



State of Parkinson's Science is Focus of PDF's 50th Anniversary Symposium

Parkinson's disease (PD) has long been diagnosed by classic motor symptoms — rigidity, slow movements, and tremor — that occur upon the death of certain cells in the brain. Since these cells normally control the body's movements by producing a chemical messenger called dopamine, most therapies to date have been aimed at restoring dopamine in order to alleviate the motor symptoms of PD.

In recent years, scientists and clinicians have revised this traditional approach to PD.

"It's increasingly recognized that Parkinson's disease is not just a dopamine deficiency disorder," said Stanley Fahn, M.D., Scientific Director of the

Parkinson's Disease Foundation (PDF), in the keynote address at PDF's 50th Anniversary Educational Symposium, held October 11 and 12, 2007 in downtown Manhattan.

The state of Parkinson's science was the focus of discussions at the symposium, which brought together more than 700 physicians, scientists, allied health professionals, caregivers, and people with

Parkinson's. Organized along two parallel tracks, one featuring sessions devoted to basic research and the other focusing on more clinical/practical aspects of the disease, the program gave people with PD the opportunity to ask questions of researchers doing cutting-edge science, while scientists could learn about the complexities of daily life with the disease.

50th Symposium

Over the two days, speakers presented research to this multi-disciplinary audience and asked: what successes have we seen in the last 10 years, and what can we expect in the coming decade?

According to Dr. Fahn, an explosion in scientific literature since the 1990s (nearly

22,500 articles related to PD have been published) has led to a change in thinking about how Parkinson's begins and progresses. Studies demonstrate that PD is set in motion long before cell death in the brain affects movement. In fact, early nonmotor symptoms like loss of smell and constipation may signal nervous system damage outside the brain's movement centers, and even outside the brain.

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NEWS IN BRIEF

New Gene Mutation Linked to Parkinson's Risk

Columbia University Medical Center researchers reported in the September 18 issue of *Neurology* that people with a mutation in the GBA gene (the beta-glucocerebrosidase gene, which is located on chromosome 1) have an increased risk of developing Parkinson's disease (PD) — especially before the age of 50. The study also found that Ashkenazi Jews (those with an Eastern European background) are more likely to carry this mutation than the general population, which means this group may run a higher risk for developing the disease. An estimated 90 percent of American Jews are of Ashkenazi lineage.

Dr. Lorraine Clark, the study's lead author, and her team performed a sequencing analysis on the GBA gene of 278 Parkinson's patients, 178 of whom were of Jewish ancestry. They also carried out a similar study among 179 men and women without the disease.

The researchers found that 14 percent of the people with PD carried mutations in the GBA gene, while only five percent of people without the disease carried the gene mutation. The GBA

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"Now is the time for all of us ... to recommit ourselves ... to finding a cure for Parkinson's disease and enhancing quality of life for those who live with it."

Ann Wasson, symposium attendee (see page 6 for her article)

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50th Anniversary Educational Symposium

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This broader approach opens the door to earlier diagnosis and new therapies that may slow the progress of PD, as well as treat its symptoms. It has also increased the attention placed on nonmotor symptoms of Parkinson's and the commitment of health professionals to addressing them, thereby improving the quality of life for people with the disease.

Genetics Leads the Way

In 1997, scientists reported the discovery of the first gene found to be involved in Parkinson's. It was the gene for alpha-synuclein, the protein that goes awry to form Lewy bodies, the accumulation of which is the hallmark of PD in people who have died with the disease.

Just 10 years later, researchers have identified as many as 13 genes that are related to PD. One that has attracted much attention is *Parkin*, in which mutations have been associated with symptoms of early onset PD. Mutations of *LRRK2*, the most common Parkinson's-related gene, are found in about 10 percent of PD cases where there is no family history of the disease. Studies on the genes *PINK1* and *DJ-1*, are leading to new insights in how dopamine neurons work.

When people with Parkinson's asked whether they should have genetic tests, speakers said that the answer for most people at this time is probably no. The test is expensive and even a positive result neither changes the way Parkinson's is treated, nor predicts how or when disease will progress. On the other hand, by participating in an organized genetic research project, people with PD and their families contribute to scientists' broader understanding of the disease. Although few people have PD that is caused purely by malfunctioning genes, studying rare forms of the disease helps shed light on the molecular and cellular processes common to all. In turn, this knowledge is leading to new approaches to diagnosis and treatment. (To learn more about ongoing clinical research, please visit www.PDtrials.org.)

While genes certainly play a role, Dr. Caroline M. Tanner, of The Parkinson's Institute forcefully communicated that, "genetics loads the gun, environment

pulls the trigger." Pinpointing and measuring the precise contribution of environmental factors — which can include exposure to chemicals, infections, and aspects of lifestyle — is difficult to do with current knowledge. MPTP is the only substance that has been proven to cause Parkinsonian motor symptoms. Scientists have long suspected that exposure to certain chemical pesticides with chemical structures similar to MPTP, such as paraquat, rotenone, and organochlorines, can also set off PD. Dr. Tanner hopes to settle that question in a study now underway that focuses on California farmers whose pesticide and herbicide exposures have been well documented.

How Does Parkinson's Disease Begin?

By the time a person with Parkinson's develops tremor or stiffness, half of the dopamine-producing cells in the brain have already died. Scientists are now questioning what biological events preceded this cell death.



Dr. Lucien Côté, Co-Chair of PDF's symposium, discusses the state of Parkinson's disease science with an attendee.

Research from the last decade points to a "preclinical" phase for PD — a period during which cell death is occurring but physical symptoms are not yet evident. In this phase, cell damage begins in areas of the brain that control activities like heartbeat, digestion, and smell. Later, the damage moves to the areas that are responsible for moving and thinking. If scientists can find ways to measure these earlier changes, they can develop ways to predict who is at risk for PD.

