



ACCELERATING *the* CURE

WINTER/SPRING 2007 NEWSLETTER



FOUNDATION COMMITS \$10 MILLION IN FUNDING FOR LEAPS 2007

In December The Michael J. Fox Foundation announced the launch of its *LEAPS (Linked Efforts to Accelerate Parkinson's Solutions)* 2007 effort, committing up to \$10 million to support ambitious research that will translate into new treatments or otherwise tangibly impact Parkinson's disease research. *LEAPS* is a novel research paradigm designed to hasten progress toward better Parkinson's disease therapies and a cure by funding collaborative, milestone-driven approaches to major unanswered research questions.

"*LEAPS* captured the imagination of the scientific community and attracted innovative and potentially high-impact concepts in 2003 and 2005," said *LEAPS* Chair Tim Greenamyre, MD, PhD, director of the Pittsburgh Institute for Neurodegenerative Diseases and a member of the MJFF Scientific Advisory Board. "As the program continues to gain recognition and attention throughout the Parkinson's research field, we are confident that our third outing will catalyze another round of similarly creative and exciting projects."

LEAPS are multi-year, multi-million-dollar grants awarded to "all-star" teams of investigators who interact regularly with MJFF to discuss elements of the project, research directions and progress against stated milestones.

"Top-down" Approach

LEAPS takes a "top-down" approach, requiring that teams start by outlining a particular outcome they are seeking, and then draft and implement a realistic workplan that will take them to their goal.

"*LEAPS* is in many ways emblematic of the Foundation's overall research strategy," said Deborah W. Brooks, the Foundation's president

and co-founder. "Our focus is on driving the best research into the clinic and to patients. *LEAPS* leverages academic-industry collaboration and pooled resources to create teams that include experts in every phase of the development pipeline, from discovery work to early clinical research. The model accelerates 'hand-offs' that keep promising approaches moving steadily forward."

LEAPS 2005 Projects Under Way

A *LEAPS 2005* award currently in progress aims to develop a new form of gene therapy that would allow clinicians to control gene expression in a patient's brain following transplantation. The team, led by Intrexon Inc. (formerly RheoGene, Inc.), is focused on two main challenges: developing and testing a vector system; and developing an orally administered drug that would be used to activate gene expression. To date, the team has conclusively demonstrated that its drug candidate has the ability to activate gene expression in a living system, and an oral formulation of the drug has been found to perform well in a rodent model of PD. Development of the vector system is ongoing, with the first major milestone, clear evidence of vector performance in rodent models, set for evaluation in March.

A second *LEAPS 2005* team is seeking a therapy to inhibit alpha-synuclein, a protein whose over-expression is linked to Parkinson's risk. This team, led by Proteotech, Inc., has identified several compounds with the ability to inhibit or protect against alpha-synuclein aggregation. One compound in particular has demonstrated the ability to block aggregation in vitro and in cellular models, and it shows some slight neuroprotective ability in a *C. elegans* model of PD. Several derivatives of this compound have been generated for further testing.

NEWS FROM THE PRESIDENT & CO-FOUNDER



Mark Solinger

In 2006 more than 90 percent of our funding went to translational or clinical research. In 2007 we continue to build on multiple initiatives designed to

help bridge the translational gap. You'll read about many of them in this newsletter, including our compelling investment in Ceregene, Inc.'s Phase II gene therapy clinical trial; our alliance with Elan Pharmaceuticals to advance validated drug targets one step closer to the clinic; and our \$4.6 million *Therapeutics Development Initiative* to expand industry investment in Parkinson's drug development.

With the support of friends like you, we are steadily approaching the \$100-million mark in research funded to date, directly or through partnerships. We continue to strategically expand our portfolio of investments toward the impact whose urgency is so clear to us, to the community, and to you, our donors.

We believe without fail that ours is a winnable war. Thank you for being part of the fight.

Warm regards,

Debi Brooks

Deborah W. Brooks
 President and Co-Founder

P.S. You may have noticed that my title has changed. This spring I am relocating to Delaware with my family, and while I will not be leaving the Foundation, day-to-day oversight of the organization will shift to Sarah Orsay, our newly hired CEO. See page 7 to learn more about Sarah and why we're thrilled she's made the decision to join us.

MJFF-FUNDED RESEARCHERS FIND “BEGINNING OF BEGINNINGS” OF BLOOD TEST FOR PARKINSON’S RISK

In January, researchers funded by The Michael J. Fox Foundation announced a possible breakthrough in the search for a biomarker of Parkinson’s disease. Work conducted by Clemens Scherzer, MD, and colleagues at Brigham & Women’s Hospital (Harvard Medical School) in Boston, Massachusetts, revealed a specific expression pattern of eight genes that might someday be used to spot people at high risk of developing Parkinson’s disease.

