

Repairing the Parkinson's Pipeline

By Robin Elliott

A decade ago, hopes were high in the Parkinson's disease (PD) community. We were riding a new wave of research opportunities and many people — including scientists — were anticipating not only new treatments, but were also speculating that there could be a cure in as little as five to 10 years.

In contrast, today's seemingly widespread feelings of disappointment — in the pace of progress toward treating and understanding PD — make it difficult to remember the optimism of the 1990s.

To understand today's discontent, we must look backwards and ask: Why were we so confident then? There were several reasons.

Increased funding for medical research in general. Thanks to the efforts of a visionary bipartisan group in Congress and an effective coalition of universities and disease-advocacy groups, the budget of the National Institutes of Health (NIH) more than doubled in seven years — from \$11.9



billion in 1996 to \$27 billion in 2003.

Increased funding for Parkinson's research specifically. In 1997, President Clinton signed the Morris K. Udall Act for Parkinson's Research, which authorized up to \$100 million a year for PD research. Three years later, NIH issued the first Parkinson's Disease Research Agenda. These

events increased federal funding for PD research from about \$72 million in the mid-1990s (as estimated by the Parkinson's Action Network) to \$230 million in 2003.

The not-for-profit sector played its own part in the rise of research investments. A new

foundation created by Michael J. Fox in 2000 began injecting millions into PD research, while the established foundations (the Parkinson's Disease Foundation, the American Parkinson Disease Foundation and the National Parkinson Foundation), more than doubled their collective research investments between 1996 and 2006.

Advances in Parkinson's science and treatments. A new generation of

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NEWS IN BRIEF

High Uric Acid Levels Correlate with Slower PD Progression

Men living with Parkinson's disease (PD) who have naturally high blood levels of urate (uric acid), the agent that causes gout, may experience a slower progression of Parkinson's and its symptoms, according to a report in the April 14 online edition of *Archives of Neurology*.

Because urate is an antioxidant, similar in effects to ascorbic acid (Vitamin C), researchers speculate that it can prevent cell damage that results from oxidative stress, which is thought to contribute to PD.

Michael A. Schwarzschild, M.D., Ph.D., and researchers from Massachusetts General Hospital Institute for Neurodegenerative Disease (MGH-MIND) and Harvard School of Public Health (HSPH) performed a prospective study using data from a clinical trial (known as PRECEPT), which enrolled 804 participants between 2002 and 2004. All participants were newly diagnosed with PD at the start of the trial, and took no Parkinson's medication when their urate levels were first measured.

Dr. Schwarzschild and his colleagues compared participants' baseline urate lev-

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Bringing Leading Parkinson's Scientists to You

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els to the rate of their disease progression. Disease progression was determined by clinical evaluations as well as by a single photon emission computed tomography (or SPECT) scan that measured brain dopamine. The team found that men with the highest baseline levels of urate showed a slower progression of symptoms and required PD medication at approximately half the rate of those with lower baseline urate. According to the SPECT scans, the same group of men showed a slower decline of dopamine cells in the brain. Among women, who generally have lower urate levels than men, the study produced no significant findings.

For some time, scientists have been aware that high levels of urate are associated with a decreased risk of developing PD. The new study shows a correlation between urate levels and slower disease progression in men with early, mild PD.

Although no medication or vitamin has yet been shown to slow the rate of PD progression, the new study offers a new potential treatment approach: drugs that may have effects on urate and its precursors, such as inosine. The authors stress, however, that any benefits must be weighed against urate's potentially negative effects, such as high blood pressure, stroke, coronary disease, kidney stones, gout and arthritis. They advise people with PD to avoid taking urate supplements until more is known about the balance of its risks and benefits.

**Cell Transplants Survive Long Term and May Ease PD Symptoms**

Cell transplants used in the experimental treatment of Parkinson's disease (PD) may survive for many years and may improve some symptoms of the disease. According to three separate studies published in the April 6 issue of *Nature Medicine*, some brain cell implants may be vulnerable to the effects of PD, while others are not.

The first study, led by Olle Lindvall, M.D., Ph.D., and Patrik Brundin, M.D., Ph.D., of Wallenberg Neuroscience Center in Sweden, studied the brains of two people with PD who had received implants 12 and 16 years prior. Another study, led by Jeffrey H. Kordower, Ph.D., of Rush Univer-

sity Medical Center in Chicago, IL, examined the effects of grafted neurons in a person who had received the treatment 14 years earlier. In all three cases, the person with the implant had died and donated his or her brain to science.

In both studies, researchers found that the implanted cells had survived for up to 16 years. However, the transplants in both studies contained abnormal Lewy bodies — clumps of the protein alpha-synuclein that are a well-known sign of Parkinson's — implying that the disease had spread to the transplanted cells. This may have implications for future cell transplantation treatments, perhaps limiting the duration of time for which transplants remain effective.

Despite abnormal changes in the implanted cells, researchers noted that the majority of the cells were still functioning years later and some individuals had reported experiencing continuing relief from their Parkinson's symptoms.

A third investigation, by Ivar Mendez, M.D., Ph.D., F.R.C.S., of Dalhousie University in Halifax, Nova Scotia, and Ole Isacson, M.D., of Harvard Medical School in Boston, MA, examined the brains of five people with PD, who had received transplants between three and 14 years earlier. In contrast to the two other studies, this one found healthy-appearing, surviving transplant tissue, with no signs of Parkinson's.

To date, the number of people who have undergone brain cell implantation for Parkinson's is very small, and so no definitive conclusions can be drawn. Researchers remain hopeful about the potential of cell transplantation and will continue to study this technique as a means of treating PD.