In particular, researchers have found changes in the olfactory bulb, the part of the brain that processes smell. "Loss of smell seems to be very specific for Parkinson's disease — it may be a very early marker," says Dr. Matthew Stern, of the

University of Pennsylvania. Dr. Stern leads a study in which a scratch-and-sniff test for smell loss is being studied on thousands of people who have relatives living with Parkinson's, and who therefore have a somewhat higher risk of developing the disease than the general population. Combined with other risk factors, the smell test may point to ways of predicting a person's chances of developing Parkinson's disease and diagnosing it early.

New Directions in Therapy

Levodopa, a breakthrough at the time of its arrival in the 1960s, remains the gold standard for treating PD. Certainly, the way that levodopa is used has changed. Doctors are now able to delay its use for several years and use it in combination with other drugs to enhance and prolong its positive effects.

In the meantime, new therapies show promise in treating the disease differently. For instance, could the progress of PD be slowed or even stopped? Scientists call this idea "neuroprotection." This tantalizing goal is not yet a reality, but a variety of approaches show potential.

A clinical trial is currently underway to assess the neuroprotective potential of Coenzyme Q10, a substance that occurs naturally in the body and that is available as a supplement both over the counter and by prescription. Tests so far have proven that it is safe. Within a year or so, scientists will know whether it is effective, and if so, at what dose.

Dr. Ira Shoulson of the University of Rochester School of Medicine and co-Founder of the Parkinson Study Group gave an update on the halted trial of the neuroprotective experimental drug, CEP-1347, on which the PD community had pinned great hope. Dr. Shoulson reported that, while the study's outcome was disappointing in that the treatment did not prove successful, additional studies planned for the original clinical trial group may be incredibly valuable for the future. To date, 65 percent of participants from the original PRECEPT trial have agreed to allow their data to be used in further investigations about how Parkinson's progresses, and also in testing other potential treatments. Since the

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SPOTLIGHT

on Research

Supported by PDF

Claire Henchcliffe, M.D., D.Phil

Director of the Parkinson's and Movement Disorders Institute at Weill Cornell Medical Center, New York, NY

Tests of balance, probing questions, interviews of friends and family: to a person with Parkinson's disease (PD), these assessments will sound familiar, because they represent several of the ways in which doctors diagnose PD.



Dr. Claire Henchcliffe

Unlike other conditions that can be diagnosed through blood tests or biopsies there is no definitive test, or "biomarker" that can identify PD or trace its development. A clinician, researcher and teacher, Dr. Claire Henchcliffe is aiming her sights on finding that elusive biomarker.

Dr. Henchcliffe has had constant contact with patients during her past six years as a movement disorder specialist, a practice that began during her clinical fel-

lowship with Dr. Stanley Fahn at Columbia University. Through her practice and her role as founder of a PD support group at Weill Cornell, she has seen firsthand the limitations that exist without a reliable PD measurement tool.

Why is a biomarker so important? Dr. Henchcliffe says a biomarker would enable physicians to diagnose Parkinson's earlier, perhaps even before physical symptoms appear. This in turn would allow for earlier treatment, including the testing of therapies that may prevent the cell death that causes PD. Additionally, she says, "PD is a very heterogeneous disease." Its symptoms, from tremors, to slowness, to depression, can vary tremendously among people with PD, as can responses to treatments. Since people with PD do not fall into a single category, neither, in Dr. Henchcliffe's opinion, should their treatment. A biomarker would allow physicians to detect differences among patients and therefore develop individualized treatment plans.

As a researcher, Dr. Henchcliffe, under the tutelage of Dr. M. Flint Beal, is especially interested in the role of the mitochondria, the part of a cell that generates its energy, in Parkinson's disease.

They are currently studying two potential avenues for biomarking that are related to the mitochondria. The first, magnetic resonance spectroscopy (MRS) would non-invasively measure specific chemicals in the brain to study both how well the mitochondria of the cell are

functioning and whether there are any differences in metabolism among different areas of the brain. The team is also investigating a potential PD blood test that would utilize "metabolomics" to evaluate cellular processes, including cellular energy metabolism and mitochondrial function. Studies using both methods have demonstrated great promise to date.

Dr. Henchcliffe believes that using biomarkers could lead to improved treatments and is pursuing this path through her involvement in the clinical trial for Coenzyme Q10 (CoQ10), funded by the National Institute of Neurological Disorders and Stroke. CoQ10, a naturally occurring substance in the body, plays a key role in the function of the mitochondria. It is an over-the-counter diet supplement and may be capable of slowing the progression of PD. This winter, a CoQ10 clinical trial, led by Dr. Beal, will begin enrolling 600 people who have early-stage PD and who are not taking any medications.

In addition to her dual roles of clinician and researcher, Dr. Henchcliffe co-chairs the Working Group on Biomarkers of the Parkinson Study Group (PSG). She also mentors medical students and residents and frequently lectures and writes about PD.

Dr. Henchcliffe's work is supported as part of PDF's Center Grant to Weill Cornell Medical Center. For FY 2008, PDF's grant of \$100,000 provides partial funding to Dr. Henchcliffe's research.

News In Brief

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gene mutation was found in 22 percent of patients who were diagnosed before the age of 50 compared to 10 percent of people whose disease onset occurred after 50.

Dr. Clark's team then examined how Jewish ancestry affected the probability of developing PD. Of patients with Ashkenazi ancestry, 17 percent carried the GBA gene mutation, while only eight percent of patients who did not report having Ashkenazi ancestry had the abnormality.

Although the data are preliminary and it is uncertain whether the GBA mutation itself is responsible for PD or perhaps one of many contributing factors, Clark's findings

may have important implications regarding the pathology of PD that could affect future research and eventually, treatments.

PDF is pleased to have provided funding to support this study.

Research Shows Nicotine Reduces Levodopa-Induced Dyskinesias

In the October 24 online issue of *Annals of Neurology*, The Parkinson's Institute announced research findings suggesting that nicotine may have therapeutic value in easing the involuntary movements that can be a side-effect of levodopa, the gold-standard treatment for PD.

Although scientists have studied nicotine's effects on PD before, this is the first time the tobacco ingredient's effect on drug-

induced dyskinesias has been examined.

Levodopa, the most commonly prescribed drug for Parkinson's disease, is initially effective with few side effects, but long-term use causes dyskinesias, which are broad, writhing or jerking movements of the arms and legs.

