's Disease: You are Not Alone*; an original and popular exercise video, entitled *Motivating Moves for People with Parkinson's*; and an authoritative brochure on the most helpful web resources that are

Brain Stimulation for Parkinson's Disease (previously entitled *Surgery for Parkinson's Disease*), written by Blair Ford, M.D., the Scientific Editor of our newsletter, and *Parkinson's Disease Q&A*, a guide to the most frequently-asked questions about PD written for patients and their families.

We have also freshened up the appearance of our quarterly newsletter, *PDF News & Review*, and have taken steps to strengthen the content of patient-oriented issues. Among the enrichments are columns written by prominent physicians and scientists, as well as essays from people with Parkinson's on specific aspects of living with the disease.

Before initiating work on a new publication, PDF performs a careful review of needs and collaborates with members of the community through personal correspondence and informal focus groups. These steps help to ensure that we produce quality materials that meet a specific need. Our efforts have yielded impressive results, spurring an increase of more than 50 percent in requests for our educational materials in 2006 compared to 2005 — including a notable number of requests from outside the United States.



THE PDF WEBSITE

One major recent focus of our efforts to serve the Parkinson's community has been updating the content and structure of the PDF website (www.pdf.org) and its ability to meet the needs of information-seekers. Our visitors have commented favorably on the increased ease of finding the information they seek. The structure of the website is now clean, crisp and simple to navigate.

We have also been finding ways to broaden the site's reach and increase its capacity to provide timely coverage of scientific news and other developments in the Parkinson's community. For information on the basics of the disease and how to live with it, a person can now preview and request free print copies of PDF publications from the website and all of our new materials are available for downloading. The result of our efforts has been a substantial increase over the past two years in total visitors to our website to an average of 90,000 per month. The increased traffic on our site also means an increase in questions that are submitted in the "Ask the Expert" section, a feature that continues to grow in popularity.

PDTRIALS: INCREASING PARKINSON'S CLINICAL TRIAL EDUCATION AND AWARENESS

According to a 2005 Harris Interactive survey, 95 percent of people with Parkinson's agree that clinical trials are necessary to find better treatments and 80 percent would be likely to participate

in a clinical trial if one were available in their area. However, only 11 percent of people with Parkinson's report that their physician has suggested that they participate in a clinical trial. In fact, the majority of physicians who treat people with Parkinson's refer 10 percent or fewer of their patients for clinical trials.

It is estimated that one percent of people in the US living with Parkinson's disease participate in clinical research. This is far short of the number of individuals that researchers anticipate will be needed over the next two to three years — potentially resulting in severe delays in

new treatments that could offer relief to those who live with Parkinson's disease.

In response to this concern, PDF convened a summit of the major Parkinson's disease groups in February 2004 to discuss the core components of an

awareness and education campaign devoted to clinical trials for potential Parkinson's disease treatments. Later that year, PDF launched *PDtrials*, a community initiative led by PDF in collaboration with the American Parkinson Disease Association, The Michael J. Fox Foundation for Parkinson's Research, the National Parkinson Foundation, the Parkinson's Action Network, The Parkinson Alliance and WE MOVE. The campaign is advised by representatives of the National



PDtrials
WWW.PDTRIALS.ORG

To learn about Parkinson's clinical trials, visit www.PDtrials.org or call (800) 801-9484.

EDUCATION


Institute of Neurological Disorders and Stroke (National Institutes of Health), the Parkinson Study Group, the Parkinson Pipeline Project and The Parkinson's Institute.

Accomplishments of this program to date include:

- creation of www.PDtrials.org, a website in English and Spanish that provides general information on clinical trials and a list of Parkinson's trials that are currently enrolling volunteers;
- development and distribution of a comprehensive set of print clinical trial educational materials;
- creation of the *PDtrials* Email Bulletin, a monthly clinical trial update.