**Parkinson's Patch Recalled in US**

On March 20, UCB Inc., announced a recall of all US and some European batches of Neupro® (rotigotine transdermal system), a treatment used to ease the symptoms of Parkinson's disease in its early stages.

Neupro is a dopamine agonist, a dopamine-like drug that shows the same effectiveness as other available agonists, such as pramipexole and ropinirole. The novel aspect of Neupro is its once-a-day application in the form of a skin patch.

Neupro was first approved for use in

the United States by the Food and Drug Administration (FDA) in May 2007 for people in early stages of PD. It is not known when and if the medication will be available again in the US, although it is still available in Europe, where the European Medicines Agency (EMA) has approved its use for those already on the medication (no new patients will be initiated on Neupro).

UCB has stated that the recall was due neither to safety concerns, like contamination or toxicity of the medication, nor to problems with the efficacy of the medication in its true form. Rather, regular monitoring of the patch revealed a problem in its manufacturing that deviated from the approved process. In some cases, this caused the medication to crystallize. Crystallization reduced the amount of the medication that was available to be absorbed through the skin, lowering its efficacy.

People who are using Neupro have been advised to contact their physicians to arrange for their doses to be reduced slowly over time. Sudden discontinuation of the treatment is not advised. Christopher Goetz, M.D., Director of the Parkinson's Disease Foundation Research Center at Rush University Medical Center in Chicago, IL, noted that physicians will likely recommend switching to another dopamine agonist in place of Neupro.

**Impaired Sense of Smell Signals PD Risk in Men**

An impaired sense of smell may be an early warning sign of developing Parkinson's disease (PD) among men, according to a study published in the February 2008 issue of the *Annals of Neurology*.

From 1991 to 1996, G. Webster Ross, M.D., and his team from the VA Pacific Islands Health Care System and the Pacific Health Research Institute in Honolulu, HI, followed 2,267 men (ages 71 to 95) through the Honolulu-Asia Aging Study (HAAS). All men were free of clinical Parkinson's and dementia at the start of the study. Researchers examined and rated participants' sense of smell on 12 odor test items, each with four choices.

Dr. Ross's team found that 35 of these men went on to develop Parkinson's dis-

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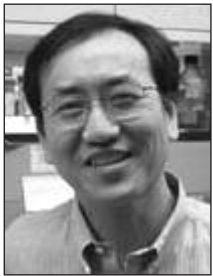
SPOTLIGHT

on Research

Supported by PDF

Un Jung Kang, M.D.

Dr. Un Jung Kang has a clear focus to his work: building a bridge between basic science discoveries and clinical practice.



Dr. Un Jung Kang

As a young researcher, he realized the importance of building bridges between areas of science and among scientists themselves. Now he uses this knowl-

edge in all of his roles — laboratory scientist, clinician, clinical trial investigator and teacher — to build bridges between science and real treatments for people living with Parkinson's disease (PD).

Early in his career, Dr. Kang used seed-grant funding from PDF to develop his theories about antioxidants and PD. These grants enabled him to gather enough data to win a larger and longer-term grant — an RO1 — from the National Institutes of Health (NIH) in 2003. Preparing an RO1 proposal requires significant preparatory research and outside funding. Dr. Kang told *News & Review*, "PDF funding of \$105,000 over three years became the seed to expand my research into a \$1.2 million research project for the next five years."

Dr. Kang continues to develop his ideas through what he calls multidisciplinary and translational approaches to PD. A neurologist by training, he performed his fellowship at Columbia University Medical Center under Stanley Fahn, M.D. His

current research at the University of Chicago Medical Center, which he joined in 1993, focuses on both the causes of PD and the motor complications of its therapies.

His PDF-funded studies focused on how environmental toxins lead to the damage of dopamine neurons by examining the vulnerability of these neurons to oxidative stress and mitochondrial disruption. His recent studies extend these findings by studying how certain genes contribute to the same destructive processes. The evolution of his research has made Dr. Kang an important contributor to our understanding of how environmental factors and genetics interact to cause PD.

Dr. Kang believes that his role as a clinician strengthens his work as a scientist, and vice versa. His clinical work led him to establish the University of Chicago Center for Parkinson's Disease and Movement Disorders, which brings together medical specialists to treat and research movement disorders.

He advances treatments by working to develop biomarkers — tools that would enable us to track PD's progress and evaluate potential treatments — and by participating in several late-stage clinical research studies. He also devotes considerable time to teaching and mentoring undergraduate, graduate and medical students, neurology residents and others.

Dr. Kang's experience demonstrates the importance of seed-grant programs. They help gifted young investigators to grow their careers, keep their interest in Parkinson's, and ensure that their innovative ideas are executed through the research pipeline. We look forward to seeing the new bridges between science and patient care that Dr. Kang will be building, and the mysteries his work will unveil.

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ease in the next eight years. The incidence of PD was highest among the group that demonstrated the poorest ability to identify odors on the initial tests. Specifically, researchers found that those men with the lowest scores were most likely to develop Parkinson's within four years of the tests.

These results build upon existing evidence that a poor sense of smell is common in people with Parkinson's and may be an early indicator of the disease, perhaps present even before motor symptoms emerge. However, most studies linking PD with an impaired sense of smell involve people who already have the disease. This study, a large investigation of people living in the general community, involved people with PD and their family members. It is the first study to demonstrate the development of PD in normal individuals who have an impaired sense of smell.

The authors noted that smell tests, "together with screening for other potential early indicators of PD such as constipation or sleep disturbances, could provide a simple and relatively economical means of identifying individuals at high risk for developing PD who could participate in trials of medications designed to prevent or slow disease progression."