In the study, Dr. Maryka Quik's team administered nicotine-laced Gatorade to parkinsonian monkeys and then treated them with levodopa. The nicotine-treated monkeys experienced up to 50 percent less dyskinesias than the monkeys that were not treated with nicotine. The monkeys experienced up to 35 percent fewer dyskinesias when given nicotine after being treated with levodopa.

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Not Just a Movement Disorder: Cognitive Changes in PD

By Laura Marsh, M.D.

Distractibility, disorganization, forgetfulness, and difficulties with planning; it frequently comes as a surprise to people with Parkinson's disease (PD) and their families that "cognitive changes" — alterations in memory, attention, and thinking — are often part of PD. After all, in 1817, when James Parkinson first described the "shaking palsy" he said that, "the senses and intellect were uninjured." While he was correct in most of his assertions, Dr. Parkinson did miss the mark with this claim.



Dr. Laura Marsh

Cognitive changes can impact people's everyday lives as much, and sometimes more than, the physical effects of PD. While physicians are increasingly recognizing the importance of addressing cognitive and other nonmotor symptoms, many still primarily focus on treating physical (motor) symptoms. This means that cognitive changes may go under-treated or untreated. It is critical that we, as physicians, understand how to prevent and treat cognitive difficulties. It is equally crucial that people with PD and their families understand what types of changes to look for in order to communicate concerns to their physicians. Increased awareness and treatment of cognitive difficulties can lead to improved quality of life for people with PD and their families.

Prevalence and Forms of Cognitive Changes in PD

'Cognition' is a general term used to refer to the various mental abilities involved in processing and using information. Examples include memory, attention, abstract thinking, problem-solving, language, and visual-perceptual abilities.

Nearly every person with PD experi-

ences some degree of cognitive change, which can range from mild to severe. The terms, 'mild cognitive impairment' (MCI) and 'cognitive impairment' are generally used when changes are not severe and affect fairly narrow aspects of memory or thinking abilities. Some people who experience cognitive impairment may merely note that changes in mental abilities are a nuisance, while others report symptoms noticeable enough to affect performance at work or in managing things at home.

'Dementia,' a different classification altogether, is used to describe more extensive difficulties that affect multiple areas of cognitive function. People living with Parkinson's with dementia (PD-D) may be unable to live independently, even if their physical symptoms are not advanced. In

“Increased awareness and treatment of cognitive difficulties can lead to improved quality of life”

general, large-scale population-based studies show that PD-D usually develops many years *after* the initial onset of PD. When a dementia syndrome develops *before or concurrently* with PD motor signs, this is diagnosed as Dementia with Lewy Bodies (DLB).

Cognitive impairment, in its varying degrees, affects the majority of individuals who have PD, while dementia is estimated to affect only one-third. The exact prevalence is unclear since there is not currently a single established measurement system for diagnosing cognitive impairment or PD-D.

If someone experiences mild cognitive impairment or cognitive impairment

early in PD, is this any indication that they may develop dementia in the future? The evidence is mixed. Some research suggests that early cognitive impairment represents the initial stages of progression to dementia. However, other studies suggest the opposite. For example, studies show that people with PD without dementia, when compared to those with PD-D, experience cognitive impairments very differently.

Types of Cognitive Difficulties in PD

PD affects a variety of cognitive functions. Problems with executive function are often regarded as the most common. However, some people may undergo memory problems more significantly, while others will experience a mixture of difficulties. Most people retain their general intellectual abilities and knowledge as well as the short and long-term memories they acquired prior to the onset of PD.

Executive dysfunction: Executive functions are higher-order mental processes such as problem-solving and planning, initiating and following through on tasks, and multi-tasking ideas or projects. For a person with PD, paying bills or even taking part in group conversations can be difficult. Why? Because these activities require a person to be flexible and be able to shift from one category of information or one specific goal to another. People with PD may describe getting overwhelmed or 'freezing' in situations that require the formulation of a series of strategic choices, yet they appear to function perfectly when someone else helps them initiate and persist with a task. In the absence of some sort of "intellectual scaffolding," it is more efficient for the person with PD to focus on one goal or concept at a time. An example is a person who was unable to initiate a project to clean his messy basement, but who successfully completed the task after his wife provided structure and cues by breaking down the task into parts and providing explicit instructions that focused on one single area at a time.

Memory disturbances: Remembering information that has already been learned is the most common difficulty for those with PD and can be improved through use of memory cues. For a person with PD to effectively learn and retain new

information, repetition may be needed. PD-D affects both short-term and long-term memory functions more severely.

Attention difficulties: As the complexity of a situation increases, it can be difficult for a person with PD to maintain his or her focus or divide his or her attention. For example, patients may find they can no longer “walk and chew gum at the same time.” This affects intellectual pursuits and everyday activities such as walking, maintaining balance, and carrying on a conversation.

Bradyphrenia (slowed mental processing): People with PD say that the disease affects how quickly they can process and respond to information. Slowness in information processing impacts both other cognitive processes (such as problem-solving and retrieving information) and daily activities (such as conversing).

Language dysfunction: The most common language-related difficulty for people with PD is word-finding. As a person's PD progresses, he or she may also experience problems with naming or mis-naming, may have difficulty comprehending complex information, and may use more simplified and less spontaneous speech.

Visual-spatial disturbances: Trouble perceiving, processing, discriminating, and acting on visual information in the environment can affect daily life. For example, it may become difficult to navigate around the house or estimate distances when reaching for something, thereby increasing the risk of falls. In some cases, visual-spatial impairment in PD may also lead to visual misperceptions, or illusions.

Causes of Cognitive Changes in PD

Our understanding of the causes of cognitive changes in PD is incomplete. We do know that problems with cognition are related to the same underlying brain changes that result in motor symptoms — that is, premature death of nerve cells, changes in brain neurochemistry, and subsequent alterations in brain circuitry between different brain regions. In addition, Lewy bodies, the abnormal collections of proteins that are found in nerve cells in PD, are related to changes in motor pathways and to pathways affecting cognitive processes.