One of the new initiatives of the project is outreach to general neurologists and other physicians, finding ways to encourage them to refer their patients to trials. Another is to study the problem "on the ground" in several targeted cities — beginning with Chicago and New York, taking advantage of PDF's strong local presence and office location.

The *PDtrials* coalition will also work to address the barriers to Parkinson's clinical trial participation among populations that are traditionally underrepresented, such as women and people of diverse racial and cultural backgrounds.



FOCUS on PDF Programs EDUCATION

- Providing information and support to people with Parkinson's, their families, caregivers and healthcare professionals through our Parkinson's Information Service (PINS), available by web, mail and telephone.
- Publishing and distributing a growing portfolio of educational materials that are available by request and through the PDF website (www.pdf.org).
- Updating our website with accurate and timely content to meet the needs of information-seekers.
- Leading the *PDtrials* awareness and education campaign for clinical trials of potential Parkinson's disease treatments.

WORLD Parkinson Congress

In 2004, PDF took the lead in creating an independent, non-profit organization, the World Parkinson Congress Inc., which staged the first-ever World Parkinson Congress (WPC) in Washington, DC, in February 2006. This unique venture, which combined the best of science with the best practices of Parkinson's care and education, won the support of more than 100 organizational partners in the United States and throughout the world, including strong support from the National Institutes of Health, the research programs of the Department of Defense, the Movement Disorder Society and dozens of patient-voluntary associations.

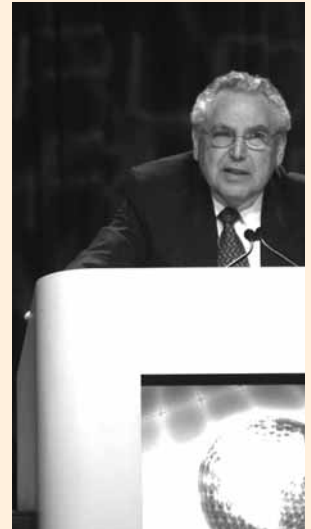
The unprecedented event drew more than 3,000 participants from 25 countries, including scientists, researchers, people living with Parkinson's, caregivers, members of the media and industry representatives.

PDF's leadership role included volunteering seed funding and providing space in our New York headquarters to host

with education and training, care initiatives and quality of life issues.

Another unique segment of the WPC was the Creativity and Parkinson's art exhibit that showcased the creative and artistic works of people with Parkinson's. The initiative was produced, directed and sponsored by PDF, and chaired by Oliver Sacks, M.D., author of [Awakenings](#).

The exhibition included works of art by 186 artists from 13 different countries. Behind each piece of artwork is a creative individual who, through determination and inspiration, defied the



Dr. Stanley Fahn delivers the welcoming remarks to a packed house at the WPC 2006 Opening Ceremonies.

"After five straight days of scientific and care delivery symposia, social gatherings, meetings and networking, I can testify that the WPC was a truly marvelous experience — both energizing and exhausting!"

– Jean B., Parkinson's advocate
Sun Lakes, AZ

the project's professional staff and volunteer committees. Dr. Stanley Fahn, PDF's Scientific Director, served as Chair of the WPC, and several members of our Board and professional staff served on key Congress committees.

A distinctive aspect of the Congress was its comprehensive scope, combining issues of medical and scientific research

challenges of living with Parkinson's disease. In 2007, PDF will be sponsoring seminars and forums to identify research projects involving quality of life issues. These studies may help us identify the potential benefits of quality of life research for people living with Parkinson's.

ADVOCACY

that champions the interests of the Parkinson's disease community with government, news media and industry.



ADVOCATING for the Interests of the PD Community

For more than a decade, the Parkinson's Disease Foundation has assumed the role of advocate on behalf of, and in collaboration with, people with Parkinson's, their families and caregivers. Our advocacy efforts take a variety of forms, such as representing the interests of the Parkinson's community with government leaders; supporting advocates in their individual efforts to influence change; facilitating conversations with researchers on clinical trial outcomes; working with news media on healthcare issues that affect those living with Parkinson's disease; and creating a formal place at the decision-making table for people with Parkinson's.