No biomarker of Parkinson’s disease currently exists. Finding one is crucial to the development of the “Holy Grail” of Parkinson’s research, a neuroprotective treatment — meaning a treatment that could slow or stop progression of the disease, rather than just mask its symptoms. Biomarkers could help identify people early in the course of the disease, when such treatments would be most effective, or they could be used to track disease progression in people trying a new drug compared to people on placebo. The markers identified by Scherzer and his team could potentially be useful on both fronts, although further work must be completed before the true potential of these findings is known.

“This work was partly born out of the realization that, even if a neuroprotective therapy were discovered tomorrow, it alone would not be enough to cure Parkinson’s,” said Dr. Scherzer. “By the time PD is diagnosed, 70 percent of dopamine neurons have already been lost — the horse is out of the barn, so to speak. There is a crucial need for a biomarker that could identify the earliest clinical stages of Parkinson’s disease.” Only with such a marker in place could candidates for a neuropro-

TECTIVE treatment be identified in time to prevent symptoms of the disease from affecting patients’ lives.

Studying a population of 105 Parkinson’s patients and controls, the researchers scanned 22,000 genes to find those where the expression was different in the blood of people with PD compared to healthy subjects. Genes are the DNA ‘blueprints’ instructing cells how to make any one of the tens of thousands of different proteins crucial to various cell functions. Although all cells contain the same total set of genes, different cell types ‘express’ different genes and this can alter how a particular cell functions. The level of this expression can be measured easily in the laboratory using current technology.

The researchers’ results, published in the January 10 issue of the journal *Proceedings of the National Academy of Sciences*, found that a composite score measuring the expression of eight genes in blood can serve as a specific ‘fingerprint’ of PD. High scores were associated with a five-fold increased risk of PD.

They also found 22 additional genes whose expression was low in blood of people with Parkinson’s disease compared to healthy controls. The expression of one gene in particular, called ST13, was reduced by 40 percent in two separate populations of early-stage Parkinson’s patients as compared to healthy controls.

The protein product of the ST13 gene activates another protein called heat shock protein 70 (HSP70). HSP70 is one of the few known suppres-

sors of alpha-synuclein toxicity in flies, yeast, and mice. Alpha-synuclein aggregation, or clumping, is a hallmark of Parkinson’s pathology. “So the finding makes perfect biologic sense,” Dr. Scherzer said.

The Foundation moved quickly to advance the initial findings, and has provided supplemental funding for a follow-up study Dr. Scherzer and colleagues are currently conducting in Boston. It aims to validate the original results in a larger population. An additional multi-center follow-up “PROBE study” is being conducted at 20 sites across the United States.

If the results are validated, they hold potential to be transformed into a robust, simple, and inexpensive risk marker of PD that can be measured by widely available and precise technology.

“This work is the beginning of the beginnings of a simple blood test for Parkinson’s disease,” said Dr. Scherzer. “That is still a ways off. But I expect we will more quickly see these results incorporated into clinical trials and playing an important role in drug development.”

“I’m deeply grateful to The Michael J. Fox Foundation for its support of this work,” said Dr. Scherzer. “Back in 2001 when we were starting this work, the MJFF was among the first to foresee that biomarkers are an essential tool for curing PD. The Foundation got us started. We look forward to continued fruitful collaboration that will bring us still closer to improved treatments for Parkinson’s patients.”

The work was funded under the Foundation’s *Biomarkers* initiative.

NEWSBRIEFS: RECENT AWARDS

Researcher bios and grant abstracts are available at www.michaeljfox.org/research.

In November the Foundation awarded \$2.3 million in total funding for six research projects under its *Dopamine-Non-Responsive Symptoms of PD* initiative. The funding will drive pre-clinical focus on and clinical development for the range of Parkinson’s symptoms — including depression, constipation, postural instability and gait, cognitive dysfunction, sleep disorders, fatigue and pain, among others — that do not respond to existing dopamine replacement therapies.

In December, 12 research teams were awarded nearly \$1.5 million in total funding under the Foundation’s *Community Fast Track 2006* initiative. The program drives one-year projects to further the search for improved Parkinson’s disease treatments and, ultimately, a cure. The 2006 awards include funding for new and novel research into neurotrophic factors, cellular function of PD-implicated genes, and the role of the immune system in Parkinson’s disease. For more information on the evolution of *Community Fast Track* into the new *Rapid Response Innovation Awards*, please see page 4.