It is important to note that the research involved only men whose average age was nearly 80 at the start of the study. It is not known whether the study's conclusions would hold true for women, or for younger individuals. Additionally, there are many other causes for a decreased sense of smell, including coffee intake, cigarette smoking, and the aging process itself.

For the latest in Parkinson's news, visit www.pdf.org.

Dr. Kang is Associate Professor and Associate Chair for Clinical Affairs in Neurology and Director of the University of Chicago Center for Parkinson's Disease and Movement Disorders. Between 1986 and 2003, he received five PDF grants, which totaled \$280,000.

Repairing the Parkinson's Pipeline

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dopamine agonists (pramipexole and ropinirole) and a new surgery — deep brain stimulation (DBS) — promised more effective relief of several PD symptoms. In addition, impressive strides were made in the basic science of Parkinson's. Just one example: the first gene to be linked to PD appeared in 1997. A decade later, we had as many as 12 genes.

The activities of a powerful group of celebrities with Parkinson's.

Muhammad Ali, US Attorney General Janet Reno and actor Michael J. Fox were ready not just to “go public,” but to roll up their sleeves for the fight to support PD research.

Setbacks and Slowdowns

Today, our optimism in new treatments seems to have waned. We have observed treatment breakthroughs become few and far between, seen that new drugs that do move through the pipeline are fewer and less successful, and watched funding for basic and translational science drop. Our observations are supported by a startling statistic: the number of new molecular entities approved by the US Food and Drug Administration fell from 53 in 1996 to just 18 a decade later.

In 2004, the trial of GDNF, a promising growth factor, was abruptly halted for what its sponsors and investigators said was failure to show efficacy. In the same year, a trial of CEP-1347 was abandoned for similar reasons. In 2006, two other potential treatments were dropped — first Sarizotan, an anti-dyskinesia medication, and then GPI 1485, a treatment that the developer hoped would help regenerate damaged nerve cells.

In February of this year, the manufacturer of istradefylline, another experimental treatment, received a “Not Approvable” letter from the FDA and the company thereupon issued a letter indicating that it was suspending further development of the drug. On

March 20, a long-awaited dopamine-agonist patch had to be recalled by its manufacturer because of production errors that reduced its efficacy.

We all know that the progress of science is checkered with setbacks, disappointments and blind alleys, but it does seem that there has been a string of them lately, and people are understandably disappointed. Certainly there remain some very interesting potential Parkinson's treatments making their way through the pipeline — including three separate gene therapy initiatives — but definitive results remain years away.

While disappointments in drug development accumulate, we have seen federal support of basic and translational research falter. At the NIH, after five years of unprecedented growth, funding first flattened out, then — corrected for inflation — actually dipped. The NIH budget in FY2008 is \$29.465 billion — an increase of less than one-half of one percent above the level of the previous year. Meanwhile, funding for Parkinson's research at the Department of Defense was cut from \$26.5 million in 2007 to \$20 million in 2008.

One result of the decline in NIH funding has been a sharp drop in the number of PD applications that get funded. The success percentage among grant applicants to the National Institute of Neurological Disorders and Stroke (NINDS) — where most PD research is funded — dropped from 25 percent in 2003 to just nine percent in 2007.

Looking Ahead

How do we turn this situation around? Just as the process of drug development is multi-dimensional, so is its solution. It is not just a matter of spending more money, or reengineering the philosophy of research, or changing the political culture in which it operates; it is all of these, and more.

On the level of basic research, we need to give the NIH resources to

build the knowledge infrastructure on which drug development depends. Unfortunately, in the current presidential campaign, other than a good statement of principle on the website of Senator Barack Obama, discussion of medical research, and in particular funding for NIH, has been virtually nonexistent.

Moving further along the pipeline, we need to “bridge the gap” — that stretch between basic science discoveries and successful drug development, where such discoveries get stuck on the shelf rather than explored by biotech and pharmaceutical companies. Therefore, we need to both encourage NIH to reach *forward* in the process (that is, to fund more translational research) and to identify incentives to encourage biotech and pharmaceutical companies to reach *back* (that is, investing in earlier stages of drug development). Encouraging companies to do so may include exploring ways of subsidizing their risk (as the Fox Foundation is trying to do). Part of this may involve taking a hard look at tort law and assessing the role that class actions — not all certainly, but those of the nuisance variety — may play in increasing risk aversion among companies, that in turn can slow drug development.

We need to ensure that medications that do make it to market are both safe and available by insuring that the FDA has sufficient funding to do its job effectively and that the regulatory process properly balances the protection of public health with the expeditious testing and processing of potentially life-saving treatments.

We need to re-examine the way we go about chasing cures, beginning by reviewing the very philosophy of the drug development process. As Greg Simon, CEO of Faster Cures, has written: we should be “more strategic about how resources are used; address the growing gap in the research continuum between basic

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Resources for People with Parkinson's

If you or a loved one has Parkinson's disease (PD), you may often find yourself looking for guidance on how to save on medications, locate a local exercise class, or modify your home because of the physical challenges presented by the disease.

There are resources specifically designed to assist you with these tasks. Many are geared toward people age 62 and older, while others serve to help people with disabilities and their families. Below, we have listed a sampling of some that we most often reference through our Parkinson's Information Services (PINS).

Community Resources

If you are interested in accessing local community resources, you may wish to tap into the services of your local Agency on Aging (AoA). It can assist with such challenges as finding senior volunteer programs and community exercise groups, accessing Meals-on-Wheels and obtaining senior transportation. An AoA can often provide you with guidance and counseling on Medicare rules, in-home care and reverse mortgages and offer help with rebate checks and tax preparation (some even have AARP trained accountants that will do free basic tax preparation). An AoA may also may organize community social activities, such as group trips to the theater or luncheons. To find the office closest to you, contact AoA Eldercare at (800) 677-1116 or visit www.eldercare.gov.