SECURING FEDERAL FUNDING FOR PARKINSON'S RESEARCH

PDF recognizes the tremendous role of the federal government in the funding of Parkinson's disease research, as well as on the healthcare policy issues that are so critical to the Parkinson's disease community. We also know that our community is best served when represented by a single voice before policy makers — be it in Congress, federal agencies or the White House. For this reason, PDF was the first Parkinson's organization to provide financial support to the Washington-based Parkinson's Action Network (PAN), the unified advocacy voice on federal funding and public policy issues. To this day one of PAN's most reliable and generous supporters, PDF contributed \$150,000 to PAN in 2006, and our Executive Director, Robin Elliott, serves on the organization's Board of Directors.

When PAN was created in the early 1990s, total NIH spending on Parkinson's research was estimated at just \$25 million, or about \$25 per patient (com-

pared with more than \$300 per patient in the area of heart disease). By 2004, in significant part because of the work of dedicated advocates and organizations such as PDF, NIH expenditures on Parkinson's had risen to \$250 million, or about \$250 per patient.

Another important focus for PAN has been identifying and expanding other sources of support for PD research in other agencies of the federal government, including the Department of Defense (DoD) and the Department of Veterans Affairs. One novel program is the Neurotoxin Exposure Treatment Research Program (NETRP), to which DoD allocates more than \$25 million a year to support innovative Parkinson's science.

THE PEOPLE WITH PARKINSON'S ADVISORY COUNCIL

In spring of 2006, PDF launched the People with Parkinson's Advisory Council (PPAC) to provide the perspective of the patient to our processes of program development and priority-setting.

Of the 14 founding members of PPAC, 11 are people living with Parkinson's disease and three are caregivers, with representatives from around the country. The professional backgrounds of these accomplished individuals include



ADVOCACY

social research, medicine, law, technology and writing.

The members of PPAC, who serve two-year terms, will provide PDF with perspectives on research-funding priorities and ways that we can better serve

disease is committed to identifying and overcoming barriers to the acceleration of clinical research through educational and advocacy efforts. In early 2007, PDF worked in collaboration with the Parkinson Pipeline Project to create and host a

*“I'm very excited about your new People with Parkinson's Advisory Council and once again applaud ... PDF for your **forward thinking and innovation.**”*

– Bill Bell, Executive Director
Northwest Parkinson's Foundation

people living with Parkinson's through our information and education programs. PPAC members will also represent PDF within the local Parkinson's community and attend relevant conferences and meetings.

THE PEOPLE WITH PARKINSON'S CLINICAL RESEARCH ADVOCACY INITIATIVE

In 2006, PDF created an initiative that provides technical consulting and financial support to clinical research advocacy projects that are led by people with Parkinson's. In the inaugural year of this initiative, PDF selected the Parkinson Pipeline Project as its focus. This group of people with Parkinson's

roundtable, Building Patient Trust: A New Era of Clinical Research Rights and Responsibilities. During the spring of 2007, Pipeline Project members will deliver presentations on the importance of clinical research at regional and local Parkinson's events.

THE FDA PATIENT CONSULTANT PROGRAM

PDF's support of the Parkinson Pipeline Project in earlier years was a major factor in the US Food and Drug Administration's (FDA) creation of a Patient Consultant Program for Parkinson's Disease. This program, which is managed by the Office of Special Health Issues, represents a growing effort by the FDA

INAUGURAL MEMBERS OF THE PEOPLE WITH PARKINSON'S ADVISORY COUNCIL

Carey Christensen Washington	Rhona Johnson Connecticut	Michael O'Leary Arizona	Bruce Talbot Vermont
Joy Dryfoos Massachusetts	Daniel Kiefer California	Lillian Snyder Illinois	James Trussell Georgia
David Eger New York	Jo-Anne Lazarus Wisconsin	Joanna Steichen New York	Ann Wasson Kentucky
Melinda Hermanns Texas	Meredith Mucha Ohio		


to seek out patient perspectives on the development of new therapies. The initial panel of three advisors includes PDF Board Member Marshall Loeb and PPAC Member David Eger, Ph.D.