In January the Foundation announced \$4.6 million in total funding to 10 industry research teams under its first industry-exclusive funding program, the *Therapeutics Development Initiative*. The Foundation launched the program in 2006 as a key element in its strategy to ‘de-risk’ pre-clinical Parkinson’s disease research for biotech and pharmaceutical companies, thus expanding and catalyzing industry investments in the development of improved PD treatments and a cure.

ANDRES LOZANO, MD, PHD, TALKS TO MJFF ABOUT DEEP BRAIN STIMULATION

Deep Brain Stimulation (DBS) was approved by the FDA to treat Parkinson's disease in 1997. It has since been performed on thousands of people with Parkinson's and is currently the most common Parkinson's disease surgery.

In the surgery, doctors implant a small, battery-operated medical device called a neurostimulator into the brain. Once implanted, it delivers electrical stimulation to targeted areas that control movement, blocking the abnormal nerve signals that cause some of the symptoms of PD. DBS's precise mechanism of action is not known.

To mark the 10th anniversary of FDA approval, the Foundation asked Andres Lozano, MD, PhD, a DBS pioneer and long-time member of the Foundation's Scientific Advisory Board, some practical questions about where the procedure stands today and where it might be heading in the future.



Andres Lozano, MD, PhD

Ten years after FDA approval of DBS surgery, are we any closer to understanding how it works?

Well, I'd begin my answer by saying that we're in good compa-

ny not understanding exactly how DBS works; we don't understand how a great deal of medical interventions work. If you asked a group of doctors to explain how aspirin works, you'd probably get several different answers because we don't fully know. With that said, this is an important issue, because if we understood how DBS worked, we could refine the procedure and make it even better.

Parkinson's disease is a consequence of degeneration in the brain. This degeneration causes a malfunction in particular brain circuitry; certain circuits start firing in an abnormal way. We believe DBS works because electricity counters this abnormal pattern. But we don't know exactly how. Does the electricity stop the circuit firing? Does it make it faster or slower? We don't know. We simply know that there is an abnormal signal you can diminish with electricity, and that brings about a beneficial effect.

Work is ongoing, both in animal models and in patients, to refine our understanding in this area.

But it's not a simple question, and it's going to take more time.

Understanding that there's no such thing as "typical" in Parkinson's disease, please describe the type of patient who might stand to benefit most from DBS.

We estimate that approximately 10 to 15 percent of PD patients will benefit. It's really only for those patients who are running into difficulties in spite of their medication regimens. This might mean that their symptoms aren't responding to medication, they are experiencing too many adverse effects, such as dyskinesias, or they are enduring motor fluctuations — unpredictable shifts throughout the day between being completely off their meds and rigid; on with good function; and on with dyskinesia.

For those who are good candidates, DBS tends to smooth out functioning over the course of the day. On meds, patients may experience on- and off-phases throughout the day. Following surgery, the same patients will tend to be on for most of the day.

Certain symptoms don't respond to DBS at all. Unfortunately, they are the same symptoms that don't respond to dopamine replacement: cognitive impairment, speech problems, balance problems, and others. If you are disabled by dopamine-non-responsive symptoms, you are not a good candidate for DBS surgery.

The symptoms that don't respond to medication also don't respond to surgery? How frustrating.

True, but that's where the research comes in. Right now, for example, our team is working on a new intervention targeting a structure in the brain called the pedunculopontine nucleus (PPN). It seems to play a role in walking and balance problems in PD. We currently have Phase I and Phase II clinical trials under way to investigate the effects of implanting electrodes into the PPN, and the results look quite promising so far. The Michael J. Fox Foundation is funding similar research in Grenoble, France.

Speaking of dopamine-non-responsive symptoms — some surveys indicate that as many as 80 percent of PD patients will experience depression at some point in the course of their disease. Interestingly, DBS has been used with some success to treat non-PD-associated clinical depression. Is there any useful connection here?

We often hear that Parkinson's patients are more burdened overall by depression than by their motor symptoms. But we don't know whether depression in Parkinson's is the same as classic clinical depression. We don't know if it involves the same pathways, the same substrates. But there will be a great deal to learn from observing the effects of DBS on clinical depression, whether it may also be effective against other forms of depression.

In the meantime, there are other new treatment options coming along that show promise in relieving the depression we see in Parkinson's. Transcranial magnetic stimulation, or TMS, is one example. The Michael J. Fox Foundation is funding some research into TMS as a treatment for apathy, another non-dopamine-responsive symptom closely related to depression. TMS is a nonsurgical, noninvasive method of altering the firing patterns of neurons in the cortex. A physician holds a powerful magnet over the frontal regions of a patient's skull and delivers magnetic pulses. The procedure is usually repeated several times over the course of a few weeks.

As a patient, how can you know whether you are likely to benefit from DBS? Is there anything you can do beyond seeking a second opinion if you're not sure?