Other elements can cause and aggravate cognitive difficulties. Untreated

depression, anxiety, psychosis, sleep, and other behavioral difficulties can exacerbate cognitive difficulties. In addition, some medications, whether for PD or other conditions, can cause negative cognitive effects as can some non-PD-related general medical conditions, such as infections.

Treatment of Cognitive Changes in PD

The basis of all effective treatment is a thorough diagnostic evaluation. When an initial history is taken, by a primary care physician or a neurologist, it is important for a person with PD (and his or her caregiver) to bring up any observations or concerns about cognitive changes. Referral to a neurologist, neuropsychiatrist, or geriatric psychiatrist who specializes in the treatment of cognitive problems or dementia can be helpful. Additional tests may also be conducted to ascertain if a person's difficulties are due to PD or to other reversible causes. Once other causes are excluded, a neuropsychological exam, involving paper-and-pencil tests, will be performed by a neuropsychologist to characterize the quality and extent of problems and to identify areas of strength.

Treatments for cognitive changes aim to reduce symptoms or improve daily life through using compensatory strategies (that is, coping mechanisms that help a person adapt to his or her cognitive limitations). For instance, clocks or timers may help a person remember when to take medication, and devices such as planners or voice recorders may help him or her recall an appointment.

Occupational therapists can also assist, by providing insights into how cognitive difficulties impact daily life, suggesting adaptive strategies, or providing formal treatment programs. Speech therapists can help with language functions and information processing.

Medications used to treat cognitive dysfunction in Parkinson's are largely based on treatments used for Alzheimer's disease and are usually reserved for these patients who already have dementia. At present, rivastigmine (Exelon®) is the only medication approved by the US Food and Drug Administration for the treatment of dementia in PD. Further research is needed to identify treatments that can help those who experience less severe cognitive

impairments that occur earlier in the course of PD.

Conclusions

Cognitive changes are present to some degree in almost every person with PD and are a prominent feature of PD over its course. Although they have received less attention than motor symptoms, cognitive changes have obvious effects on daily life, including how people adapt to their motor symptoms. While we do not yet have definitive treatments for cognitive dysfunction in PD, recognition of what changes have occurred is important in order to take advantage of currently available medication and behavioral strategies.

Dr. Marsh is a geriatric psychiatrist, an Associate Professor of Psychiatry and Neurology at Johns Hopkins University School of Medicine, and Director of the Clinical Research Program of the Johns Hopkins Morris K. Udall Parkinson's Disease Research Center of Excellence. Her research focuses on neuropsychiatric aspects of PD.

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“Creativity and Parkinson's – Insights 2008” features the artwork and creativity of people with PD.

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PDCreativity.org

My Reflections on PDF's 50th Anniversary Educational Symposium

By Ann Wasson

On the evening of October 10, as my husband Greg and I arrived in New York City, we were not even two steps inside our hotel in the city's historic South Street Seaport, when PDF's 50th Anniversary Educational Symposium unofficially began.



Ann Wasson

First, we ran into two long-time friends with Parkinson's disease (PD)

who we rarely see except at conferences and we arranged to meet them for dinner. After we had checked in and were heading off to the restaurant, our friend recognized Dr. James Surmeier, a Parkinson's scientist who is on the faculty at Northwestern University. She introduced us and we spent the next half-hour standing on the street corner discussing Dr. Surmeier's research about Parkinson's. He seemed pleased to find "patients" who were not only eager for information, but also knowledgeable enough to have a meaningful discussion about his work.

As we were standing there, Dr. J. William Langston, the Founder and CEO of The Parkinson's Institute in Sunnyvale, CA, arrived at the hotel. We greeted him and agreed to try to find time to catch up on the progress of the California Registry program (a state wide registry that will be collecting data on Californians living with Parkinson's disease).

The next morning, as the conference officially began, we joined top neurologists, scientists, and researchers to talk over muffins and corn flakes.

These instances of casual contact may not seem like much, but they are, in fact, almost unheard of at scientific conferences, where "patients" and "doctors" are normally separated not only by a po-

dium and microphone, but also by independent hotel accommodations, seating assignments, and even entrances and exits. Throughout the PDF symposium, time and circumstances were created to foster contact.

The symposium was organized mostly along two parallel tracks, one aimed at a research level audience and the other at a broader audience. Attendees were encouraged to cross over from one to the other as their interests led them. Personally, I didn't understand everything in the basic science sessions, but I could follow the overall concepts, discussion, and passion of the presentations and sense their potential impact upon how my disease is both measured and treated.

“Now is the time for all of us ... to recommit ourselves ... to finding a cure for Parkinson's disease and enhancing quality of life for those who live with it.”

The clinical and quality of life sessions were equally exciting. Topics that were once rarely discussed in conference programs and at doctors' offices (though not so new to many people with Parkinson's) — such as depression, sleep, pain disorders, driving, and exercise — were center stage at the symposium, presented clinically and scientifically by doctors and other health professionals.

The community interaction continued through two special meals. An innovative luncheon program on Day Two was built around hosted tables, each with a designated expert leading discussion on a

PD-related topic of interest, such as exercise or living alone with PD. The conversations were wildly successful.

The other event was the awards dinner that concluded Day One, recognizing, among others, the wonderful Rhona Johnson of Greenwich, CT, who was selected by PDF's People with Parkinson's Advisory Committee (of which I am a co-chair) to receive the Leadership in Caregiving Award. The dinner evolved into a *Who's Who* of movement disorders, beginning with Advancement of Parkinson's Science Award winners Drs. Alim-Louis Benabid and Mahlon DeLong and ending with Dr. Bill Langston presenting the James Parkinson Medal to Dr. Stanley Fahn. Because we were staying at the same hotel, I was able to personally congratulate Dr. Fahn as we rode up in the elevator later that night.

The symposium was an unqualified success. As the "patient/doctor" divides fell, all groups came together to recognize PDF's fifty years of service and support in the Parkinson's community. However, as Robin Elliott, PDF's Executive Director, stated in his welcoming remarks, this time is not for celebration, but for recommitment. Now is the time for all of us, whether we work in the laboratories of science or in the halls of nursing homes, whether we have PD or not, to recommit ourselves along with PDF to finding a cure for Parkinson's disease and to enhancing quality of life for those who live with it. I know I am not alone in my hope that fifty years from now, the Parkinson's Disease Foundation, under a different name and with a different mission, will be well on its way to helping solve a quite different disease.