SUPPORTING RESEARCH INVOLVING STEM CELLS

Not all the federal issues in Parkinson's have to do with money. One major issue for the PD community in recent years has been challenging the government's partial ban on federal support of research involving embryonic stem cells. These tiny "building blocks" of the body have the potential to develop into any one of a variety of tissues, ranging from cardiac tissue, to kidney cells, to specific brain cells, such as dopamine neurons.

The Bush Administration's decision in August 2001 to restrict federal research funding to a small number of stem cells sharply limited the opportunities available to scientists in pursuing a promising area of research. To combat this restriction, PDF and more than 80 other research advocacy organizations formed the Coalition for the Advancement of Medical Research (CAMR), a group dedicated to lifting restrictions on federal funding for stem-cell research.

On the state level in New York — the place of our founding and the center of our current operations — PDF has played a leading role. In 2003, we led the creation of New Yorkers for the Advancement of Medical Research (NYAMR), a coalition of New York State-based disease advocacy groups, university research centers and biotech industry leaders. These groups have assembled to achieve legislation that would affirm and support scientific research involving embryonic stem cells and other DNA therapies.



FOCUS on PDF Programs **ADVOCACY**

- Placing the interests of the Parkinson's disease community front and center with our government leaders to increase federal funding for Parkinson's research.
- Creating the People with Parkinson's Advisory Council to provide a formal place at the table within PDF for people with Parkinson's disease.
- Facilitating conversations with researchers on clinical trial outcomes.
- Reaching out to media on healthcare issues that affect people who live with Parkinson's to provide the PD community's perspective.

ADVOCACY

FINANCIAL REPORTS

In recognition of the integrity and prudence of its programs and finances, the Parkinson's Disease Foundation has been awarded the premier four-star rating by Charity Navigator and the Wise Giving Alliance of the Better Business Bureau (BBB) Charity Seal of Approval.



FINANCIAL Reports

Statement of Financial Position

June 30

	2006	2005
Assets		
Cash and cash equivalents	\$959,130	\$1,225,000
Contributions and other receivables	172,966	134,350
Other current assets	41,747	58,366
Investments, at fair value	10,922,447	11,765,634
Fixed assets, net	661,909	391,886
Other assets	361,331	361,331
Investments — restricted as to use	408,620	845,510
Total assets	\$13,528,150	\$14,782,077
Liabilities and net assets		
Accounts payable and accrued expenses	\$776,044	\$382,644
Grants payable	688,500	768,674
Deferred compensation plan	408,620	845,510
Total liabilities	1,873,164	1,996,828
Net assets		
Unrestricted	10,602,794	11,400,139
Temporarily restricted	1,052,192	1,385,110
Total net assets	11,654,986	12,785,249
Total liabilities and net assets	\$13,528,150	\$14,782,077