We have some indicators or predictors that help us determine who will benefit from DBS. For example, you can ask your doctor for something called the levodopa challenge test. This test helps us estimate what the surgery is likely to achieve in an individual patient and identify those who should — and should not — undergo the procedure.

Here's how it works: A patient comes into her doctor's office with no medication in their system whatsoever. The doctor administers the morning dose of levodopa and closely measures the benefit the patient derives from the medication.

Recall that symptoms that do not respond to levodopa also will not respond to surgery. So we use the levodopa challenge to take a precise snapshot of the symptoms the patient is experiencing and how responsive they are to dopamine replacement. The snapshot becomes our benchmark, meaning that we will not perform the surgery unless the patient is experiencing the symptoms that typically respond to surgery, and we are confident that they will derive at minimum the same benefit from the surgery as they are currently getting from the medication.

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NEWSBRIEFS: PROGRAM LAUNCHES

More information is available at www.michaeljfox.org/research.

In September the Foundation announced a new *PD Subtypes* initiative, up to \$1 million for research projects to initially characterize Parkinson's disease subtypes — distinct forms of the disease that may differ in onset, progression and response to treatment. This information could significantly alter our understanding of PD, improve ability to treat patients with existing therapies, and enhance development of novel treatments. Funding is anticipated by May.

In October the Foundation committed up to \$2 million to advance well-validated drug targets along the therapeutics development pipeline. The funding, anticipated by May, will be awarded under a new initiative, *Novel Approaches to Drug Discovery for Parkinson's Disease*, made possible by generous leadership funding from the neuroscience-based biotech firm Elan Pharmaceuticals, Inc.

Concurrent with *Novel Approaches*, the Foundation launched its \$ 2-million 2007 *Target Validation* effort. This annual program is designed to validate the therapeutic potential of various scientific discoveries and push them one step closer to the clinic. Funding is anticipated by June.

In January the Foundation announced the launch of its new *Rapid Response Innovation Awards*. With no deadline, the initiative will accept proposals on a rolling basis and will speed grants of up to \$75,000 to one-year 'high-risk, high-reward' basic or preclinical research projects in any Parkinson's-relevant arena. (See below, "From Fast Track to Rapid Response," for more information.)

PDGENE: FIRST-OF-ITS-KIND PD GENETICS DATABASE

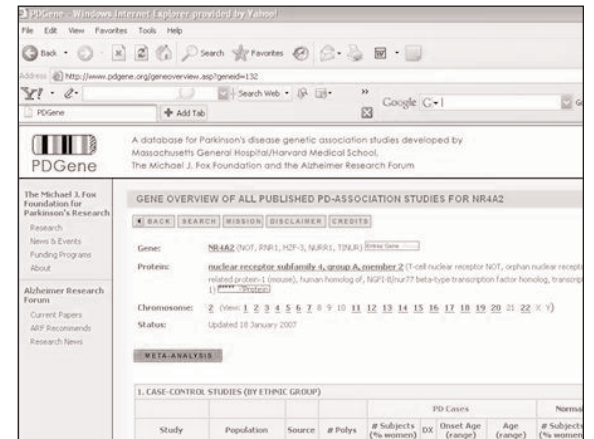
Last fall The Michael J. Fox Foundation and collaborators Lars Bertram, MD, of Harvard Medical School, and the Alzheimer Research Forum (AlzForum), announced the launch of PDGene (www.pdgene.org), an online inventory of studies on genes implicated in Parkinson's disease.

"Given the rapid pace of genetic discovery and the previous lack of a centralized information source for these discoveries, the development of PDGene is an essential step in raising awareness to translate genetic discoveries into treatments," said Deborah W. Brooks, the Foundation's president and CEO. "With this database we are aiming to keep the field informed and unify future steps toward improved therapies that will significantly impact patients' lives."

A Centralized Resource for Scientists

The first tool of its kind for Parkinson's, PDGene is a nod to the field's need for a more refined understanding of possible genetic contributions to Parkinson's disease risk. To date, only a handful of genes have been strongly linked to rare hereditary forms of Parkinson's disease. For the vast majority of Parkinson's cases, recent work indicates that there is no single shared genetic 'smoking gun.' More likely, multiple gene variants, as well as environmental factors, may interact to affect risk. The combination of factors may also differ from group to group, complicating attempts to understand the disease and making it difficult to replicate genetic findings from one study to the next.