Legal Advice

Another resource for older or disabled persons is the "Elder Law" Attorney, who can optimize resources to give clients the best quality of life. He or she can help with concerns about

such matters as long-term care planning, in-home care resources, disability benefits, as well as pertinent provisions of the laws in your state. Keep in mind that an elder law attorney normally focuses specifically on one area of law, such as medical decision-making or estate tax and gift tax planning. The National Academy of Elder Law Attorneys (NAELA) offers a comprehensive list of the elder law attorneys in the US, searchable by state. To find an attorney, contact NAELA at (520) 881-4005 or visit www.naela.org.

Home Accommodation

If you are a homeowner who is interested in making necessary modifications and repairs, you may wish to contact Rebuilding Together. This nonprofit organization can implement handrails, ramps, non-slip surfaces on steps and more. To qualify for assistance, you must be a low income homeowner and either a senior, a person with a disability or someone raising a family with children. Rebuilding Together operates 225 affiliates throughout the US. To find the affiliate closest to you, contact (800) 473-4229 or visit www.rebuildingtogether.org.

Employment Assistance

If you need advice on how Parkinson's may affect your employment, the Job Accommodation Network (JAN) is available to assist you. JAN is a no-cost job consulting program designed to help people adapt their job skills to their current employment settings and to increase the employability of people with disabilities. A service the Office of Disability Employment Policy (ODEP) of the US Department of Labor, JAN can help

you individualize physical work settings (by suggesting what are termed 'accommodation solutions' — e.g., creating an ergonomic workstation). JAN also offers technical assistance regarding the American Disabilities Act (ADA) and other disability related legislation and helps callers identify options for self-employment. Contact JAN at (800) 526-7234 or www.jan.wvu.edu.

Medication and Equipment Costs

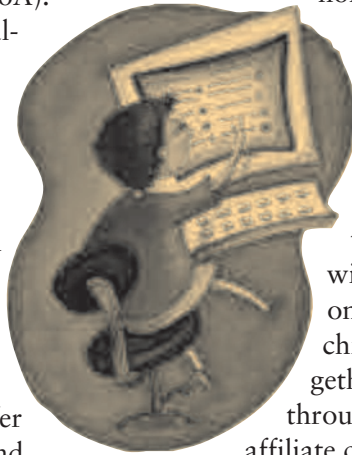
You may need financial assistance for medications or equipment. Most pharmaceutical companies that manufacture PD medications offer limited drug assistance programs for the medically needy. Eligibility requirements for these programs can vary and often they are best accessed through your doctor. To learn more, visit, www.pdf.org/AboutPD/med_treatment.cfm#anchor4.

The Melvin Weinstein Parkinson's Foundation (MWPf) provides help to people with PD experiencing financial difficulty, by providing eligible applicants with much needed durable medical equipment or other quality of life resources. To find out if you qualify for assistance, contact MWPf at (757) 313-9729 or visit www.mwpcf.org.

If you need more information on other national and local resources, please call our Parkinson's Information Service (PINS) at (800) 457-6676, or email info@pdf.org. We will do our best to find the resources you need to live well with PD.

Coming Soon ...

In January 2009, PDF plans to publish a comprehensive print and online Parkinson's Disease Resource Guide to help you locate the services that you need to live better with PD. Check our next newsletter and website, www.pdf.org, for details.



PDF Awards \$950,000 in Seed Grants

The Parkinson's Disease Foundation (PDF) is pleased to announce awards of \$950,000 toward its 2008-2009 International Research Grants and Fellowship Program (IRGFP). The funding will support the research of 19 Parkinson's scientists, chosen on April 11 from a group of almost 100 candidates by a scientific review committee led by Stanley Fahn, M.D., PDF's Scientific Director.

This year's outstanding awardees, who hail from around the world, include two who are investigating paths to new potential therapies for Parkinson's disease (PD).

Matthew Goldberg, Ph.D., of the UT Southwestern Medical Center at Dallas, TX, now in his second year as a recipient of IRGFP funding, continues his quest to develop an "animal model" for PD — one that would reproduce the age-dependent progressive loss of dopamine-producing

neurons that underlies the primary symptoms of Parkinson's.

"It is a great honor to be awarded this IRGFP grant," said Dr. Goldberg. "With the support of PDF, we are able to tackle some of the greatest challenges in Parkinson's research: understanding why dopamine neurons progressively die, and developing laboratory animals that spontaneously undergo progressive dopamine neuron loss by similar mechanisms. This would provide an enormously valuable tool for discovering and testing neuroprotective therapies for Parkinson's disease."

Because human clinical trials are very expensive and time-consuming, laboratory animals are needed to rapidly test novel treatments that might slow down or prevent the progressive loss of dopamine-producing neurons that results in Parkinson's. The lack of adequate animal models of pro-

gressive neuron loss in the area of the brain most affected in Parkinson's (known as the substantia nigra) has been a major impediment to discovering better treatments for PD.

To address this problem, Dr. Goldberg is working on a new animal model based on the hypothesis that oxidative stress causes PD. He proposes that laboratory mice that are deficient in certain protective antioxidant enzymes, such as superoxide dismutase, in combination with mutations in the genes DJ-1 and Parkin (linked to familial PD), will experience progressive loss of dopamine neurons and other features of PD.

In research of potential treatments, it is important not only to have the means to explore them, as Dr. Goldberg is doing, but to have tangible theories for how they work. This is the focus of the research of Sandra M. Lynch, Ph.D., M.Sc., M.B.A., of the Wadsworth Center of the New York State Department of Health.

