

Citing Progress and Charting Prospects: The New NIH Parkinson's Research Plan

By Robin Elliott

Six years ago, the National Institutes of Health (NIH) issued the *PD Research Agenda*, its first comprehensive “plan” for Parkinson’s research. That report, drawing on the expertise of dozens of leading PD scientists, identified multiple pathways to exploring the disease and placed a price-tag on the work — over five years — of about \$1 billion.

Today, people are asking: How far have we come on our path to finding the causes of the disease and its cure? Where is PD research headed?

These are the questions that government research administrators wrestle with in the *2006 Parkinson's Research Plan*. The 34-page document is based on recommendations from a PD Summit that was organized by the National Institute of Neurological Disorders and Stroke (NINDS) in June 2005. Attendees included leading academic and industry clinicians, scientists, patient advocacy groups and NIH representatives. The plan is a comprehensive overview of the progress of investments in PD research by government and other agencies from 2000 to 2004. It also aims to identify promising



directions for future research.

While the report does not attempt to pinpoint just where we are in our drive to beat Parkinson’s, the authors note with pride the number and range of scientific studies that have been sponsored since the earlier report in 2000. They also point to gains that have been achieved in “accelerating therapeutics discovery and translational research” — that is, over and above the “basic” research that remains the core of the work that is supported by the NIH. This strengthened emphasis on translational research has been a major priority of the PD community in recent years.

Improving our understanding of PD

Of all the areas of basic Parkinson’s science, none has shown more progress than genetics. Since 1997, when the link was discovered between certain cases of PD and a mutation in the gene for a protein called alpha-synuclein, five additional genes have been linked to Parkinson’s and “evidence suggests the existence of additional, as yet unidentified genes.” These advances “provide a direct window into the cellular causes of disease, not only for individuals with hereditary disease, but

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NEWS IN BRIEF

Study Suggests DBS More Effective than Meds Alone for Advanced PD

A study that compared best medical therapy to deep brain stimulation (DBS) in people with advanced PD showed that DBS may be more effective in managing Parkinson’s symptoms.

Published in the August 31 edition of *The New England Journal of Medicine*, this study was conducted in Germany and Austria with 156 people with Parkinson’s under the age of 75 who had severe motor symptoms, wearing-off episodes and dyskinesias. Participants were randomly assigned to receive medical management or to undergo DBS in the subthalamic nucleus.

After six months, assessments showed that the DBS group had a nearly 25 percent improvement in mobility, emotional well-being and physical discomfort. The medication group remained at nearly the same level that was observed at the start of the trial.

Overall incidence of adverse effects was higher in the medication group. However, serious adverse effects, including one fatal brain hemorrhage, were more common in the DBS group.

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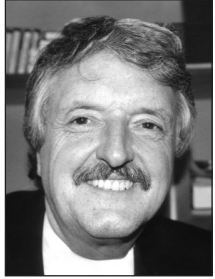


**Join PDF for our 50th
Anniversary Educational
Symposium**

See page 9 for more information

Educating and Supporting the Parkinson's Community

In the Fall issue of *PDF News & Review*, as part of our celebration of PDF's 50th anniversary in 2007, we described the research dimension of our three-part mission.



Robin Elliott

In this issue, we highlight how we fulfill the second part of our mission: providing accurate, accessible information and education on Parkinson's.

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

Parkinson's Information Service (PINS)

At PDF, we understand that people have personal, specific questions that need answers. That is why we take great pride in our Parkinson's Information Service (PINS), a multi-faceted approach to responding to the Parkinson's community's needs and questions.

One of the main features of the service is a US toll-free number, (800) 457-6676, which is available from 10 AM to 5 PM EST. This line is staffed by a team of Parkinson's information specialists, including a licensed clinical social worker, who are trained to answer general questions about Parkinson's disease, its treatments and therapies, research advances and coping strategies. Our staff also maintains referral lists of experienced neurologists and we are often able to direct callers to other resources in their area, such as support groups.

After speaking with an information specialist, callers can request a custom-tailored package of print and audiovisual materials on Parkinson's. The package

covers a wide range of topics and can be used as a reference for future questions.

For people who are more comfortable with the Internet, access to our services is available through "Ask the Expert," a section of the PDF website, located at www.pdf.org. Visitors can submit a question or review our archives of frequently-asked questions.

Educational materials

PDF has published and distributed patient-education materials, including this newsletter, since our founding in 1957. In recent years, we have expanded and refined this program.

"PDF performs a careful review of needs and collaborates with members of the community to ensure the production of quality materials"

Among the current products is a video and print package for the newly-diagnosed patient, entitled *Diagnosis Parkinson's Disease: You are not alone*; an original exercise video, entitled *Motivating Moves for People with Parkinson's*; and an authoritative brochure on the most helpful web resources for the Parkinson's community. The list also includes updates of existing publications, such as *Deep Brain Stimulation for Parkinson's Disease* and *Parkinson's Disease Q & A*, a guide to the most frequently-asked questions about PD.

Before initiating work on a new publication, PDF performs a careful review of needs and collaborates with members of the community to ensure the production of quality materials that meet a specific need. Our efforts have yielded impressive

results, spurring a more than 50 percent increase in requests for our educational materials in 2006 compared to 2005 — including many from beyond the US.

The PDF website

One major focus of our efforts to better serve the Parkinson's community has been improving the content and structure of the PDF website (www.pdf.org). With the help of design and website consultants, we have freshened and re-organized our site. The content has been enriched with a detailed section on treatments (including descriptions of Parkinson's medications, possible drug interactions and tips to save money) and a growing series of fact sheets that addresses some of the most pressing issues that people with Parkinson's face.

Visitors can now preview and request print copies of PDF publications from the website, and all of our new materials are available for downloading. As we continue to add to the website and make it even more user-friendly, we are noticing an impressive surge of visitors in 2006: nearly double last year's numbers!

Clinical trial education and awareness

It is estimated that less than one percent of the one million people in the US with Parkinson's disease have ever participated in a clinical trial. This is far short of the number of individuals that researchers anticipate will be needed over the next few years — potentially resulting in severe delays in new treatments.