PDGene is a centralized and regularly updated Web portal for scientists, who will now find in one place information about every gene that previous research has implicated in Parkinson's. The site includes a list of all published papers that looked for a link between a gene and PD (whether supportive or not); basic information about each study; and an overall determination of how strong the evidence is for a gene's link to



PD, based on pooled results from the published studies. To encourage dialogue and collaboration, scientists may also submit comments about each study. Content decisions are made by Dr. Bertram's team at MGH with oversight from a Scientific Advisory Board of PD researchers and geneticists, including MJFF representation. To ensure objectivity, only those studies published in peer-reviewed journals may be considered for inclusion in the database. Papers also must be available in English.

"A Crucial Need"

"I am pleased to be working alongside MJFF and AlzForum to develop this important tool for the PD community," said Dr. Bertram. "Genetics' role in Parkinson's is complex. There is a crucial need for shared tools and resources."

PDGene models an existing database called AlzGene, also created by Dr. Bertram and his group in collaboration with AlzForum.

"We are delighted to work with Lars and MJFF on PDGene," said June Kinoshita, executive editor of AlzForum. "We hope this project will help foster greater interaction among researchers who are studying Parkinson's, as AlzGene has done for those studying Alzheimer's."

Links to PDGene are available on the Foundation's Web site (www.michaeljfox.org) and The AlzForum site (www.alzforum.org).

FROM FAST TRACK TO RAPID RESPONSE: EVOLUTION OF "JUST IN TIME" FUNDING FOR NOVEL PD RESEARCH

In January the Foundation announced that a new program, *The Rapid Response Innovation Awards (RRIA)*, would replace *Community Fast Track* in the Foundation's portfolio of funding initiatives. Foundation SAB member Marie-Francoise Chesselet, MD, PhD, was a strong proponent of the change, which she calls an "upgrade":

"RRIA is a prime example of how the Foundation is

always looking for ways to take its work to the next level," said Dr. Chesselet. "It was a natural evolution from the already responsive *Community Fast Track* model to RRIA, which provides an even nimbler mechanism for fast review and greater risk-taking. The program offers researchers a greater opportunity to test novel ideas that may have little or no preliminary evidence, but hold potential to significantly impact the field."

RRIA is designed for speed. The program has no deadline, accepting submissions on a rolling basis throughout the year, and its three-page application is even more streamlined than MJFF's standard five-page version. "The structure allows the Foundation to adjust to the needs of the scientific community," explained Dr. Chesselet. "It's another thoughtful strategy to ultimately help narrow the gap between discovery and the clinic."

FOUNDATION AWARDS \$1.9 MILLION TO SUPPORT CEREGENE, INC. PHASE II CLINICAL TRIAL

As part of a continuing partnership with San Diego-based biotech firm Ceregene Inc., The Michael J. Fox Foundation has awarded \$1.9 million in support for the next stage of the company's Phase II clinical study of CERE-120. This novel gene therapy product uses avector to deliver neurturin, a potent nervous system trophic factor. The funding, awarded last fall, followed on promising results from Ceregene's open-label Phase I trial of CERE-120, which also received MJFF support.

Trophic factors, also known as neurotrophic or growth factors, are considered one of the most promising avenues for Parkinson's therapies because they promote survival and improve function of neurons. Neurturin was discovered by Eugene Johnson, PhD, MJFF chief scientific advisor, and colleagues at Washington University in St. Louis. It is a member of the same protein family as GDNF and, like GDNF, has shown potential in pre-

clinical studies to slow or stop PD progression.

"Our partnership with Ceregene bears out two of our top priorities: advancing trophic factor research and moving quickly on clinical research with potential to significantly impact patients' lives," said Deborah W. Brooks, president and co-founder of The Michael J. Fox Foundation. "We're enthusiastic about the preliminary safety results from the Phase I CERE-120 trial, with no significant adverse effects seen."

Foundation funding is providing general support for the Phase II trial and enabling Ceregene's program, which is headed by Ceregene's chief operating officer and head of preclinical and clinical development Raymond T. Bartus, PhD, to gather more long-term efficacy and safety data than would otherwise be possible. Assuming positive safety and efficacy results, this additional data may also help identify trends that could

aid in the design of future trials testing CERE-120's potential neuroprotective effect in patients.

The MJFF funding complements Ceregene's own multi-million dollar investment in the study, which opened in November and is enrolling approximately 34 total patients at nine sites throughout the United States. (*For more information about the trial and enrolling, visit www.pdtrials.org and search for "Ceregene."*)

"We are heartened by the Phase I results and pleased that the Foundation has continued its support of CERE-120's clinical testing," said Jeffrey M. Ostrove, PhD, president and CEO of Ceregene. "We look forward to working with the Foundation's research staff and scientific advisors, who share our goal of establishing as efficiently as possible whether this therapy will fulfill its promise for Parkinson's patients."