2008 – 2009 IRGFP Awardees

PDF congratulates this year's IRGFP grant recipients:

Zdenek Berger, Ph.D.

Brigham and Women's Hospital
Boston, MA

C. Savio Chan, Ph.D.

Northwestern University
Chicago, IL

Alessandra Chesi, Ph.D.

University of Pennsylvania
Philadelphia, PA

Simone Engelender, M.D., Ph.D.

Technion-Israel Institute of Technology
Haifa, Israel

Matthew Goldberg, Ph.D.

University of Texas Southwestern
Medical Center
Dallas, TX

Ledia F. Hernandez, Ph.D.

Massachusetts Institute of Technology
Cambridge, MA

Michael Higley, M.D., Ph.D.

Harvard Medical School
Boston, MA

David Hinkle, M.D., Ph.D.

University of Pittsburgh School
of Medicine
Pittsburgh, PA

Milan Joksimovic, Ph.D.

Northwestern University
Chicago, IL

Sandra Lynch, Ph.D., M.Sc., M.B.A.

Wadsworth Center, New York State
Department of Health
Albany, NY

Alison McCormack, Ph.D.

The Parkinson's Institute and
Clinical Center
Sunnyvale, CA

Carlos Moraes, Ph.D.

University of Miami
Miami, FL

David Park, Ph.D.

Ottawa Health Research Institute
Ottawa, Canada

Jean-Christophe Rochet, Ph.D.

Purdue University
West Lafayette, IN

Enrique Torre, Ph.D.

Emory University School of Medicine
Atlanta, GA

Shaji Theodore, Ph.D.

University of Alabama-Birmingham
Birmingham, AL

Carles Vilariño-Güell, Ph.D.

Mayo Clinic Jacksonville
Jacksonville, FL

Georg Vogler, Ph.D.

Burnham Institute for Medical Research
La Jolla, CA

Wenbo Zhou, Ph.D.

University of Colorado-Denver
Denver, CO

Dr. Lynch will be using her grant from PDF to explore a variant of antibodies known as “intrabodies” (called such, because they perform work inside of cells) as a potential treatment for people with PD.

She plans to engineer these intrabodies to see if they prevent clumping of the protein alpha-synuclein, which leads to the formation of Lewy bodies — already known as a hallmark of PD. Researchers believe that destroying the clumping of alpha-synuclein may stop the disease in its tracks.

Dr. Lynch is hopeful that her efforts will have high potential to move to clinical trials because past evidence has shown antibodies to be effective therapies for other diseases. In Parkinson’s models, recent research has revealed that intrabodies can indeed inhibit protein aggregation and toxicity. Dr. Lynch sees the possibility that eventually, engineered intrabodies may be found to halt the loss of dopaminergic neurons in people

with Parkinson’s disease.

Of this year’s IRGFP recipients, PDF Scientific Director, Dr. Stanley Fahn said, “PDF is pleased to have another strong pool of candidates who are focused on understanding and treating Parkinson’s. Today, unfortunately, funding for science through the National Institutes of Health (NIH) trails the rate of inflation. This means that programs such as the IRGFP are increasingly important — especially for young investigators whose track record for federal funding is not yet well established and whose opportunities for funding are dwindling.”

The IRGFP is part of PDF’s four-pronged approach to funding Parkinson science. In fiscal year 2009, PDF will contribute more than \$4.8 million to support Parkinson’s disease research. Since 1957, PDF has funded over \$70 million worth of scientific research in Parkinson’s disease, supporting the work of leading scientists throughout the world.

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discovery and commercial development; foster collaborations; and apply some management to the science that can help drive progress along the continuum.”

We need to improve the clinical research enterprise, by raising levels of awareness, trust and participation in the process — among doctors as well as people with PD. Current barriers include low levels of public awareness of what trials are available, and where; the failure of doctors to educate people with PD about the opportunity to participate in clinical research; and the breakdown in trust that can occur when industry sponsors exhibit cavalier behavior towards trial participants. (These and related issues are the focus of PDF’s Advancing Parkinson’s Therapies Programs (APT)). A key concept in this thinking is to see the person with PD as a central agent of change in the clinical research process.

And we need to expect that private foundations like PDF take advantage of their natural nimbleness to build boldly on traditional commitments (for example, the long-term support of Columbia University and other leading research centers that is the core of PDF’s research funding) to fund important new research in innovative new ways — especially in the areas where government and businesses, for whatever reasons, are not providing the support that is needed.

The revolution in molecular biology, genetics and other areas of science has revealed opportunities for new treatments that would have been almost unimaginable a half-century ago. Now we need to muster the political will, capitalist ingenuity and social imagination to take advantage of them.

Robin Elliott is the Executive Director of the Parkinson’s Disease Foundation (PDF).

Relaunched Website Empowers People Seeking PD Clinical Trials

A relaunched website, www.PDtrials.org, can help you and your family members learn about clinical trials — the phase of research so vital to developing new therapies for Parkinson’s disease (PD).

Originally launched in 2004, the site lists information about 60 clinical trials across the US that are currently enrolling participants.

The site will make it easier for potential participants, including family members and others who do not have PD, to locate trials close to home, or to find a trial by searching for a specific symptom or by keyword.

The website also includes clinical research news, educational infor-

mation and personal stories from people who have participated in trials. The entire website is available in English and in Spanish.

PDtrials is 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 the National Institute of Neurological Disorders and Stroke (National Institutes of Health), the Parkinson Study Group, the Parkinson Pipeline Project and The Parkinson’s Institute and Clinical Center.