In response to this concern, PDF launched a community initiative called *PDtrials* in collaboration with the other national Parkinson's organizations. Accomplishments to date include the creation of www.PDtrials.org, a website in English and Spanish that provides general information on clinical trials and a list of Parkinson's trials that are enrolling volunteers. *PDtrials* also offers a comprehensive set of educational materials.

One initiative of the project is outreach to general neurologists and other physicians, finding ways to encourage them to refer their patients to trials.

All of these essential services are made possible only because of your support. We are so grateful!

Robin Elliott is Executive Director of the Parkinson's Disease Foundation.

SPOTLIGHT

on Research
Supported by PDF

Profile of David Sulzer, Ph.D.
Associate Professor, Departments
of Neurology and Psychiatry
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At the Parkinson's Disease Foundation (PDF), we invest a substantial portion of our research dollars in funding basic sci-



Dr. David Sulzer

ence to determine the causes of, and find a cure for, Parkinson's disease. An exciting microcosm of this work is the laboratory of Dr. David Sulzer at Columbia University. For more than 20 years, Dr. Sulzer has

worked to provide a deeper understanding of why the brain works the way it does, and to shed light on what goes wrong when Parkinson's occurs.

Dr. Sulzer's days are divided between his work in the labs and his educational endeavors. His laboratory has two focuses, the first of which is to understand how

the brain circuits that control learning, motor movement and habit formation function in a normal brain. The literature on this topic is surprisingly scant, and Dr. Sulzer's team has enriched it significantly. One of its contributions is to develop a new technology, using an electrode and carbon fibers, that allows researchers to actually see neurons as they release dopamine, the neurotransmitter that is deficient in Parkinson's. Through this technology, one can take a more in-depth look at how the circuits of the brain interact.

The second focus of Dr. Sulzer's lab is to explore the question of why neurons die in this disease. He and his colleagues are currently concentrating on alpha-synuclein, a protein that in mutant forms causes some cases of inherited Parkinson's, and is likely mishandled in almost all cases of the disease. Their hypothesis: that in Parkinson's disease, mutant and altered forms of alpha-synuclein cannot be disposed of properly and build up inside of neurons, eventually turning into a structure called the Lewy body (a pathological hallmark of Parkinson's disease).

Work by Dr. Sulzer's laboratory in collaboration with Dr. Ana Maria Cuervo at the Albert Einstein College of Medicine showed how alpha-synuclein is normally broken down, and why this does not occur with the mutant forms in Parkinson's. Their recent work is indicating why normal alpha-synuclein breakdown does not

occur in the most common forms of Parkinson's, which appears to result from a reaction between the protein and dopamine. With this information, Dr. Sulzer's lab is working to determine how the non-degraded alpha-synuclein then damages neurons. The team is currently experimenting with a viral vector in an animal model of Parkinson's to package and deliver dopamine to these neurons in a way that will prevent the damaging reaction between alpha-synuclein and dopamine.

In 2004, Dr. Sulzer received a \$2 million University Training Grant from the NIH to implement and lead Columbia University's Neuroscience Training Program. A total of 40 postdoctoral fellows trained from 2004–2009 will benefit from Dr. Sulzer's instruction.

Dr. Sulzer serves as a reviewer for several prestigious scientific journals, organizes conferences for numerous scientific societies, lectures widely and is a reviewer for grant proposals submitted to PDF and other PD organizations. He has mentored nearly 30 postdoctoral candidates, fellows and visiting students at Columbia University.

Dr. Sulzer's work is supported as part of PDF's Center Grant to Columbia University. For fiscal year 2007, PDF's grant of more than \$2 million provides important funding to one of the world's largest and most influential teams of Parkinson's disease scientists.

News In Brief

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Results Presented from Early Gene Therapy Trials

In October, two research teams announced the results from early-phase human trials of gene therapy to treat Parkinson's disease. Gene therapy is an experimental treatment method that injects a gene carried by a virus deep into the brain where Parkinson's occurs. The goal of gene therapy is to slow the course of the disease by preventing brain cells from dying.

At the Society for Neuroscience meeting, Dr. Matthew J. During of Weill Medical College of Cornell University (a PDF Center Grant recipient) presented data from a trial that tested the safety of the therapy using a gene for an enzyme related to a neuro-

transmitter called gamma-amino-butyric acid, or GABA, which is essential for controlling muscle movements. Dr. During and his colleagues surgically implanted one of three doses of the enzyme into the brain on one side of the subthalamic nucleus in 12 people with Parkinson's. No serious side-effects developed and by six months, patients showed improvement in their parkinsonian impairments. Brain scans showed increased GABA activity.

At the American Neurological Association meeting, Dr. William J. Marks reported on a trial led by scientists from Rush University Medical Center (another PDF Center Grant recipient) and the University of California, San Francisco. The team tested neurturin, a nerve growth factor that occurs naturally in the brain.

Researchers injected a gene carrying neurturin into the putamen of 12 people with Parkinson's. Both sides of the brain received the implant and two doses were used. No serious side-effects occurred. At six months the patients' parkinsonian signs seemed to improve.

Scientists note that while the data from both studies are encouraging, the trials are early and were focused primarily on safety, not efficacy. Also, some patients might have been experiencing the "placebo effect" often observed in surgical trials.

Risks of gene therapy include infection, bleeding and barriers to easy termination of the treatment if side-effects occur. Follow up on the participants will continue, and controlled Phase II trials to assess efficacy are in the planning stages.

Nutrition and Parkinson's Disease: What Matters Most?

Navigating the maze of nutrition information and advice available to the public is challenging, even for a healthy consumer. Add Parkinson's disease to the mix and the challenges spiral higher. The nutritional issues faced by people with PD are complex and diverse, and many of the issues do not have clear answers.

When it comes to nutrition, what matters most? Here we help you to answer that question.