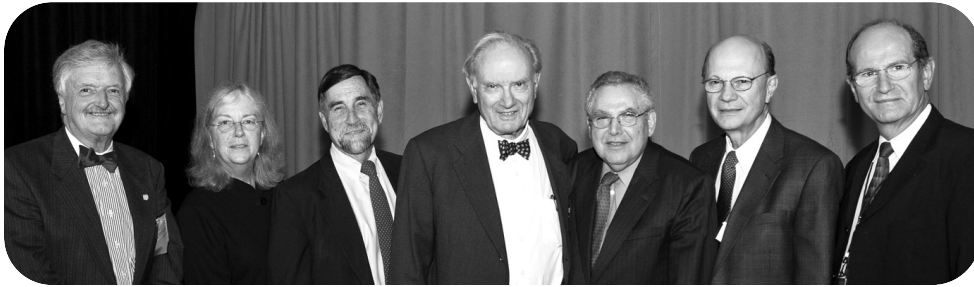
Ann Wasson is a person with Parkinson's disease and caregiver to her husband Greg, who also has PD. She is co-chair of PDF's People with Parkinson's Advisory Council (PPAC) and has been active in the PD community in the state of California and on a national level with the Parkinson's Action Network (PAN).

Stay Tuned for Details ...
World Parkinson Congress
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Recognizing Excellence in the PD Community

A special feature of PDF's 50th Anniversary event on October 11 was an awards dinner at which we were able to recognize four outstanding contributors to the Parkinson's community.

Dr. Stanley Fahn, PDF's Scientific Director since 1973, received the James Parkinson Medal, PDF's highest honor. This medal, given only once each decade, recognizes Dr. Fahn's lifetime of achieve-



Robin Elliott joins presenters Dr. Anne Young, Dr. J. William Langston, and Dr. Lewis P. Rowland and award winners, Dr. Stanley Fahn, Dr. Mahlon DeLong, and Dr. Alim-Louis Benabid.

ment as a scientist and clinician in Parkinson's disease (PD). In his acceptance remarks Dr. Fahn thanked his wife, Charlotte, and colleagues Dr. Lewis Rowland and Dr. Ira Shoulson. He also recounted to the audience how it was he came to work on Parkinson's disease. In 1965, during Dr. Fahn's first year at Columbia as a neuroscientist, he attended a special lecture by Dr. Oleh Hornykiewicz, a noted young Austrian scientist.



Dr. Bill Langston presents PDF's Scientific Director, Dr. Stanley Fahn, with the James Parkinson Medal.

"When I heard Dr. Hornykiewicz describe his discovery of low dopamine levels in the basal ganglia of people who die of Parkinson's ... I was so impressed ... that I came away from the lecture, and I

said to myself, this is the field I want to go into." Dr. Hornykiewicz was touched to hear this story for the first time and sent Dr. Fahn a letter of congratulations.

Rhona Johnson, a long-time spokesperson for caregiving and a member of PDF's People with Parkinson's Advisory Committee (PPAC), became the first recipient of the Award for Leadership in Caregiving. Ms. Johnson became involved with Parkinson's community upon the diagnosis of her late husband Bob, for whom she then became sole caregiver. Upon accepting her award, she said, "The national spotlight is directed increasingly to the role of caregivers across

the US and their work and devotion reflects directly in the lives of people with Parkinson's for whom they care. So I accept this award on their behalf."



Caregiver award recipient and valued PDF friend Rhona Johnson (center), with her nephew, Kent and Robin Elliott.

The 50th Anniversary Award for Exemplary Contributions to the Advancement of Parkinson's Science was awarded jointly to Dr. Alim-Louis Benabid, Chairman of Neurosurgery at Joseph Fourier University in Grenoble, France, and Dr. Mahlon DeLong, Professor of Neurology at Emory University, for their pioneering work in developing deep brain stimulation (DBS) for Parkinson's. Each scientist expressed his thanks and respect to the other for his contributions to the science of Parkinson's sur-

gery. Dr. DeLong also observed the great changes in the field from pre-levodopa times to the present. Dr. Benabid noted that the award was really about a treatment that he believes helps patients, and "this, after all, is what lies behind all of our commitment."

PDF congratulates all award recipients on their exceptional work and well-deserved accolades.

PDF thanks the following generous symposium supporters

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This event was jointly sponsored by the Parkinson's Disease Foundation and The Movement Disorder Society.

pdfchampions *in action*

The Parkinson's Disease Foundation (PDF) *News & Review* is pleased to highlight five more inspiring stories from our PDF Champions — individuals, families and organizations that have shown incredible dedication to Parkinson's research, education and advocacy by making PDF their charity of choice. We applaud our featured Champions, and all others who signed up for the task in the last few months.

Lenny: Connecticut Golfers Support One of Their Own

Lenny's friends called him a medical miracle. He had been living with Parkinson's disease (PD) for years and had fared better than some others with the disease. This past year, however, has been more challenging for Lenny, and his friends have rallied around him.



Lenny with friend and PDF Champion Jim Hanlon after the Pro-Am Tournament.

On August 15, 2007, Lenny's fellow golfers at The Farms Country Club in Wallingford, CT, led by Jim Hanlon, the club's Head Golf Professional, held a day-long Pro-Am tournament in Lenny's honor. The event included 18 holes of golf, played by 100 club members and 25 golf professionals, as well as a pre-tournament lunch and post-event dinner/awards ceremony.

The event — the first of what Jim says will be an annual gather-

ing — raised an astounding \$87,000. This is due to the many friends who wanted to support Lenny and his wife Sue, including the hardworking team that raised additional funds: Kathy Smith, Jim McMahon, Toby and Karen Brimberg, Tom Valentino and Dave Melillo.