PDtrials
WWW.PDTRIALS.ORG

Watch Top PD Researchers on the Web!

PDF invites people with Parkinson's disease (PD), family members and allied health professionals to "Mind, Mood and Body: Understanding Non-motor Symptoms of PD," an educational symposium to be webcast on Friday, July 18 from Lansing, MI.

Not in your neighborhood? No problem! You can watch the event — live or later — on the web, for free!

This event is the second in a four-part series entitled, *Parkinson's Science: Innovations and New Perspectives*, that is bringing Parkinson's disease experts to four US cities to discuss the latest advances in research and treatments.

The Lansing symposium is being presented in collaboration with the Michigan Parkinson Foundation (MPF). The faculty includes Ronald Pfeiffer, M.D., of the University of Tennessee Health Science Center who will discuss, "When Parkinson's Interferes with Gastrointestinal, Urological, Sexual and Other Functions," and Matthew Menza, M.D., of the Robert Wood Johnson Medical School who will address, "Emotional and Cognitive Aspects of Parkinson's Disease." Peter LeWitt, M.D., of Henry Ford Hospital, will lead a panel discussion featuring three respected local movement disorders specialists: Doree Ann V. Espiritu, M.D., of Henry Ford Hospital; Edwin

B. George, M.D., Ph.D., of Wayne State University School of Medicine; and John L. Goudreau, D.O., Ph.D., of Michigan State University.

Debby Orloff, CEO of MPF, notes, "We are pleased to welcome some of the leading Parkinson's researchers in the US and the top clinicians in Michigan to this event. We look forward to hearing valuable insights on how people with PD can better manage nonmotor symptoms, which are increasingly recognized as having as much, if not more, of an impact on daily life than Parkinson's motor symptoms."

PDF Executive Director, Robin Elliott adds, "PDF and MPF seek to provide the PD community with access to up-to-date information about research, disease management and treatments. We hope that by making this webcast available on the web, 24 hours a day, seven days a week, those who cannot easily attend meetings can join us online and learn ways to improve their daily lives."

The first webcast, "What's in the PD Pipeline?," took place in Charlotte, NC on May 9. A live audience and webcast viewers provided lively interaction with three distinguished speakers, who discussed the role of genetics in PD and new potential treatments in the pipeline.

▶ PDWEBCAST

Registration Now Open:

Mind, Mood and Body: Understanding Nonmotor Symptoms of PD*

Friday, July 18, 2008

Lansing, MI

With the Michigan Parkinson Foundation

Archived Webcasts Now Available:

What's in the PD Pipeline?*

Presented in Charlotte, NC
With the Parkinson Association of the Carolinas

50th Anniversary Educational Symposium**

Presented in New York, NY
Hosted by PDF

Future Webcasts:

Surgical Advances, DBS and Parkinson's Disease*

Saturday, October 11, 2008
Spokane, WA

With the Northwest Parkinson's Foundation

Quality of Life and Parkinson's Disease*

Saturday, April 4, 2009
Houston, TX

With the Houston Area Parkinson Society

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PDF Team Launched at 14th Unity Walk

By **Bruce Talbot**

“I was blown away by the experience,” Carey Christensen said. “Joined by my daughter, step-daughter and their dad, never before had I been in the midst of so many thousands all united for the PD cause. I have never felt more at home.”

Carey, a member of the Parkinson’s Disease Foundation’s (PDF’s) People with Parkinson’s Advisory Council (PPAC) who hails from the Seattle area, had wanted to participate in the Parkinson’s Unity Walk ever since she was diagnosed nine years ago, but the trip proved too costly. This year, she made it.

She, along with 25 other members of PPAC, the PDF staff and PDF’s Board of Directors, and myself as the elected team Captain, formed PDF’s first Unity Walk team, the “PDF Pacers.” The day was perfect for the two-mile walk thorough New York’s Central Park, where our team joined over 10,000 people with Parkinson’s, families, friends and supporters.

What moved the walkers the most was the camaraderie with thousands

like themselves who live with Parkinson’s disease (PD). Joanna Steichen, another PPAC member, summed up these sentiments when she said, “I realized that I had received a wonderful gift: to spend two hours with bright, interesting, opinionated people who



The author (and team Captain) Bruce Talbot (back row center) and other members of the inaugural “PDF Pacers” team, at the finish of the Parkinson’s Unity Walk in NYC.

understood and accepted without explanation all of our different physical quirks.”

The annual walk gives 100 percent of money raised to the research programs of seven US Parkinson’s organizations. PDF Executive Director Robin Elliott noted, “PDF has been a happy and grateful beneficiary of the

walk since its beginnings in 1994 when Margot Zobel and Ken Aidekman rounded up a couple of hundred brave souls to march through Manhattan’s Riverside Park and raise a few thousand dollars for Parkinson’s research. How far we have come since those days!”

The Pacers team, with a modest first-year goal of \$1,000, ended up raising almost \$5,000 towards the total proceeds of \$1.8 million — a record. (The Pacers’ goal next year: \$10,000!).

While these numbers are important, they barely capture the spirit of the event. Joanna wasn’t sure she was up to the challenge, but with the help of a walker she completed the entire route. “Exhausted, empowered by sheer will,” she said, “we shuffled to the finish line. Though tired, I felt an exuberance that had been missing for a long time.”

And that — at least if not more than the money — is what the Unity Walk is all about.

Bruce Talbot is a member of PDF’s People with Parkinson’s Advisory Council. He lives with his family in Moretown, Vermont.

Order Your **FREE** Educational Materials from PDF!