Eat a balanced diet

It is difficult for a person to feel well and maintain energy when he or she is not eating properly. Eating properly involves eating regularly (no meal skipping), eating a variety of foods from all of the food groups (grains, vegetables, fruit, milk/dairy, meat/beans) and eating prudently to maintain a healthy weight. Although this sounds like simple advice, implementing it can be a challenge, particularly if you have a hectic lifestyle or if the symptoms of Parkinson's are affecting your ability to shop, prepare food and eat.

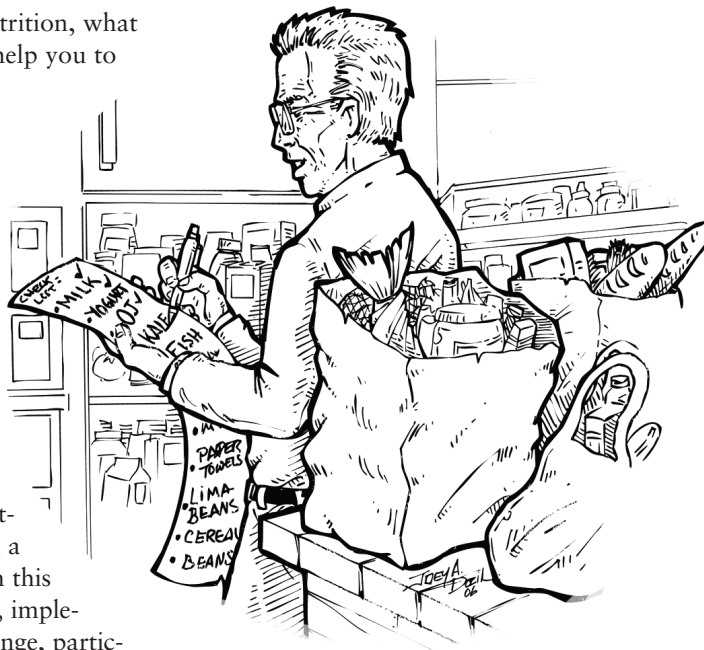
If you are not eating as well as you should, you may wish to consult a registered dietitian who can help assess your food intake and discuss with you strategies for improving your diet. It is also helpful to seek the assistance of others for shopping and meal preparation, and to keep easy-to-eat, nutritious foods on hand. If you have any problems with depression, this can interfere with appetite; be sure to discuss the problem with your doctor.

Maintain bone health

People with Parkinson's are prone to osteoporosis, a disease caused by low bone-mineral density. Risk factors for osteoporosis include older age, low body

weight, smoking, excessive alcohol intake, limited exposure to sunlight, inadequate intake of vitamin D and calcium and lack of weight-bearing exercise.

Osteoporosis can be especially worrisome to a person with Parkinson's who faces an increased risk of falling. The inevitable result is an increased risk of fractures, which are dangerous and painful and tend to be detrimental to one's quality of life. Ask your doctor about having your bone-mineral density checked. If it turns out to be low, medical treatments may be available.



To maintain bone health, make sure your diet includes plenty of calcium and vitamin D. People who are over the age of 50 should consume 1500 mg of calcium and 800 IU of vitamin D daily. Milk and milk products are the richest dietary source of calcium. Three servings per day are recommended (one serving is one cup of milk or yogurt, or one and one-half ounces of hard cheese). Although there are other calcium-containing foods (e.g., tofu, calcium-fortified soy-based beverages, orange juice and dark leafy greens), calcium from non-dairy sources may not be well-absorbed.

You can also obtain vitamin D by getting outdoors regularly and consuming foods rich in vitamin D (e.g., vitamin D-fortified milk, yogurt or breakfast cereals

and fatty fish). If you live in a region with limited sunshine and/or do not consume many vitamin D-rich foods, use of a nutritional supplement is recommended.

Supplements come in several forms. Some are easier to tolerate than others. Your pharmacist will be able to advise you on the different kinds available.

Maintain bowel regularity

Constipation is common in Parkinson's disease. While this can be an embarrassing issue to raise with your healthcare provider, prevention and treatment of constipation is critical, as severe constipation can lead to bowel obstruction, a potentially life-threatening condition.

Although the constipation observed in Parkinson's is due in large part to the disease itself, lifestyle measures can be useful for managing it. These include eating foods high in fiber (whole grain bread, bran cereals or muffins, fruits and vegetables, beans and legumes and prunes) and drinking plenty of fluid. Then there is exercise, which helps maintain bone density as well as eases constipation.

If you are not able to achieve bowel regularity through lifestyle alone, laxatives and other bowel interventions may be required. Make sure to see your doctor if constipation persists.

Balance medications and food

The medications used for Parkinson's can themselves cause nutrition-related side-effects, such as nausea and poor appetite. Typically these side-effects are most severe when a medication is first prescribed but some individuals have continuing problems with them. Taking a small snack (such as ginger ale and a few crackers) along with medications may help to control these side-effects. If nausea or poor appetite persist, contact your doctor, as these symptoms can lead to undesired weight loss.

Amino acids (from dietary protein) can interfere with the uptake of levodopa into the brain. If you find (not everyone experiences this) that eating high-protein food (such as meat, fish, poultry and dairy products) decreases the effectiveness of levodopa, keep the meat portion of your meal to about the size of a deck of cards and take your Sinemet® half an hour prior to a protein-containing meal.

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Join the pdfchampions

Since 1957, the Parkinson's Disease Foundation (PDF) has funded more than \$50 million worth of the most promising scientific research while providing education and support to people living with the disease. Our efforts have been greatly enhanced by people across the country who have joined the fight against Parkinson's by organizing events to benefit PDF. People with Parkinson's, their friends, family and colleagues have generously given their time and energy to raise funds for PDF through concerts, marathons, bike rides, bake sales and many more creative endeavors.

To recognize these supporters, and to encourage and provide assistance to organizers who are planning a fundraiser, we have created a new program called *PDF Champions*. By signing up as a partner in PDF's fundraising efforts, you will receive official endorsement of your event, technical assistance, PDF materials and recognition on our website.*

To get started, visit www.pdf.org to download our fundraising packet. Fill out the registration form and fax or mail it back to PDF. We will review your registration and contact you to help get you started and to answer any questions.