FOUNDATION LAUNCHES \$2.8-MILLION PRESCOTT FAMILY INITIATIVE AT THE ARIZONA PARKINSON'S DISEASE CONSORTIUM

In November The Michael J. Fox Foundation announced a \$2.8-million, three-year collaborative initiative with The Arizona Parkinson's Disease Consortium (APDC), a group of six research institutions including Mayo Clinic in Arizona and Sun Health Research Institute. *The Prescott Family Initiative at the Arizona Parkinson's Disease Consortium* will support and expand Sun Health's Brain and Body Donation Program, which conducts in-depth clinical and post-mortem studies of normal-aging adults and Parkinson's patients. The program was made possible by a leadership donation from Judi and George Prescott and their family. Mr. Prescott, a prominent Wisconsin businessman and philanthropist, sits on the Foundation's Board of Directors.

Maximizing the Potential of a Unique Resource

"The Brain and Body Donation Program is a unique resource," said Deborah W. Brooks, president and co-founder of The Michael J. Fox Foundation. "This collaboration will maximize its considerable potential to increase understanding of Parkinson's disease by comprehensively tying clinical evidence to pathological underpinnings of onset and progression. Our goals are to prioritize the collection of data that can open up new avenues of pursuit for translation, and to ensure that all data gathered is highly accessible to researchers conducting both basic and drug development research."

Sun Health started the Brain and Body Donation Program 19 years ago. The program currently has more than 780 participants, including both PD patients and healthy controls, with an enrollment goal of 1,000 within three years. Participants are evaluated annually by a movement disorders specialist, a behavioral neurologist and a neuropsychologist. All subjects agree to donation of their brain following death; some also agree to a full-body autopsy and donation of other bodily organs. The information compiled on three subsets — healthy adults; PD patients; and healthy adults who, over the course of their enrollment, experience PD onset — can offer a vivid picture of changes in the brain and the body before, during and after Parkinson's onset.

Optimization Through Three Core Research Areas

The *Prescott Family Initiative* will optimize The Brain and Body Donation Program through three core areas of research:

A **clinical core** will implement additions to the current roster of ongoing clinical assessments to drive identification of predictive clinical markers of PD onset as well as progression to dementia. These additions will include assessments of sleep disorders and autonomic dysfunction including constipation.

A **neuropathology core** will identify pathological markers of PD in both the peripheral nervous system and the central nervous system. This could allow for earlier diagnosis of PD and help test the emerging hypothesis that Parkinson's may extend beyond the substantia nigra, and even beyond the central nervous system.

A **bioinformatics core** will refine the program's database and develop systems enabling external researchers to access the information. The data gathered will be useful for testing predictive models of risk for PD onset and risk of onset of dementia in subjects already diagnosed with PD.

Ambitious Scope

The program will comprise both long-term studies comparing PD patients to healthy controls, and specific clinical and postmortem research to identify motor, non-motor and other manifestations of Parkinson's as possible early markers of disease onset. Further studies will be done to identify both cognitive and non-cognitive markers of incipient dementia in people with PD. All members of the APDC (which also includes Barrow Neurological Institute, Arizona State University, Banner Health Good Samaritan Medical Centers, and Translational Genomics) jointly participate in the recruitment and clinical assessment of subjects enrolled in the Brain and Body Donation Program, and jointly conduct research involving those subjects.

TEAMFOX

FOR PARKINSON'S RESEARCH

GARY D. LEITH FOUNDATION MAKES A GRAND ENTRANCE INTO THE PD COMMUNITY



Gary D. Leith and his mother at the GDL Foundation's 1940s-themed Black & White Gala

In June 2002 Gary Leith of Frederick, Maryland, was diagnosed with Parkinson's. His diagnosis followed his mother's in 1996. He made an empowering decision to battle Parkinson's for himself, his

mother and the millions of Parkinson's patients worldwide.

Gary founded The Gary D. Leith Foundation for Parkinson's Research in 2006. He became a charter member of Team Fox and has donated

88 percent of his foundation's proceeds to MJFF — a grand total of \$95,000, the most any Team Fox member has raised to date. Proceeds were raised through two major fundraisers — a black-and-white gala followed by a golf event the next day. The gala featured a 1940s theme, a swing band and dance lessons for guests. During the golf event, plaques were awarded in lieu of cash prizes, so that the winners would always remember the impact their day of golf made on the PD community.

"Seeing over 300 friends, family, co-workers and perfect strangers enthusiastically join me to raise money for PD research has made me truly realize the magnitude of our efforts — and how generous people can be."

STUDENTS GIVE BACK: A NEW WAY FOR STUDENTS TO GET INVOLVED IN THE FIGHT TO CURE PD

Students Give Back is a new Team Fox program providing students from kindergarten to college with creative fundraising ideas to get involved in the fight against Parkinson's disease. It offers helpful how-to guides for starting a fundraiser on campus or in the community.