Keara: The Sixth Year of *Cursus Cerebro*

On October 20, 2007, the Sixth Annual *Cursus Cerebro* 5K road race took place on Sherwood Island in Westport, CT. Keara Stewart, building on a family tradition, was race organizer.

Keara's father, John Stewart, has been living with Parkinson's disease for 12 years. Her brother Sean began the event six years ago and when he left for college, Keara took over leadership of the 5K run, the name of which is Latin for "Race for the Brain."

Now a high school senior, Keara is busy with schoolwork, college applications and her role as captain of her school's cross-country team. Still, she found the time to perform the logistical duties that come with planning a race for more than 75 runners. She wrote to family and friends for support and garnered the participation of several other local high schools. On race-day morning, Keara and her mom, Jeanne, marked out the course, which wound along Long Island Sound and through nearby woods.

The event continues to be a success. Since 2002 *Cursus Cerebro* has raised over \$40,000 for PDF.

James: Worn out Sneakers

Running 26.2 miles is no small accomplishment, so you may think it ambitious of James Rolke, a longtime runner from Woburn, MA, to complete a marathon as a means of raising funds and awareness for PD.

In fact, James did not think one marathon was good enough. So, in October 2007, James set off on an ambitious "Worn out Sneakers" campaign: to run a marathon in each of the 50 states, at a rate of two or three each year, beginning with the 2007 Chicago Marathon. The goal of his multi-year campaign is to gen-

erate a stunning \$250,000 for PDF.

From the Chicago Marathon, James raised a total of \$5,450 – \$1,000 of which he donated himself. He has promised to repeat this generous contribution for every race he runs.

James is touched by Parkinson's through his girlfriend's father. He has observed that while other diseases seem to be visible in the mainstream media, Parkinson's is not as well represented. He wants to get the word out and plans to do so by drawing media attention to the "Worn Out Sneakers" campaign during his future marathons.

James' next race will be Sarasota, FL on March 2, 2008, and after that, he speculates, will be the San Francisco marathon on August 3, 2008. We will keep you updated as James comes closer and closer to his goal!

Joe: Punching Out Parkinson's

On July 16, 2007, 200 people gathered to celebrate Joe Novello's mom and her 71st birthday. Four weeks prior to the event, Joe, who says, "my mom was my best friend growing up and she still is," was still brainstorming gift ideas. He soon realized that the best present might not be a gift he could place in his mother's hands, but one that would honor her spirit and endure for years to come.

So, with only four weeks to go, Joe, with the help of friend Laura Marshall and others, made plans for a party that would raise funds to support PDF — as tribute to his mother's struggle with PD. He quickly found a location in downtown Cincinnati, OH and started writing emails to family and friends.

In line with his passion for boxing and sports, Joe dubbed his party, "Punch out Parkinson's." To highlight the event theme, Joe and his team collected sports memorabilia for an auction and invited local athletes to attend.

The party raised \$5,000, and Joe considers this just the beginning. He says that "Punch out Parkinson's" will be an annual event and vows to make it bigger and better every year.

PDF Launches Clinical Research Learning Institute

The Parkinson's Disease Foundation (PDF) is pleased to announce the creation of a new clinical research learning institute, designed specifically for interested and talented lay members of the Parkinson's community. The institute will provide participants the tools they need to serve as leaders and knowledgeable patient representatives within clinical research — advocating for the role of the patient in the process that brings medications and medical devices from research to market.

Through several days of training sessions, the institute will prepare its graduates to take part in such activities as educating other people with Parkinson's about the importance of clinical research; serving on Institutional Review Boards (IRBs) and Data Monitoring Safety Boards; and providing research sponsors and investigators with input on trial design, implementation, and evaluation. Leaders from all sectors of the clinical research enterprise, such as researchers and clinical trial coordinators, will be invited to serve on the institute's faculty. The inaugural training is planned for the spring 2008 and its participants will be chosen by PDF through a formal application process that will commence early in 2008.

The idea for the institute came out of a roundtable discussion that PDF sponsored in January 2007, entitled: "Building Patient Trust: A New Era of Parkinson's Research Rights and Responsibilities." The meeting, which included several people with PD, clinical trial experts, as well as representatives from industry, government and voluntary organizations, focused on the challenge of how to engage members of the PD community as active advisors in the clinical research process, empowering people beyond the more passive role of trial participant.

One of the most provocative sessions of the meeting was a presentation by a representative of the National Breast Cancer Coalition (NBCC) on NBCC's

own educational program. There was wide agreement that this program could be a model for a similar venture in the PD community. Roundtable participants felt that the "patient perspective" that is central to the NBCC program could be of great benefit to the clinical research community in Parkinson's and would help accelerate the development of new PD therapies and treatments.

"Creating a place at the table for people with Parkinson's to share their viewpoints, experience, and ideas is critical to facilitating treatment development — yet it is all too often overlooked," states Robin Elliott, Executive Director of PDF. "A formal clinical research learning institute will provide this essential group of stakeholders with knowledge and a skill set that will make patient participation in the clinical research process all the more rich and valuable."

The new institute will be part of PDF's Advancing Parkinson's Therapies (APT) initiative, which is directed by Veronica Todaro. APT is a multi-pronged project that is aimed at addressing non-science barriers to the acceleration of PD therapies and treatments.

Seed funding for the new venture will be provided through PDF's general budget. Funding to sustain and develop it will be sought from outside sources.

For more information, contact PDF at (800) 457-6676 or info@pdf.org.

Maggie: Running for Bobby

A few months ago, Maggie Simpson wasn't a runner, nor was she affiliated with PDF. However, she had a big heart, a history of "giving back," and a stepfather, to whom she pointed as her inspiration.



Maggie Simpson (right) and her stepfather Bobby after she completed the NTELOS 8K.

By November 10, Maggie had completed her first road race, eight kilometers long (4.96 miles) and had raised more than \$3,000 for PDF.

Maggie's mother, Priscilla, has long been involved in philanthropic events for worthy causes such as AIDS and breast cancer. Maggie realized that she wanted to do the same for a cause much closer to her heart — Parkinson's disease. Maggie's stepfather Bobby has been living with PD for eight years.