If you are Internet-savvy, you can also register to raise funds online and create your own personal fundraising page! PDF has signed on with ActiveGiving.com to provide you with an online page as the home base for your event. Start by visiting www.pdf.org and click on "Become a PDF Champion." Once you have registered as a fundraiser, you can upload photos and write about why you are raising money for PDF. Email the link to your friends, family and colleagues! They can make a secure online donation through your webpage with proceeds going directly to PDF.

Here are some ideas of how you can raise funds online.

Organize an event

Running in a marathon? Walking, biking, sailing or bowling? For any of

the events you organize or participate in, you can create an online sponsor page so your friends, family and colleagues can lend their support.

Click to a cure

You do not have to have an event to help. You can create a personal fundraising page with your story about why you are raising funds for Parkinson's. Email the link to your contacts and ask them to help support the cause.

Honor a loved one

Honor someone you love who lives with Parkinson's disease by creating an online giving page as a tribute to a family member or friend.

Create a memorial fund

If you have lost a loved one and wish to pay tribute to them, you can create a special memorial fund online. Upload pictures, stories and memories to share their life and legacy with others.

Questions? To learn more about becoming a *PDF Champion*, visit www.pdf.org or contact Eddie Pelto, Director of Development, at (212) 923-4700 or epelto@pdf.org.

*PDF cannot offer financial assistance for individual fundraising efforts.

Nutrition and Parkinson's

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Do not use a restricted-protein diet; the problem, if you find you have one, is usually with the *timing* of the protein intake, not its total *quantity* over the course of the day.

Do "wonder" foods or supplements delay progression of Parkinson's?

Supplements (both nutritional and herbal) and dietary therapies are high on the list of complementary therapies used by people with Parkinson's. In spite of compelling theories about the effectiveness of various supplements or dietary factors in delaying progression of the disease, we lack definitive, evidence-based answers. Some therapies have been studied only in test tubes or with laboratory animals. Few human trials have been done (e.g., those examining antioxidant vitamin supplements), and most have produced disappointing results. Coenzyme Q10 is one nutritional supplement that is of considerable interest to the scientific

community and is under study to determine if it has any potential benefit in Parkinson's disease.

Some foods that are in the "won't hurt and might help" (at least in theory) category include coffee (several population studies have suggested that coffee may be protective against Parkinson's, particularly in men); green tea; a variety of fruits and vegetables; foods rich in vitamin E such as wheat germ; nuts and seeds; and vegetable oil. If the antioxidants present do not help with Parkinson's symptoms, they may help with some other aspect of health so there is certainly no reason not to use them.

When thinking about the potential value of using this or that supplement, consider the factors of cost, safety and effectiveness and be sure not to be "taken in" by hyped headlines. For example, a recent headline read, *Vitamin B6 May Cut Risk of Parkinson's Disease*. Behind the headline: this study finding, while interesting, was only observed among smokers and the study addressed only the onset, and not the progression, of Parkinson's.

However tempting it may be to seek out "wonder" foods and supplements, at this time there is not enough evidence to suggest that they play a major role.

Adjust nutritional priorities for your situation and stage of disease

Parkinson's symptoms vary from person to person and by stage of disease. Each person must set nutritional priorities based on the issues they face. In early Parkinson's, we should all emphasize eating well and maintaining a healthy weight. As the disease progresses, we should adjust our diets to manage specific new symptoms as they emerge (such as swallowing difficulties, medication side-effects, bowel issues and eating challenges). The goal of thoughtful nutrition is not just to ease PD symptoms; it is also to allow you to continue to use food as a source of pleasure in your life.

Karol Traviss, MSc, RD is a registered dietitian on faculty at the University of British Columbia in Vancouver, Canada. She has worked collaboratively with the British Columbia Parkinson's community for many years and spoke on complementary nutritional therapies at the 2006 World Parkinson Congress.

Interview with Rep. Lane Evans

At the end of 2006, Congressman Lane Evans (D-IL) will retire from public office after 23 years of service. Con-



Rep. Lane Evans

gressman Evans, who has Parkinson's disease, has played a key role in leading legislative initiatives on Parkinson's research. In October, he graciously agreed to be interviewed by the staff at the Parkinson's Action Network (PAN).

Q: How has federal PD funding changed during your time on the Hill?

In the mid-1990s when I became involved in Parkinson's-related issues, funding appropriated to the National Institutes of Health (NIH) for research on HIV/AIDS and cancer was much higher per capita than that of Parkinson's (an average of \$1,000 and \$260, respectively, was spent each year on each HIV/AIDS and cancer patient, compared to just \$26 on each Parkinson's patient). At this time, Parkinson's was not even on the radar screen for Members of Congress or the President. So, it is undeniable that there has been tremendous progress during my tenure in Congress — both in the dollars allocated and in awareness among policymakers about neurodegenerative diseases.

In 1997, Congress passed the Morris K. Udall Parkinson's Research and Education Act, which authorized \$100 million to the NIH for Parkinson's research and also established, in the Department of Defense, the Neurotoxin Exposure Treatment Research Program (NETRP) to identify the causes, diagnosis and treatments of neurological diseases.

We were successful in securing \$26.5 million for NETRP in fiscal year 2007, which is a \$3 million increase above last year's funding level.

Q: Besides introducing legislation, what are the meaningful contributions you have made in Congress?

Five years ago, I sat down with Tony Principi, then Secretary of the Depart-

The Voice From Washington

ment of Veterans Affairs, and discussed ways we could use the agency to provide comprehensive and state-of-the-art clinical care for veterans. The result was the designation and special funding of six major VA research facilities as Parkinson's Disease Research Education and Clinical Centers (PADRECCs). In addition to providing clinical care to veterans with Parkinson's disease, these centers would study the mechanisms of neurodegeneration, the epidemiology of Parkinson's, novel treatments and non-motor features of the disease.

I have also worked closely with the Congressional Working Group on Parkinson's Disease, of which I am a founding member, to increase funding for NETRP.

Q: What progress have you seen in finding better treatments and a cure for PD?