Pancakes for Parkinson's is one great example of a creative and unique fundraiser started by a student. In 2004, University of Virginia student Mary Leland's dear friend was diagnosed with PD. Mary took her love of pancakes and created a community event to help make a difference. That fall she hosted her first Pancakes for Parkinson's, now an annual event on the UVA campus bringing together

er teachers, students, alumni and parents for a pancake breakfast to raise funds for Parkinson's research. This event has raised over \$56,000 for Team Fox over the past three years, and Mary plans to expand the campaign to other schools nationwide.

"To feel like a part of the Foundation's mission and to start a tradition in my community has been extremely rewarding for me," Mary said. "I encourage everyone to take the plunge — look at your community and find the event that will bring everyone together, in pursuit of a cure."

For further information, contact David MacNiven at dmacniven@michaeljfox.org.

MARATHONERS RACE FOR A CURE



Veronique Enos, a first-time marathoner and longtime MJFF staffer, "looked beautiful... she made you want to run a marathon," said a co-worker. Her Team Fox "Vero-thon" raised more than \$20,000 for Parkinson's research.

Last November 5 was an exciting and emotional day for Team Fox members and their loved ones. Almost 90 runners from the United States and Canada joined Team Fox as part of the ING New York City marathon's expanded charity program, raising over \$250,000 for Parkinson's research.

Throughout the year, these runners prepared for the big race and participated in other marathons around the country. Many ran in honor or memory of a loved one.

Team Fox is now one of 10 U.S. charity partners in the World Marathon Majors, a collaboration of the world's elite marathons including Boston, Flora London, Real, — Berlin, The LaSalle Bank Chicago and ING NYC. Team Fox guaranteed entries are available for upcoming races in Boston on April 16 and in London on April 22. For more information about these races, visit www.worldmarathonmajors.com. To qualify for a Team Fox bib, sign up for Team Fox at www.teamfox.org.

FIGHT PD IN YOUR NECK OF THE WOODS

Come out to raise funds and awareness for PD research at these upcoming events.

NORTHEAST

New York Knicks at New Jersey Nets
Friday, April 13, 2007

\$10 of each ticket sold will benefit Team Fox and the Parkinson's Disease Foundation.

Contact: Nets group sales manager Rich Lacara (201) 635-3125 or rlacara@njnets.com

Tom Poehlmann Memorial Fundraiser

Sunday, April 1, 2007
McFadden's at Citizen Bank Park, Philadelphia, PA
Contact: josephine.poehlmann@verizon.net

MIDWEST

Elizabeth Fashions Style Show
Thursday, May 17, 2007

The Avalon in Merrillville, Indiana
Contact: elizabethfashions@comcast.net

Northwest Indiana Benefit for Parkinson's Research

Saturday, May 19, 2007
Radisson Hotel in Merrillville, Indiana
Contact: Kerry Mitchell (219) 844-4636

FOUNDATION ANNOUNCES NEW CEO, CHANGES TO SENIOR MANAGEMENT TEAM



Sarah Orsay

On March 1 Sarah Orsay joined The Michael J. Fox Foundation as Chief Executive Officer.

The search for a new CEO was initiated following a decision by

Deborah W. Brooks,

MJFF's founding president and CEO, to relocate to Delaware in mid-2007. While Ms. Brooks will remain with the Foundation as co-founder and president, her role will shift from day-to-day oversight to a greater emphasis on her critical roles in principal-gifts fundraising, advising on strategic and programmatic direction, and serving as an ambassador to new and existing external audiences.

Ms. Brooks' transition created the need for a new chief executive with the skill, experience and vision to lead the organization through its next stages of growth.

"Our challenge," said MJFF Board Chairman David Golub, "was to find an unusual combination of talents — an exceptional strategic thinker with a creative, solution-oriented approach to leadership, and with a passion for speed to match the Foundation's sense of urgency. Sarah has it all."

As CEO, Ms. Orsay will be chiefly responsible for leading development of the Foundation's strategic plan and overseeing its execution in four primary areas: fundraising, research investment and prioritization, communications and organizational growth. Working closely with the Foundation's senior management, she will provide day-to-day management

and oversight of all Foundation activities. And she will oversee all areas of financial management and controls, ensuring that the Foundation is fiscally sound and well-funded.

"This is a win-win for the Foundation," said Michael J. Fox. "Debi's new role gives us full-time access to her vision, dedication to the cause, and sense of urgency, which are an inspiration to MJFF and the Parkinson's community at large. And we are thrilled to have found, in Sarah, a leader with the rare combination of skills required to continue driving toward fulfilling our mission."