PDF offers educational materials to help you, your family and your community understand Parkinson’s and take an active role in your life with it. Order your copies today:

The PDF Introductory Packet

Contains a comprehensive selection of the materials listed here and recent issues of the *PDF News & Review*.

Parkinson’s Disease Q&A

Answers the most frequently-asked questions about Parkinson’s disease symptoms, treatments and research.

Fact Sheets

Our 5 most popular fact sheets discuss your concerns about nutrition, exercise and more, providing tips on how to improve daily life with PD.

Web Resources for People with Parkinson’s

Lists resources on the web that can help you understand PD and its treatments, learn more about coping and caregiving and put you in touch with other people with Parkinson’s.

Diagnosis Parkinson’s Disease: You are not alone (Video & Booklet)

Designed for the person newly diagnosed, the booklet and video include testimony from medical experts and from people who have dealt with the diagnosis of PD.

La Enfermedad de Parkinson: Preguntas y Respuestas

Nuestro popular folleto esta ahora disponible en Español, para responder la mayoría de las preguntas mas frecuentes acerca de la enfermedad de PD.

Deep Brain Stimulation for Parkinson’s Disease

Discusses deep brain stimulation (DBS) — the procedure, its history and risks — and answers frequently-asked questions.

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AROUND & ABOUT THE COMMUNITY

Spring Events Raise Close to \$1 Million for PDF's Research Programs

This has been a busy spring for the Parkinson's Disease Foundation (PDF). PDF's two main New York City-based events — made possible by



Dr. Lewis P. Rowland (left) and PDF Scientific Director Dr. Stanley Fahn (right).

the help of generous volunteer leaders and participants — were *Bal du Printemps*, our annual gala, and *Celebrate Spring!*, a new event designed to involve young professionals. Together, the events generated a gross of \$987,000 (about \$750,000 net) to support Parkinson's disease (PD) research!

Bal du Printemps

On May 14, PDF welcomed 450 guests to the Pierre Hotel for its annual gala, *Bal du Printemps*.

This year's event highlighted the theme of creativity in Parkinson's — as an expression of the talent and imagination in our community, and as a form of therapy for many of those who live with this chronic, degenerative disease. The theme was evident throughout the evening, from the honoring of Oliver Sacks, M.D., F.R.C.P., to the displays of numerous and varied works of art — paintings, photography, pottery and jewelry — created by people with Parkinson's.

The dinner program began with the presentation of the Isobel Robins Konecky Creativity Award to Dr. Sacks, who also served as the evening's guest speaker. Dr. Sacks, the author of *Awakenings*, which became an

iconic movie about Parkinson's disease, and most recently of another best-seller, *Musicophilia*, spoke powerfully about the therapeutic role of creativity in Parkinson's.

The evening featured two other award presentations: the Page and William Black Humanitarian Award, to long-time supporters Mel and Carol Taub and their family, and the Lifetime Achievement Award, to Lewis P. Rowland, M.D., PDF's president for more than 35 years.

Mr. and Mrs. Taub, along with their daughters Stefani ("Stevi") Gurkoff and Jill Taub Drury, and other family members and friends, have a long history of service to



Dr. Oliver Sacks (left) accepts the Isobel Robins Konecky Creativity Award from Gala Dinner Chairman, John Connolly, Ed.D. (right).

Parkinson's science through their support of PDF — most notably, in their recent leadership of a successful \$6 million fund drive to modernize the Parkinson's disease research laboratories at Columbia University Medical Center. The award was made by Lucien Côté, M.D., a beloved Columbia neurologist, and was accepted touchingly in remarks by Stevi and Jill.

Dr. Rowland was introduced by Stanley Fahn, M.D., PDF's Scientific Director and Dr. Rowland's protégé of four decades ago. Dr. Fahn lauded his mentor for his incredible commitment to PDF and his outstanding leadership in the science and practice of neurology at Columbia University

and in professional associations around the world. As Chair of the Department of Neurology for more than 25 years, Dr. Rowland played the leading role in building the de-



Mel and Carol Taub (right and second from left) and their family, were honored for their contributions to PDF. Their daughters Stevi Gurkoff (left) and Jill Taub Drury (second from right) helped lead the event to record proceeds.

partment into the international powerhouse that it remains today.

Artist Peter Thompson, a person living with Parkinson's who is active with PDF's PDCreativity project, not only attended the event but contributed several works of art to the silent auction. He said of the evening, "I felt very honored to have my photos chosen, to see the artwork of people with Parkinson's displayed so prominently throughout the night and to be in the presence of Dr. Sacks. In putting emphasis on creativity, the gala truly celebrated a positive tool of empowerment for people with PD."

The 2008 event brought in a record breaking \$887,000 for PDF's research programs. PDF thanks this year's gala leadership for making this possible: Honorary Chairs Page Morton Black, Amy Goldman and Judith Sulzberger, M.D.; Gala Co-Chairs Karen Burke Goulandris, M.D., Ph.D., and Isobel Robins Konecky; Dinner Chair, John Connolly, Ed.D., and Auction Chair Arlene Levine.

Celebrate Spring!

On April 3, PDF was joined by more than 500 party-goers at Cipriani 23rd Street for its first *Celebrate*

Janet Charles

Janet Charles

Janet Charles

AROUND & ABOUT THE COMMUNITY

Spring! event, an evening that included cocktails and dancing.

The event was the creation of G. Pennington Egbert III, his sister Melissa Egbert Sheehan, and their close friend Georgina B. Schaeffer. Both of their fathers lived with Parkinson's disease and Georgina's mother was a long-time member of the PDF Board of Directors. The three joined together to advance a cure for PD and to engage their fellow New Yorkers in the cause — hence the creation of the Young New Yorkers for the Fight Against Parkinson's Committee, now 100 members strong.