The greatest progress has come from targeted research like that conducted at the PADRECCs. Deep brain stimulation is an example of one of the technologically advanced and effective treatments in which PADRECCs have played an important role. Unfortunately, most of the treatments for Parkinson's work only by "masking" symptoms for a period of time. They do not slow the progress of cell death and eventually lose their effectiveness.

Because of such factors as Congress's inability to fully fund Parkinson's research centers, poor accounting of appropriated monies and the success of efforts to halt federal funding of stem-cell research, I do not believe great progress has been made toward finding a cure — despite the fact that Parkinson's is considered by scientists to be the most curable of the neurodegenerative diseases, and some have claimed that a cure could be found in 10 years. In addition, what we learn from curing PD will lead to cures for other neurodegenerative diseases.

Q: Have you seen any change in awareness on the Hill about Parkinson's and the number of people who are affected?

We saw the dramatic face of Parkinson's and its debilitating affects when Muhammad Ali was diagnosed in the early 1980s. As other public figures such as Michael J. Fox and Janet Reno have come forward with the disease, awareness has grown further. In terms of the culture on the Hill, I think it is becoming clearer among Members of Congress that one million Americans live with PD. We have seen our colleagues Mo Udall, Joe McDade and Joe Skeen struggle with the disease. And the Congressional Working Group on Parkinson's Disease has grown from 10 founding members in 1997 to 80 members today.

Q: What are some of the crucial steps we should be taking to find treatments and a cure for Parkinson's?

First, Congress and the medical research community need to commit to finding a cure for Parkinson's in 10 years. To achieve this goal, we need targeted and aggressive research, as well as better accounting to ensure that PD funding is being spent in the focused manner that the law requires.

Finally, it is important that Congress continue to work with PAN, PDF and other advocacy groups to bring greater attention to Parkinson's and educate the public about the disease so patients can receive accurate diagnoses and find the support, help and medical care they need.

Q: How has having Parkinson's changed your perspective about the role of a Member of Congress?

Having Parkinson's has made me a more effective Congressman because it has given me a better understanding of the difficulties and challenges that people who have health problems and their families face every day. Additionally, this disease has helped me to fully appreciate the contributions of Americans who have physical or mental limitations.

Congressman Evans has been a true champion of Parkinson's issues on Capitol Hill and a great friend to the Parkinson's community. On behalf of the entire Parkinson's community, we thank him for his dedicated service and wish him well.

Parkinson's Research Plan

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for those [the vast majority] with sporadic [i.e., non-genetic] disease.”

The authors urge further work on gene discovery, with a focus on the interaction between genes and the environment. Two areas in particular are targeted for highest priority. One is genetic studies of people with Parkinson's (along with their family members who do not have the disease but may be carriers of genetic mutations). The other is to survey people who do not have Parkinson's but whose genetic make-up could provide clues as to what causes PD.

Translating discoveries into treatments

Noting that PD research “appears to be at the stage when translational research is an important next step towards goals for feasible new drug treatments,” the NIH report highlights two areas in particular as “most important for focused translation.” These are gene therapy and cell implantation.

Gene therapy is a process by which scientists strip the patient's DNA of the genes that produce certain bad proteins, and then replace them with genes producing good proteins. The good proteins are then sent off to repair damaged brain cells using a viral delivery system. Two “good” proteins singled out by the NIH team are GDNF and neurturin.

In 2004, Amgen (the company that holds the patent to a specific delivery system of GDNF) halted clinical trials of the product, saying the treatment was not effective and might be dangerous. Work on GDNF continues at other study sites.

As for the other protein, neurturin, the Ceregene company has recently released promising results from a Phase I clinical trial, concluding that the participants experienced no significant negative side-effects. The study also suggests some preliminary evidence that the treatment may work — something that will be tested in a forthcoming Phase II trial (see *News In Brief* on page 3).

Cell implantation (or cell replacement) involves replacing damaged dopamine-producing brain cells with healthy cells from such sources as stem cells — both embryonic and adult. The history of this approach, including two major

NINDS-funded trials involving the transplantation of fetal brain tissue, has been clouded by findings that some of the participants experienced unrestrained cell growth following implantation, leading to serious dyskinesias (violent involuntary movements). The authors recommend further research on this approach.

Drug development

Traditionally, the development of new treatments has been left to the pharmaceutical industry, building on a platform created by university scientists. In this report, the NIH authors see universities as becoming increasingly more involved in drug development — especially in the process known as “high-through-

“Another marked change in the way Parkinson's is viewed is a shift in focus from strictly medical issues towards those that fall into the area known as ‘quality of life.’”

put screening,” in which thousands of drugs are run through a computer program to test for relevance to specific diseases, including Parkinson's.

The authors see this change in role as helpful in advancing new treatments in two ways. One is identifying potential new compounds for investigation and development by industry. The other is helping to identify new roles for old medicines — treatments that have already been found to be safe and effective for one medical condition, and may have relevance also for Parkinson's.

Looking to the future of NIH's involvement in drug discovery, the authors

give high priority to the development of new animal models for Parkinson's. They also recommend greater involvement of pharmaceutical companies as advisors to NIH and greater commitment by NIH in translational research, including validating drug targets and conducting studies of drug toxicity.

Finding better ways to treat Parkinson's

Noting that current treatments for Parkinson's are primarily limited to easing the symptoms of the disease, the authors urge research into treatments that may be “neuroprotective and disease modifying.”

One major NIH initiative to this end is NET-PD, a large set of clinical trials that are designed to assess interventions that may slow the progression of Parkinson's. Trials of two of these interventions — creatine and coenzyme Q10, both dietary supplements — are scheduled to begin over the next several months.

The authors also urged that scientists pay greater attention to developing treatments for people with early-stage Parkinson's, and to finding new “biomarkers” that will track the progression of the disease and responses to treatment.

Another subject addressed was deep brain stimulation (DBS), where the authors point to the need for long-term follow-up of trial participants. They urge the exploration of technical improvements and assessments of the importance of DBS for non-motor symptoms of PD, such as mood and speech.