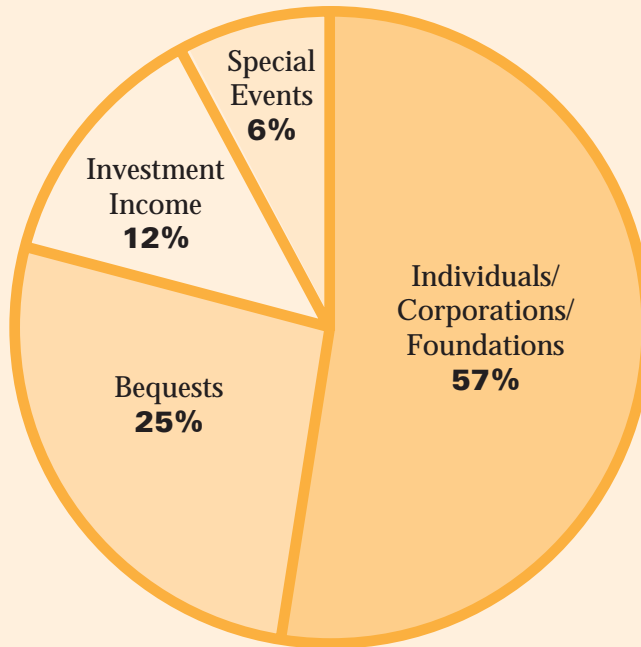
FINANCIAL REPORTS

Statement of Activities

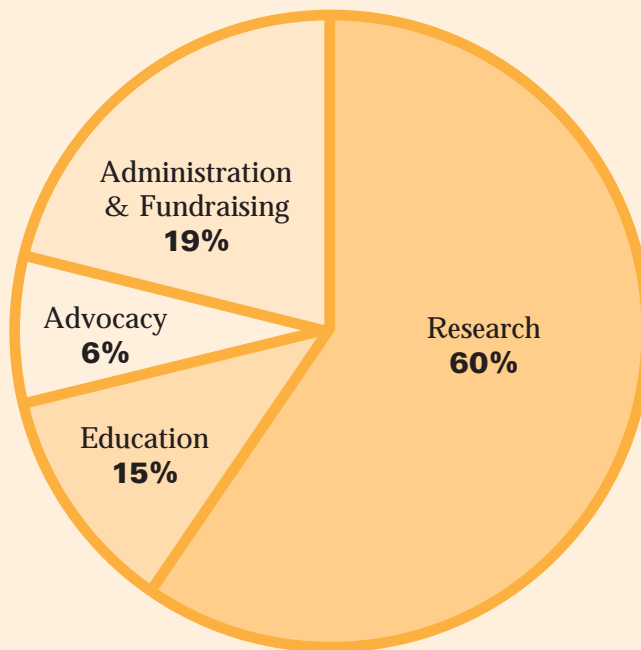
	Year ended June 30, 2006			Year ended June 30, 2005		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
Operating support and revenue and reclassifications:						
Contributions	\$4,072,159	\$77,234	\$4,149,393	\$3,671,265	\$963,779	\$4,635,044
Bequests	1,802,662	-	1,802,662	3,589,398	-	3,589,398
Special events	643,565	-	643,565	782,569	-	782,569
Direct benefit to donor costs	(228,478)	-	(228,478)	(262,567)	-	(262,567)
Net special events revenue	415,087	-	415,087	520,002	-	520,002
Investment income	956,638	-	956,638	436,362	-	436,362
Net assets released from restrictions	410,152	(410,152)	-	305,590	(305,590)	-
Total operating support and revenue and reclassifications	7,656,698	(332,918)	7,323,780	8,522,617	658,189	9,180,806
Operating expenses:						
Program services:						
Research	5,148,694	-	5,148,694	5,292,147	-	5,292,147
Public information/patient information and referral services	1,699,167	-	1,699,167	1,453,804	-	1,453,804
Total program services	6,847,861	-	6,847,861	6,745,951	-	6,745,951
Supporting services:						
Management and general	598,300	-	598,300	620,518	-	620,518
Fundraising	1,007,882	-	1,007,882	1,050,786	-	1,050,786
Total supporting services	1,606,182	-	1,606,182	1,671,304	-	1,671,304
Total operating expenses	8,454,043	-	8,454,043	8,417,255	-	8,417,255
Change in net assets	(797,345)	(332,918)	(1,130,263)	105,362	658,189	763,551
Net assets, beginning of year	11,400,139	1,385,110	12,785,249	11,294,777	726,921	12,021,698
Net assets, end of year	\$10,602,794	\$1,052,192	\$11,654,986	\$11,400,139	\$1,385,110	\$12,785,249

2006

WHERE Our Revenues Come From



HOW Our Funds Are Spent



FINANCIAL REPORTS

DONORS

The Parkinson's Disease Foundation is very grateful to the many individuals, foundations and corporations who have supported its work as a leader in Parkinson's disease research, education and public advocacy. Their contributions alone make PDF's achievements possible.