The group kicked off their cre-

ation with *Celebrate Spring!*, which raised nearly \$100,000 for Parkinson's research. Based on the success

Chance Yeh



Co-Chair, Georgina B. Schaeffer (third from right) and friends "Celebrate Spring!" at the first annual event by that name.

of this first event, the committee is already making plans for the second

Celebrate Spring! in April of 2009.

PDF's Executive Director, Robin Elliott, noted, "PDF is just delighted to join hands with this vigorous group of young professionals who are committed to fighting Parkinson's. We are pleased to announce that all funds raised from this event will be directed to PDF's research program — in particular, at the Committee's request, to research projects in the area of genetics that have been identified by Dr. Lucien Côté, a valued and long-time friend of PDF."

PDF thanks its volunteer committees for making these events possible!

pdfchampions in action

13.1 Miles for Mom

As Karen and Brian Staron prepared to run their first half-marathon, they knew it would be a challenge. For Karen, however, who has watched her mom live with Parkinson's disease (PD) for over 25 years, the training was "nothing compared to the challenges that my mom faces daily, and has faced almost my whole life."

Karen's mom, LaVerne, was diagnosed with Parkinson's in 1981 at the age of 43, when Karen was only six years old. Karen and her four brothers grew up with Parkinson's as a part of their daily lives.

When the households of Karen and her mother merged three years ago, Karen experienced in greater depth the daily realities of PD, such as the complexity of managing medications. This only further increased her admiration of her mother's spirit.

Karen and Brian knew that friends were developing a new local

half-marathon — the Palos Bank Southwest Half Marathon — that would run through the nearby south side of Chicago. When 2008 was announced as the year for its launch,



Karen Staron (left) and her husband Brian (right) with Karen's mother LaVerne, celebrating \$2,626 raised for Parkinson's research in LaVerne's honor!

Karen and Brian decided to combine their running goal with raising funds for a very personal cause — Parkinson's — in honor of LaVerne.

By the time Karen and Brian completed the race on Sunday, May 4th, they had raised an impressive \$2,626

for PDF's research programs — more than double their original goal!

PDF would like to thank Karen and Brian for their efforts to raise funds and awareness for PD!

Join the PDF Champions Marathon Team!

Are you inspired by Karen and Brian's story? If you would like to raise money for Parkinson's research and run in one of the world's major marathons, please consider joining the PDF Champions Team. We still have a few spots left for the Berlin and Chicago Marathons (on September 28 and on October 12, respectively).

By participating in the PDF Champions program, you will have access to online training programs, personalized web pages, gear, fund-raising tips and assistance from PDF staff. Runners who choose to take on this challenge, will commit to raising a minimum of \$2,500 for PDF.

If you are interested, please contact Patrick Johnson at info@pdf.org or (800) 457-6676.

Calendar of Events



Seattle to Portland Bicycle Classic

Date: Saturday, July 12 – Sunday, July 13

Place: Seattle, WA to Portland, OR

The Northwest Parkinson's Foundation is seeking riders and volunteers for the Group Health Seattle to Portland Bicycle Classic. Riders raise funds for quality of life programs and services for people living with Parkinson's. Registration costs vary.

For more information, contact Bill Bell at bbell@nwpf.org or call (877) 980-7500.

PDWEBCAST Mind, Mood and Body: Understanding Nonmotor Symptoms of PD

Date: Friday, July 18

Place: Lansing Radisson Hotel
Lansing, MI

PDF and the Michigan Parkinson Foundation present an educational symposium and webcast for people with Parkinson's, their families and health professionals. The event will feature Dr. Matthew Menza, Dr. Ronald Pfeiffer and Dr. Peter LeWitt. Join us in Michigan or watch on the web.

For more information, contact Eli Pollard at (800) 457-6676, info@pdf.org or visit www.pdf.org or www.parkinsonsmi.org.



Sixth Annual Young-Onset Parkinson Network Conference

Date: Thursday, August 7 – Saturday, August 9

Place: Omni Hotel at CNN Center
Atlanta, GA

Coordinated by and for people living with young-onset Parkinson's, the conference includes presentations by clinical experts, people with PD and professionals with expertise in caregiving and advocacy. It also provides the opportunity for social networking.

For more information, visit www.parkinson.org/yopn.

Fourth Michigan Parkinson Initiative Symposium: Promoting Health in Parkinson's Disease



Date: Friday, September 12

Place: St. John Inn and Conference Center
Plymouth, MI

This one-day symposium is geared toward people with PD, physicians and health professionals (continuing medical education units available). It will have one track for health professionals and another for a lay audience. There is a fee to attend.

For more information, contact Debby Orloff at (800) 852-9781, mpfdir@aol.com or visit www.parkinsonsmi.org.

Surgical Advances, DBS and Parkinson's Disease PDWEBCAST

Date: Saturday, October 11

Place: Doubletree Hotel
Spokane, WA

PDF and the Northwest Parkinson's Foundation present an educational symposium and webcast for people with Parkinson's, their families and health professionals. Leading Parkinson's physicians will discuss the newest surgical advances available to treat PD, including deep brain stimulation (DBS). Join us in Washington or view the symposium live on the web.

For more information, contact Eli Pollard at (800) 457-6676, info@pdf.org or visit www.pdf.org or www.nwpf.org.



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SUMMER 2008

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The Parkinson's Disease Foundation® (PDF®) is a leading national presence in Parkinson's disease research, education and public advocacy. We are working for the nearly one million people in the US who live 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 its founding in 1957, PDF has funded over \$70 million worth of scientific research in Parkinson's disease, supporting the work of leading scientists throughout the world.