A clear difference between this report and the last one is the increased attention to the non-motor symptoms of Parkinson's. It recommends additional research on such non-motor impairments in Parkinson's as sleep and fatigue; behavioral and cognitive impairments; and anxiety, depression and psychosis.

To accomplish this task, the report recommends such measures as getting non-motor manifestations of Parkinson's disease better represented in clinical trials, improving ways of measuring them and developing new animal models to test the safety and efficacy of treatments for non-motor symptoms.

Another marked change from the 2000 report is a shift in focus from strictly medical issues towards those that fall

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Parkinson's, Depression and the Wintertime Blues

Depending upon what study you read, anywhere from 30 to 80 percent of people with Parkinson's suffer from depression — and for many, it remains undiagnosed and untreated. The post-holiday months can make coping with depression more difficult than usual to manage. In this article, we suggest some ways to make it easier.

For many people with Parkinson's, feeling sad may seem natural. After all, living with a chronic disease alone is a valid reason to have such feelings. But when these emotions go beyond occasional sadness, they could be signs of depression ... and this depression, in many cases, could be related to Parkinson's.

To recognize depression, keep a look out for the primary signs. These can include experiencing anger out of proportion to the situation, sleeping too much or too little, losing interest in things that used to be exciting, feeling anxiety or finding that you are focusing almost exclusively on the negative aspects of day-to-day existence. If you or a loved one with Parkinson's has experienced two or more of these problems for two weeks or longer, it may be depression. It is essential to speak with a doctor for a professional assessment of the situation.

At its most severe, depression can generate thoughts of worthlessness or despair and sufferers may become withdrawn and isolated. People may feel that they are becoming a burden to loved ones, and that life is no longer worth living. Depressive symptoms of this degree require immediate medical attention.

Treating depression may need to be approached from more than one direction. The first step should be a visit to a doctor (either your primary care doctor or your neurologist). The doctor may prescribe an antidepressant at this time. If you are already taking medication to treat depression but are still experiencing symptoms of depression, talk to your

doctor about making adjustments in the dosage or type of medication. All of the doctors who treat you should communicate regularly with each other to avoid any possible drug interactions between Parkinson's medications and those that are used to treat depression.

Unfortunately, antidepressants — by themselves — do not smooth out all of life's problems. They cannot repair relationships, teach more effective communication skills, or help a person cope with chronic illness — all of these, problems that can potentially lead to depression or worsen it.

To address these issues, ask the doctor for a referral to a therapist who will recommend treatment that can range from therapy to lifestyle changes. Ex-

“Experts agree that the most effective treatment for depression is usually a combination of antidepressant medication and counseling.”

perts agree that the most effective treatment for depression is usually a combination of antidepressant medication and counseling. A trained therapist — that is, a psychologist, licensed clinical social worker, licensed clinical professional counselor or family therapist — can work with you to change negative behaviors and thought patterns. Your physician may be able to refer you to a therapist who is familiar with chronic illness.

There are also a variety of daily practices that you can try. The first is developing and maintaining a regular schedule. Try to wake up at the same time every day. Once out of bed, bathe and dress and plan to stay up for the rest of the day. It is very hard for a person to feel energized if they stay in their pajamas, no

matter how comfortable they may be. If a nap is required, make it a short one of 30–60 minutes. This will help assure a better sleep the following night.

People who are depressed should also eat balanced meals at regular times. If you are not very hungry, eat small meals with high nutritional content. Look for foods with high fiber content (this will help ease constipation, which can also worsen when you are depressed) and drink plenty of fluids.

Exercise is another vital key to effectively combating depression. Cold weather in many parts of the country may make it difficult to exercise out of doors, but lots of substitutes are available, from the gym to enclosed shopping malls. PDF offers two exercise programs for home use. For more information or to purchase these programs, visit www.pdf.org or call (800) 457-6676.

Of course, not everyone may feel like getting up, eating healthily or exercising. Some experts suggest the approach of trying to overcome these feelings and “do what needs doing” — in other words, making an effort to go about your daily routine even when you lack motivation.

In Parkinson's disease, depression may not be limited to the person who has the diagnosis. It can afflict care partners as well. Many of the methods described above for people with Parkinson's will also be helpful for care partners. In fact, individual counseling is one of the most effective methods for managing caregiver strain. Care partners also should discuss the situation with their doctor if they think they may be depressed.

Recovery from depression takes time. Depression affects people differently, and response to treatment will vary from person to person. Working with your therapist to provide feedback on how you are feeling and how well your treatments are working can be an important step on the road back to feeling “like yourself.” And remember — it is your commitment to taking steps to feel better and making changes in your life that will ultimately help you successfully treat depression.

For more information or questions about depression and Parkinson's disease, call our Parkinson's Information Service (PINS) toll-free at (800) 457-6676.

Parkinson's Disease Foundation
presents its

50TH ANNIVERSARY EDUCATIONAL SYMPOSIUM

Frontiers of Science and Clinical Advances in Quality of Life

in collaboration with the College of Physicians and Surgeons of Columbia University

Thursday and Friday, October 11–12, 2007 in New York City

This educational symposium will be open to everyone touched by Parkinson's including researchers, clinicians, allied health professionals, people with Parkinson's and caregivers. The parallel-track program will look at advances that have been made over the last 10 years and where we expect to see future progress.

Scientific Program Committee

Chair, Stanley Fahn, M.D.
PDF Scientific Director
Columbia University
College of Physicians and Surgeons

Topics include:

- Genetics
- Epidemiology
- Biomarkers for PD
- Gene therapy

Clinical Advances in Quality of Life Program Committee

Co-Chairs, Lucien Côté, M.D.,
and Karen Marder, M.D.
Columbia University
College of Physicians and Surgeons

Topics include:

- Maintaining independence through mobility
- Behavioral issues
- Pre-Parkinson's diagnosis
- Non-motor symptoms

Registration and the full program are available at www.pdf.org/50th/.
For more information, please call PDF at (800) 457-6676. Space is limited.

This activity has been approved for AMA PRA Category 1 Credit. CNE will also be offered to nurses.