RECOGNITION of Donors

The following are the names of individuals, foundations and corporations who have made cumulative gifts of \$5,000 or more between January 1, 2001 and October 31, 2006.

Individuals

Anonymous	Thomas Constance	Leonore Greiman
Patricia Accolti-Gil Borek	Mr. & Mrs. Edward Costikyan	Mr. & Mrs. H. Doane Griffin
Lisette Ackerberg	Gabrielle & Roger Crandall	William Grover
Stephen & Marsha Ackerman	Pearl Curtis	Robert Gruber
Mr. & Mrs. Kenneth Aidekman	Mr. & Mrs. Richard Davimos	William Gruy
Ethel Strong Allen	Gary Davis	Mr. & Mrs. Thomas Guidness
Bruce Angiolillo	Aila Dawe	Ronda Guinardo
Daniel Armstrong	Marcel Dekker	Charles Hall
Mr. & Mrs. Terry Armstrong	Donald Desmond	Julia & Barney Hallingby
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Robert Benjamin	Dr. & Mrs. Stanley Fahn	Mr. & Mrs. Thomas Hubbard
Stephen Benjamin	Mr. & Mrs. Sal Falciglia	Deborah Huber
Sandye Berger	Annette Feldman	Michael Hyatt
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Richard & Amelia Bernstein	Mr. & Mrs. Stephen Flood	John Ismond
Mr. & Mrs. Daniel Bernstein	Alan J. & Tatyana Forman	Scott Jacobs
Daniel Beveridge	Dr. & Mrs. Craig Foster	Selwyn & Marjorie Jacobs
Howard Bisgeier	Mr. & Mrs. Ronald Frank	Harold Jaeger
Page Morton Black	Connie Frankino	Mary James
James Bobo	Jonathan Franzen	Mr. & Mrs. Alan Janoff
Jonathan Boucher	John Fuqua	Donald Johnson
Ruth Bowen	Sarah Belk Gambrell	Jason Johnson
Mr. & Mrs. R. Kelly Bowles	Barry Gantz	Mr. & Mrs. Harold Johnstone
Mr. & Mrs. Nicholas Bridges	Rocco Garrio	Robert Josephson
Jill Brodowitz	Elizabeth Geiser	Gerry Kaufman
Mr. & Mrs. Joe Brown	Joann Gerardi	Robert Kelter
Mr. & Mrs. Albert Brown	Adeline & Daniel Gersen	Allen Kezsbom
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Since its founding in 1957, PDF has funded almost \$70 million worth of scientific research in Parkinson's disease, supporting the work of leading scientists throughout the world. Generous contributions from donors help us continue to support this essential research to find a cure for Parkinson's. With these gifts, we can continue to fund groundbreaking research and bring quality services and materials to people who live with Parkinson's disease.

There are many ways in which individuals can support PDF's essential work. We welcome:

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In 2002, PDF lost a valued member of the Board — **Richard Zirinsky**, a leader in the New York real estate industry. We also have bid a fond farewell and thank you for many years of Board service to **Cynthia Flood**, **Laurette Soong Fung**, **Edward M. Kalikow**, **Edward P. Pazicky**, **Marcia Meehan Schaeffer** and **Earl Ubell**.

EVENTS that Support PDF

BAL DU PRINTEMPS

The Parkinson's Disease Foundation hosts an annual gala, *Bal du Printemps*, every spring at The Pierre Hotel in New York City. This event, which raises about \$500,000 annually to fund PDF's research programs, has been cultivated



Kathie Lee Gifford celebrates the success of *Bal du Printemps* with PDF Chairman Page Morton Black.

over the years by Page Morton Black, Chairman of the PDF Board and wife of the late William Black, founder of PDF and creator of the Chock full o'Nuts company.