Bobby's courage in the face of PD inspired Maggie to get involved and to help find a cure. She chose the "NTELOS 8K," a road race that travels the neighborhoods of Richmond, VA, as her fundraising vehicle. Then she hit the Internet for training tips, created a disciplined schedule, put on her shoes and began to run.

In addition to generating awareness and needed funds for PD, Maggie found herself continuing a family tradition of philanthropy and winning the enthusiastic support of her community.

Thank you to all of our PDF Champions for your spectacular commitment to PD research, education and advocacy! To learn more about these Champions, or to become one yourself, visit us at www.pdf.org.



Watch the webcast of
PDF's 50th Anniversary
Educational Symposium
until October 2008.

www.pdf.org/50th/webcast.cfm

*CE credits are not offered on the webcast.
The webcast is supported by HealthShares.*

50th Anniversary Educational Symposium*Continued from page 2*

group represents one of the largest and best characterized databases ever compiled for PD, this PostCEPT data will provide important information for the PD community.

Gene therapy, a surgical technique that injects a specific gene deep into the brain (often by encasing it in a harmless virus that can correctly deliver it) offers another approach to slowing, and perhaps even reversing, the progress of PD. A Phase II clinical trial is now underway to test the injection of CERE-120, which consists of a virus carrying the gene neurturin. CERE-120 has been shown to alleviate symptoms in people with PD by improving the health of dopamine producing cells. Scientists at Rush University Medical Center, with Ceregene, Inc., lead the study. If the therapy works, researchers anticipate that its beneficial effects will be long lasting.

Cell transplantation is another surgical technique that aims to re-invigorate the brain's ability to make dopamine. Using fetal cell transplants, researchers have achieved limited success with this technique since the 1980s. Today scientists are looking at the possibility of using stem cells to carry growth factors to the part of the brain that produces the all-important dopamine. Dr. Anders Bjork-

lund, of Lund University, reported that because stem cells can be standardized, and a reliable supply can be generated, they hold promise as the next step in cell transplantation research.

Another important therapeutic advance discussed was deep brain stimulation (DBS), a surgical option that has been found to be very effective for some patients, but not suited for all. The PDF symposium featured presentations on how DBS can improve gait and posture in people with severe motor symptoms.

More Than a Physical Disease

As people with Parkinson's know well, even though "some forms of therapy address motor symptoms, you're left with other symptoms," said Dr. Fahn.

The symposium showed a true shift in the way Parkinson's is viewed by doctors and patients alike. The community increasingly recognizes that nonmotor symptoms such as depression, constipation, pain, urinary problems, sleep disorders, sweating, fatigue, dementia, and others drastically affect quality of life for people with Parkinson's, their caregivers, and their families.

The symposium featured sessions by clinical neurologists, nutritionists, physical therapists, speech pathologists, nurses, and others — all of whom can provide therapies, and in some cases medications, that ease the nonphysical effects of PD.

Julie Carter, R.N., M.S., of Oregon Health and Science University, told her audience that depression is the most common nonmotor symptom seen in those with PD, affecting up to 50 percent of those with the disease — but it is also under-recognized and under-treated. Therefore, it is vital for patients themselves, family members and clinicians to look for signs of depression in order to treat it. Dr. Giselle Petzinger, presented engaging research on the effects of exercise — showing that regular physical activity improves physical mobility of patients with PD. Her continued research will investigate whether exercise can actually remodel the brain as well.

Looking Forward

While the symposium brought together various populations of the PD community and hopefully provided resources and practical tips to people affected by PD — it also looked ahead to assess the most promising science. As Executive Director, Robin Elliott continually stressed throughout the event, the symposium represented a recommitment to PDF's primary goals: development of new treatments and pursuit of the cure.

A webcast of almost all the symposium sessions will be available on PDF's website for one year. To learn more or view these exciting sessions, please visit www.pdf.org/50th/webcast.cfm.

News In Brief*Continued from page 3*

Given the toxicity of nicotine in high doses, researchers would have to synthesize a drug that imitates nicotine's effects in the body, rather than using nicotine itself, in order to translate this research into treatment. The study results are exciting because they offer up a new area of research, but the topic needs significantly more investigation before leading to any potential treatment of PD.

DBS and Impulsiveness in Parkinson's

Research published in the October 25 issue of *Science* has demonstrated that deep brain stimulation (DBS) may create problems of impulse control — particularly in the area of decision-making.

DBS involves placing electrodes into the subthalamic nucleus, an area of the

midbrain that is important for controlling movement. *It is the most commonly performed surgery for PD, and is very effective at suppressing PD-related symptoms, such as tremor and dyskinesias.*

A group at the University of Arizona-Tucson, led by Dr. Michael J. Frank, studied 15 people with Parkinson's who were taking anti-Parkinson's medications, 17 others who had received DBS and 14 adults who did not have PD. The team used specialized computer games to test individuals' decision-making, and to determine whether subthalamic nucleus stimulation has an impact on decision-making.

They found that the people who had DBS tended to make hasty or impulsive decisions. Whereas individuals in both other groups tended to hesitate before a decision to consider their options, those in the

DBS group seemed to lose that ability to 'slow down' before making a decision.

It turns out that the area of the brain where DBS electrodes are implanted is the same one that plays a role in detecting conflict between choices. This area of the brain normally reacts to uncertainty by sending a signal to temporarily delay a decision for further consideration. Researchers speculate that when the DBS electrodes fire to alleviate tremor, they also block the function of the brain that causes a person to pause before making a tough decision.

Impulsivity is a potential problem in some patients with PD. More study is needed to determine the full effect of DBS on behavior and impulsivity.

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

AROUND & ABOUT THE COMMUNITY

Bal du Printemps

The Parkinson's Disease Foundation's (PDF) annual gala, *Bal du Printemps*, will be held on Wednesday, May 14, 2008, at The Pierre Hotel in New York City. Led by



Honorary Chairs

Page Morton Black, Amy Goldman and Judith Sulzberger, this gathering of PDF friends and supporters will honor several outstanding leaders of the Parkinson's disease community and raise funds for PDF's programs of research, education and public advocacy.