Parkinson's Research Plan

Continued from page 7

into the area known as “quality of life.”

Noting the attention given to such areas as exercise, music and creativity at the recent World Parkinson Congress (in which PDF played a leadership role), the authors say that such “non-invasive approaches to quality of life are extremely important to individuals living with PD.”

Improving research tools and resources

The report notes significant gains since 2000 in the core research infrastructure available to Parkinson's scientists. Notable are improvements in shared resources (e.g., animal models and human tissue banks) and in integrating and en-

hancing clinical studies of Parkinson's at the 13 universities designated by NIH as Morris K. Udall Centers of Excellence for Parkinson's Disease Research.

Looking to the future

What now? Six years after the first plan, where are we? Does the new “plan” keep us on track?

Some observers have noted that the document is not so much a “plan,” with a set of action points to follow, as it is a comprehensive, authoritative and accessible review of Parkinson's science. By identifying the most promising areas in PD science, this document can be used by the research community in planning focal points for studies to find the cause(s) of

and a cure for Parkinson's.

Leaders in the Parkinson's community also commend Dr. Story Landis, Director of NINDS, and her team for their forthright response to changes both in the medical and sociological definitions of Parkinson's and the pointers to its management. This includes recognizing the potential role of the NIH in translational research and drug development and being open to redefinitions of PD that take better account of non-motor symptoms.

For the full document, visit http://www.ninds.nih.gov/disorders/parkinsons_disease/parkinsons_disease.htm.

Robin Elliott is Executive Director of the Parkinson's Disease Foundation.

The Parkinson's MAILBAG



By James Trussell

PD Advocacy: The Difference it Makes

A few weeks ago I had the opportunity to speak to a high school science class on the subject of genetic diseases. Even though Parkinson's disease is rarely inherited, the opportunity was intriguing to me, and I jumped at the chance.

About midway through my presentation, one of the students asked me how I got involved with the local Parkinson's disease support group. It dawned on me that I had not yet told them that I had Parkinson's disease. So I took a deep breath, laid down my notes, took off my jacket and told them about my diagnosis. Although they knew of the well-publicized battles with Parkinson's of people like Michael J. Fox and Muhammad Ali, the illness did not seem real to them until I shared my story.

I gave them details about the symptoms and treatment options. I told them that a person does not die from Parkinson's disease and that the life expectancy is the same as that of anyone else. After answering several questions, I sat down to let the two students who had invited me finish presenting their project. I never expected what came next.

One of the students, a young man named Austin, stopped and said, "What Mr. Trussell failed to tell you during his presentation is that even though a person

with Parkinson's disease has the same life expectancy as anyone else, the quality of their life is what really suffers. Imagine having to live your life around when you take medications and how long they will last, knowing that there is no cure." He continued, "Now we all know someone with Parkinson's disease and it is up to us to find the cure — we have to find a way to help!"

Needless to say my chin hit the floor. I looked at the teacher, and with tears in my eyes I said, "They really get it."

One hour out of my time. Thirty-two lives (counting mine) changed forever. I was reminded why I had gotten involved in Parkinson's advocacy in the first place.

How to be an Advocate

- Keep yourself educated and informed about Parkinson's disease.
- Give a speech. It does not have to be fancy. Just tell your story!
- Organize a fundraiser. People like to help with worthy causes.
- Get involved with a support group.
- Start a Parkinson's support group if there is not one in your area.
- Learn more about being a political advocate for the Parkinson's Action Network at www.parkinsonsaction.org.
- Most importantly, do not hide — and never, ever be ashamed of your battle with Parkinson's disease.

Becoming an advocate can change your life forever. I never imagined that at 41 years of age, I would walk into a room full of people, whether they be students, local officials or business leaders, and say: "Good evening, I'm James Trussell and I have Parkinson's disease," much

less, "We must find the cause and a cure for this illness. I need your help and your money!" The "old me" would never have been that bold.

What changed?

There was a time when I did not want anyone to know that I had Parkinson's disease. I took small steps. My father tried to encourage me to talk about it, and in 2004, my friend Kristin Poulsen and I started the first Parkinson's support group in our area. Even then, I tried to hide my illness whenever I could.

Then, one evening, I was at a restaurant and overheard another guest ask the hostess not to seat her family next to my table. She did not want to expose her children to someone whom she thought was a drug addict. I realized then that I had to tell people I had Parkinson's disease! I walked over to her table, knelt down and said, "I'm sorry that you are upset by my shaking hands, but I have Parkinson's disease. I forgot to bring my medication and that is why I am having problems eating. Yes, I do have a drug problem, just not the kind you thought."

The look on her face was priceless. She apologized and asked me to explain what Parkinson's disease was and how someone so young could have it. I have not stopped talking since that day.

That was only the beginning!

I recently heard a preacher say: "Yesterday is history. Tomorrow is a mystery. Today is a present. Open the box and enjoy life!"

My take on advocacy is simple. Not everyone wants to be a "poster child" for PD. Not everyone can stand in front of a crowd of people and talk about his or her disease. Not everyone is interested in politics or research or writing the next book on Parkinson's disease. But everyone can do something: even if it is simply raising awareness by wearing a Parkinson's t-shirt or putting a bumper sticker on your car.

James Trussell is Founder and Chief Volunteer Officer of the Northwest Georgia Parkinson Disease Association (a chapter of the National Parkinson Foundation). He is a Congressional Coordinator for the Parkinson's Action Network and was named to PDF's People with Parkinson's Advisory Council in 2006.

AROUND & ABOUT THE COMMUNITY

Third Annual Copa Benefit is Most Successful Yet!

On an unseasonably warm November night, more than 600 people (our largest crowd to date!) swarmed to the Parkinson's Disease Foundation's *Third Annual Carnival at the Copa* to raise funds for PDF's research programs. New York City's legendary Copacabana nightclub served for the third time on November 15 as the venue for an evening of fun and philanthropy, especially among young professionals in the metropolitan area. Total proceeds of the event, including profits from spectacular live and silent auctions, were nearly \$220,000 — the best yet!

holds if it is properly funded. Taking Peter's words to heart, guests bid on the fantastic silent auction items and packed around casino tables to give all that they could to support Parkinson's research. Throughout the night, the band GDO

Lucas Stoffel



Copa attendees try their luck at the casino games.