The result of Mrs. Black's tireless work is an elegant and enjoyable affair, packed with people who join PDF in celebrating good deeds and funding good science. Attendees have included Madonna, Muhammad Ali, Frank and Kathie Lee Gifford and Lynn Redgrave.



Dr. Lewis Rowland (R), PDF Board President, presents Dr. Stanley Fahn (L) with the 2006 Page and William Black Lifetime Achievement Award.

The spirit of the evening is to celebrate the scientific leaders who advance Parkinson's research and the philanthropic leaders who make these advances possible with their generous financial

support. At the dinner, PDF recognizes and honors outstanding figures in the Parkinson's community.

PDF thanks the many people, including the Gala Chairs, Corporate Chairs and members of our Board, who have generously given their time over the years to make *Bal du Printemps* such a special night.



Board members Margo Catsimatidis, Isobel Robins Konecky and Domna Stanton, Ph.D. celebrate another successful gala in 2006.

Past honorees at the *Bal du Printemps* include:

- **Paul Greengard, Ph.D. and Arvid Carlsson, M.D., Ph.D.**
recipients of the 2000 Nobel Prize for Physiology or Medicine
- **Herbert Pardes, M.D.**
President and Chief Executive Officer, New York Presbyterian Hospital
- **Gerald D. Fischbach, M.D.**
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Professor of Neurology at Columbia University
- **Stanley Fahn, M.D.**
Chief of Movement Disorders at Columbia University and Scientific Director of PDF
- **Lukas Foss**
musician, conductor and composer

EVENTS

CARNAVAL AT THE COPA

In 2003, a new event was added to our fundraising calendar: *Carnaval at the Copa*. The brainchild and gift of Peter Dorn, a co-owner of the Copacabana nightclub and a PDF Board Member, the event is geared toward young, urban professionals who are looking for a fun evening while contributing to a great cause. Over the past three years, the event has raised more than \$650,000 for PDF's research programs.



2005 Copa Steering Committee Co-Chairs Doug Stern and Peter Dorn celebrate the evening's success with NBC's Bruce Beck (center), Master of Ceremonies for the event.

PARKINSON'S UNITY WALK

The Parkinson's Unity Walk, held each year in Central Park in New York City, raises funds for PDF and five other national Parkinson's organizations. Since 1994, thousands of members and friends of the Parkinson's community have turned out to "walk for Parkinson's" while raising awareness of the disease. Over the past six years, these walks have raised more than \$600,000 for PDF's research programs.



Bob Benjamin accepts the 2006 Alan Bonander Humanitarian Award for his work in Parkinson's advocacy and fundraising at the 12th Annual Parkinson's Unity Walk.

PDF CHAMPIONS

In 2006, PDF Champions was created to recognize our supporters and provide assistance to fundraising organizers. People who join PDF's fundraising efforts receive official PDF endorsement of the event, technical assistance, PDF materials and recognition on our website. From

holding bake sales to hosting dinner parties to running

a marathon, PDF Champions is the perfect way to join forces with PDF to raise funds for Parkinson's research! These events generated more than \$175,000 in 2006 and the program continues to grow.



Runners gather for the start of the 4th Annual Cursus Cerebro ("Race for the Brain"), an event created and organized by Sean Stewart of Westport, CT, to raise funds for Parkinson's research in his father's name.

PDF Grant Recipients

The Parkinson's Disease Foundation offers a diverse portfolio of awards to generate interest in Parkinson's research and patient care among younger scientists and clinicians. The following are recipients of our International Research Grants Program (IRGP) and Post-Doctoral Fellowship Programs for FY 2004 through FY 2007.

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**For this funding cycle, PDF was joined by the National Parkinson Foundation. Together, the two foundations awarded a total of \$1.2 million to 30 scientists.*

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