This year's event will include cocktails, dinner, dancing and a silent auction. PDF is grateful for the leadership of John Connolly, Ed.D., who will serve as the 2008 Dinner Chair. The night will also feature an awards presentation recognizing Dr. Lewis P. Rowland, PDF's President since 1979, and Mel and Carol Taub and family, major supporters of PDF for more than a decade.

Dr. Rowland will receive PDF's Lifetime Achievement Award, in appreciation of his commitment to PDF and his outstanding leadership in the science and

practice of neurology at Columbia University. As Chair of the Department of Neurology for more than 25 years, Dr. Rowland played a major role in building the department into the powerhouse it is today. Dr. Rowland was also the person who recruited to Columbia Dr. Stanley Fahn, who is the world's leading figure in Parkinson's science and clinical practice. Dr. Rowland is the editor of Merritt's Textbook of Neurology, the leading textbook in his field, and serves as Chief Editor of *Neurology Today*.

The Taub family, in turn, will be receiving the Page and William Black Humanitarian Award for their long and devoted service to Parkinson's science through their support of PDF. Mr. Taub has served as a member of PDF's Board of Directors since 1999, and he and his wife Carol, along with their daughters Stefani Gurkoff and Jill Drury, have raised more than \$500,000 to support PD research through PDF. In addition, from 2003 through 2006, Mr. Taub led a successful \$6 million campaign to modernize the Parkinson's disease laboratories at Columbia University.

For additional information on *Bal du Printemps*, or to make a reservation to attend, contact Carla Capone at (212) 213-1166 or pdf@carlacapone.com.

Robin Elliott Appointed to Empire State Stem Cell Board

On July 26, 2007, NY State Governor Eliot Spitzer appointed Robin Elliott, PDF's Executive Director, to the Empire State Stem Cell Board.

This 24-member board, composed of people from widely diverse backgrounds, including scientists, health care leaders, scholars, business people and private citizens, is charged with the oversight and administration of the Empire State Stem Cell Trust Fund. The fund has been granted \$600 million over 11 years to promote stem cell research and development, including an initial appropriation of \$100 million for 2007-2008. Stem cells hold promise for treating Parkinson's and other diseases, such as Alzheimer's, ALS, blindness, heart disease, cancer, and diabetes.

The Board will consist of both a Funding Committee and an Ethics Committee; Mr. Elliott will serve on the former. PDF's President, Dr. Lewis P. Rowland, commented, "As an advocate for people living with Parkinson's disease and as a longtime supporter of great science, the Parkinson's Disease Foundation applauds this initiative of the State of New York to discover the potential of stem cell research."

PDF Announces 2008 Research Grant Cycle

Visit www.pdf.org/research for more information and to apply.

We are now accepting applications for the following:

- International Research Grants • Postdoctoral Research Fellowships
- Postdoctoral Fellowships for Neurologists • Summer Student Fellowships

Application deadline is February 1, 2008.
Get your application in today!

For more information, contact Sharon Stone at [ssstone@pdf.org](mailto:sstone@pdf.org) or Valerie Holt at vholt@pdf.org.

¿NECESITA INFORMACIÓN EN ESPAÑOL?

Si tiene preguntas sobre le enfermedad de Parkinson, los expertos pueden ayudarle. Visite www.pdf.org/ask.

Presente sus preguntas, y un especialista le responderá en un plazo de 8-10 días.



Parkinson's
Disease
Foundation

Calendar of Events



14th Annual Parkinson's Action Network Research & Public Policy Forum

Date: Saturday, February 2 – Monday, February 4, 2008

Place: Hyatt Regency on Capitol Hill
400 New Jersey Ave., NW
Washington, DC

Forum attendees learn about PAN's 2008 legislative agenda and develop skills to better convey PAN's message. The Forum also provides a unique opportunity to interact with others in the Parkinson's community and see the power of advocacy in action.

For more information, email info@parkinsonsaction.org.



Team Parkinson at the Los Angeles Marathon

Date: Sunday, March 2, 2008

Place: Los Angeles, CA

Pick up the pace with Team Parkinson in the Los Angeles Marathon! Participants may walk, run or ride on race day to raise funds to benefit Parkinson's research.

For more information, visit www.team-parkinson.org.



Parkinson's Disease Foundation PDF Cocktail Party

Date: Thursday, April 3, 2008

Time: 8:00 PM

Place: Cipriani 23rd Street
200 Fifth Avenue
New York, NY

Bring your friends to a night of cocktails and dancing, all the while supporting PDF. Light hors d'oeuvres will be served.

For more information, contact Patrick Johnson at (212) 923-4700 or pjohnson@pdf.org.

14th Annual Parkinson's Unity Walk

Date: Saturday, April 26, 2008

Time: Booths Open at 10:00 AM

Program Starts at 12:00 PM

Walk Begins at 1:00 PM

Place: Central Park
New York, NY



Join the PD community for a two-mile walk.

Learn from medical experts, talk to friends and raise awareness about Parkinson's disease.

Because all expenses are covered by corporate sponsors, one hundred percent of donations will go directly to Parkinson's research.

For more information, call (866) PUW-WALK / (866) 789-9255 or visit www.unitywalk.org.

Pups for Parkinson's

Date: April 2008

Place: Belmont Lake State Park
Babylon, NY



Join Hope For A Cure Foundation for

Parkinson's Research as they put their "best paws forward" in this one-mile walk to raise money for Parkinson's disease.

For more information, please visit www.hopeforacure.org.

Bal du Printemps

Date: Wednesday, May 14, 2008

Time: 6:30 PM

Place: The Pierre
New York, NY

Led by PDF Chairman Page Morton Black, PDF's annual gala, *Bal du Printemps*, is an elegant evening to celebrate philanthropy and raise funds for Parkinson's disease.

For more information, contact Carla Capone at (212) 213-1166 or pdf@carlacapone.com.



Parkinson's Disease Foundation



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50 Years of Research • Education • Advocacy

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- Submit a question to our "Ask the Expert" online service or view those frequently asked by others.
- Visit www.pdf.org to download PDF publications and order print copies.