Soul provided their rocking sound to keep the dance floor full.

The talented and impressive volunteer steering committee, headed by event Co-Chairs Peter Dorn, Sharon Klein and Doug Stern, joins PDF in thanking the many people who helped make this event a success. This group would particularly like to thank our gracious Honorary Chair Julianna Margulies; dynamic emcee Bruce Beck; the outstanding Copa staff; and of course the friends and sponsors whose contributions made the entire event so wonderful. Special thanks are also extended to the anonymous friend of PDF who generously donated a matching gift of \$50,000.

Stay tuned for information on the next *Carnival at the Copa*!

PDF & AANF Initiate Joint Fellowship

The Parkinson's Disease Foundation (PDF) and the American Academy of Neurology Foundation (AANF) are pleased to announce a two-year Clinician Scientist Development Award of \$75,000 per year.

The PDF-AANF Clinician Scientist Development Award will foster the productivity of young research clinician scientists who have demonstrated the potential to make significant contributions to Parkinson's disease clinical research.

"We're thrilled to work with AANF on this exciting new venture that further reinforces our commitment to recruiting

PINS: The One-Stop Shop for Information on Parkinson's!**Get your questions answered today!**

The Parkinson's Disease Foundation (PDF) is proud to announce the expansion of our *Parkinson's Information Service (PINS)*: the "one-stop shop" for answering your questions about Parkinson's disease!

To access PINS:

- Call our toll-free helpline, (800) 457-6676, from 10 AM – 5 PM EST.
- Use our *Ask the Expert* feature found at www.pdf.org to submit a question or find answers to commonly-asked questions.
- Visit www.pdf.org to download PDF publications and order print copies.

top talent to choose a career in Parkinson's clinical research and care," said Dr. Stanley Fahn, PDF's Scientific Director. "This grant is in line with several of PDF's other programs that are designed to ensure that Parkinson's research is being conducted by the best and brightest in the field."

The grant will support two years of research training at an institution where talented clinicians focus on Parkinson's science. It is expected that upon completion of the program, participants will be committed to a research or combined clinical/research career in Parkinson's and will be qualified to direct such programs. The second year of funding will depend on results of a progress report on the first year's work.

Applications are evaluated by PDF's Scientific Review Committee and the Clinical Research Subcommittee of the Science Committee of the AAN. The application deadline is February 1, 2007 for a July 1 start date. For more information, eligibility criteria and to apply, visit www.neurofoundation.org/research/erf.cfm or call Jane Wester at AANF at (651) 695-2755.

Lucas Stoffel



Guests get into the "Carnaval" spirit with fun and festive Mardi Gras masks.

Peter Dorn, PDF Board Member, event Co-Chair and co-owner of the Copa, welcomed the crowd and explained the potential that Parkinson's science

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- ✓ Sign-up for updates on new trials
- ✓ Order a free clinical trial information kit

Visit www.PDtrials.org
or call (800) 801-9484

Calendar of Events



2007 Chevron Houston Marathon

Date: Sunday, January 14, 2007

Place: Houston, TX

The Houston Area Parkinson Society (HAPS) is an official charity of the 2007 Chevron Houston Marathon. Join HAPS and more than 20,000 participants, 200,000 spectators and 5,000 volunteers for Houston's largest single-day sporting event. All runners — from "serious" to "fun" — are invited to join in and help raise much-needed funds for Parkinson's research.

For details or to register, visit www.hapsonline.org.

13th Parkinson's Unity Walk

Date: Saturday, April 28, 2007

Place: Central Park

New York, NY



Come and join thousands at the Parkinson's Unity Walk in Manhattan's beautiful Central Park. Learn from medical experts, talk to friends and walk to raise awareness of Parkinson's disease. One hundred percent of all donations goes directly to Parkinson's research.

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

Bal du Printemps

Date: Wednesday,

May 16, 2007

Place: The Pierre

2 East 61st Street

New York, NY



Parkinson's
Disease
Foundation

Led by PDF Chairman Page Morton Black, *Bal du Printemps* is an elegant celebration of philanthropy and science to raise funds for, and awareness of, Parkinson's disease. Proceeds will support PDF's research programs.

For more information, contact event organizer Carla Capone at (212) 213-1166 or email PDFgala@carlacapone.com.



13th Annual Parkinson's Action Network Research and Education and Public Policy Forum

Date: Sunday, February 11 – Tuesday, February 13, 2007

Place: Washington Plaza Hotel
10 Thomas Circle, NW
Washington, DC

The Parkinson's Action Network (PAN) sponsors three days of scientific and legislative updates, concluding with a visit to Capitol Hill.

Participants will undergo advocacy training and be updated by top scientists on the current state of Parkinson's research. PAN offers a limited number of scholarships for advocates with financial limitations; details are available at www.parkinsonsaction.org.

For more information, call PAN at (800) 850-4726.



2007 Los Angeles Marathon

Date: Sunday, March 4, 2007

Place: Los Angeles, CA

Lace up with Team Parkinson to make strides in fighting Parkinson's disease! The team will once again tackle a 26.2 mile course with a field of 25,000 runners, walkers and wheelchair athletes. Under the guidance of The Parkinson Alliance and the Parkinson's Unity Walk, Team Parkinson raises funds for PD research.

For more information or to sign up, visit www.team-parkinson.org or call (866) 822-CURE.



In an upcoming issue, we will be reviewing suggestions on how to manage life with Parkinson's disease. Send us your suggestions by mail or email them to info@pdf.org. Selected tips will be printed in a future issue and one reader will receive a *Six-Alarm Vibrating Medication Reminder Watch* worth \$99.95, generously donated by e-pill, LLC, and available at www.MEDclock.com.



Parkinson's
Disease
Foundation

1957 - 2007

50 Years of Research • Education • Advocacy

WINTER 2006/07

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