Ms. Orsay comes to the Foundation from Goldman, Sachs & Co., where she was Managing Director and Head of the Endowment and Foundation Coverage Group in New York. Partly inspired by a meeting with Ms. Brooks in 2005, Ms. Orsay had been seeking a career change to the not-for-profit sector.

"It was clear to me that the Foundation is an environment as enterprising, challenging, exciting, and personally fulfilling as the career from which I am transitioning," said Ms. Orsay. "I'm excited to apply my energy and experience to help lead this unique organization. And as someone with a PD connection in my own family, I have firsthand knowledge of the urgent need for improved treatments and a cure."

Prior to Goldman Sachs, Ms. Orsay ran the Pension, Endowment and Foundation Coverage Team for Morgan Stanley's Institutional Securities Division. She was promoted to managing director and partner in 2002. Ms. Orsay began her Wall Street career at Bankers Trust company in 1991.

"Throughout her career, Sarah has demonstrated exceptional talent and ability. Both I and the Foundation's entire senior management team are excited to have her join us in steering the organization toward improved treatments and a cure for PD," said Ms. Brooks. "I look forward not only to a smooth transition to our new leadership structure, but to working closely with Sarah on the challenges and opportunities that will undoubtedly arise as she ramps up into her new role."

Ms. Orsay earned her BA, *magna cum laude*, from the University of Pennsylvania. She received a Certificate of Completion from the Pushkin Institute of Russian Language, located in Moscow, Russia. She was enrolled as a PhD candidate in Political Science at Columbia University and the Harriman Institute for the Advanced Study of the Soviet Union from 1988 until 1990.

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FOUNDATION RAISES NEARLY \$5.7 MILLION AT "FUNNY THING" 2006

The Michael J. Fox Foundation raised nearly \$5.7 million for Parkinson's research at the record-breaking sixth installment of its gala event, "A Funny Thing Happened on the Way to Cure Parkinson's," Saturday, November 11, 2006. The evening was co-chaired by Lonnie and Muhammad Ali, Cheryl and David Einhorn, Holly Andersen and Douglas Hirsch, and Helen and Martin Scorsese.

Nearly 1,000 guests — including Denis Leary, Susan Sarandon, Donny Deutsch, Ronald O. Perelman, Ryan Reynolds, Famke Janssen and New York Mets MVP David Wright — joined

Michael J. Fox and Tracy Pollan for the British Invasion-themed party. Performances of classic Beatles tunes by The Fab Faux, a Beatles tribute band, and by rock icons Sheryl Crow, Rob Thomas and Elvis Costello had guests dancing at their tables. Early in the evening, surprise guest Axl Rose took the stage for a masterful rendition of Paul McCartney's "Live and Let Die."

The Foundation's Board of Directors covered the costs of putting on the event, so every dollar raised will go straight to the Foundation's research program. Michael J. Fox and the Foundation staff thank the co-chairs, performers

and guests who made the evening such an incredible success. Funny Thing 2007 will be held on December 1.



The evening ended with a spirited jam session that included performances of "Revolution," "Back in the U.S.S.R.," and "Twist and Shout."

Photo by Kevin Mazur



Grand Central Station, P.O. Box 4777
New York, New York 10163
www.michaeljfox.org

WINTER/SPRING 2007 NEWSLETTER

DBS: STATE OF THE FIELD AND NEW HORIZONS,
Continued from Page 3

This same test can be useful in other situations as well. Say a PD patient has arthritis in one knee. The knee is stiff, but how can you measure the proportion of the problem being caused by Parkinson's? The levodopa challenge test can gauge that for you.

There's been some concern over doctors performing DBS on Parkinson's patients who are not necessarily good candidates.

That may be the case, but I think a bigger issue is whether all the good candidates for DBS have access to it.

There are approximately 1 to 1.5 million people with Parkinson's in North America. If 15 percent of them could benefit from DBS, as we estimate, you'd expect around 150,000 PD patients in North America alone to have undergone it. But the worldwide total figure to date is just 35,000.

So there's some degree of underpenetration for the procedure, and the question is: why? Do patients not know about DBS? Do they perceive it as too risky? Are doctors not buying into performing it? Is the equipment too difficult to come by? These questions deserve serious consideration, as we have a significant population of people with PD

who might be helped by DBS but are not getting it.

With that said, DBS is decidedly not for everyone. As with any other aspect of a PD treatment regimen, the most important thing is to work closely with your doctor to determine what works for you.

Dr. Lozano is Professor of Neurosurgery and Canada Research Chair in Neuroscience at the University of Toronto and the Toronto Western Hospital, Toronto, Canada. You can read more about him and his research at www.michaeljfox.org.

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