

Improving Brain Function with Exercise, Connectedness and Creativity

By Julie H. Carter, R.N., M.S., A.N.P.

Over the past 30 years, we have come to better understand the role that people with Parkinson's disease (PD) may play in altering the progression of their disease. When I began working in the field, we used to tell people who were newly diagnosed — who understandably wanted to know what to expect from the disease — “Parkinson's is a highly variable disease. We wish we could be more definitive, but some people progress slowly and others progress more rapidly.”

Today, I am glad to report that we can give a different answer: you actually *can* have some control over the symptoms of this disease.

Parkinson's disease varies from person to person, as do the rates at which it progresses. But we now know that in addition to your medications, there are some activities that may ease your motor symptoms, im-

prove your quality of life...and perhaps even change your brain.

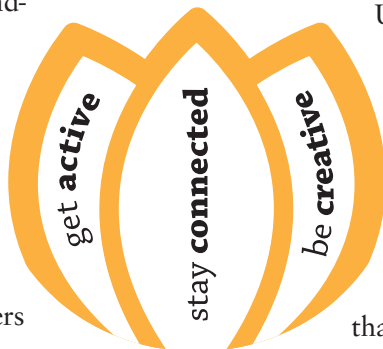
Changing Your Brain: A Three-Part Plan

What has changed in the last three decades is that we now know that the brain can change and adapt to new circumstances, an ability we call neuroplasticity.

Until recently, the scientific community believed that brain development stopped at adulthood. Research has shown otherwise, demonstrating three key findings: areas of the brain that are used intensely can

increase slightly in size; new pathways of communication among brain cells can form; and the brain has the ability to make new cells.

Because of the nature of Parkinson's, in which dopamine neurons in the brain are lost and damaged, these findings are incredibly pertinent. In addition, there is now scientific evidence to suggest that certain activities — exercise, social connectedness and



>> Read more on page 8

NEWS IN BRIEF

Three Factors Contribute to Cell Death in Parkinson's

Scientists have confirmed a long-standing hypothesis that too much dopamine inside certain brain cells leads to the cell death that causes Parkinson's disease (PD). However, whether neurons die also depends on calcium levels and the presence of the protein alpha-synuclein. The study, led by Eugene V. Mosharov, Ph.D., and David Sulzer, Ph.D., of Columbia University, appeared in the April 30 edition of the journal *Neuron*.

Investigators asked the question: what are the features of dopamine neurons in PD that make them susceptible to cell death? Using a novel procedure called intracellular patch electrochemistry, they determined that dopamine cells in PD have elevated levels of dopamine floating free within them, higher than normal calcium levels and an accumulation of the protein alpha-synuclein.

As researchers predicted, the elevated levels of the so-called cytosolic dopamine were toxic to neurons. Decreasing these levels, either genetically or by using drugs, successfully prevented cell death. Alternatively, even with high dopamine levels, decreasing

>> Read more on page 10



PDF Commits \$700,000 to Promising Scientists

See page 5 for more information

IN THIS ISSUE

PDF Financial Assistance Program	2
New PD Resource List	2
Spotlight on Research	3
Managing Mid-Stage Parkinson's	4
Profiles of CRLI Grads	6
Sharing Stories	7
Around and About the Community	10

PDF Announces Financial Assistance Program for People with PD

The Parkinson's Disease Foundation (PDF), in partnership with the Melvin Weinstein Parkinson's Foundation (MWPF), is pleased to announce a new financial assistance program for people who are living with Parkinson's disease (PD).

The program, to be known as the Helen M. Lynch Direct Aid Fund of the Parkinson's Disease Foundation and the Melvin Weinstein Parkinson's Foundation, was established in 2008 with the help of a private gift. It addresses a common problem faced by people with Parkinson's: handling the continuing costs that are associated with home adjustments and medical

equipment that can quickly become overwhelming. For individuals who meet certain eligibility requirements, the new fund offers assistance to cover, temporarily, such costs as home healthcare and the purchase of medical equipment, such as wheelchairs, walkers and canes.

According to Marsha Anthony, she and Traci Corcoran, co-directors of MWPF, "are frequently in contact with people living with Parkinson's whose lives could truly be made easier by items such as durable medical equipment or a home health aide. We have also seen first-hand the difference that assistance, no matter how big or

small, can make in keeping that person more independent and safer. That is why this collaboration between MWPF and PDF is so vital."

PDF's Executive Director, Robin Elliott said of the new program, "PDF frequently hears from our helpline callers that financial matters are of great concern. It is crucial that all people with Parkinson's have access to the equipment and services they need to manage their disease most effectively. We hope that this program can help, in some small way, to address this need."

Do you or does someone you know need help covering the costs of PD-related care or equipment? To find out if you are eligible for support, please contact the Melvin Weinstein Parkinson's Foundation at help@mwpf.org or (757) 313-9729.

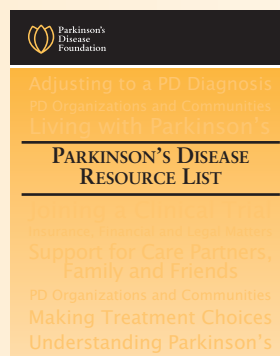
New Publication Lists Hundreds of Resources for People with Parkinson's

The Parkinson's Disease Foundation (PDF) is pleased to offer the *Parkinson's Disease Resource List*, a free publication designed for people living with Parkinson's disease (PD), their families and caregivers and health professionals.

This 100-page comprehensive print and online guide lists more than 650 community resources located throughout the US and around the world. It includes many of the resources that may be needed by a person living with Parkinson's, such as national and local Parkinson's groups and movement disorder centers and resources addressing clinical trials, medical equipment, financial, legal and insurance assistance and caregiver support. The *PD Resource List* also includes personal stories from people living with Parkinson's and sections geared specifically toward the newly

diagnosed and those living with young onset and advanced PD.

The concept for the *PD Resource List* developed from conversations with PDF's People with Parkinson's Advisory Council (PPAC). Its 13



members spoke of the urgent need for a centralized resource that would compile information from all sources — websites, books, organizations, audio-visual materials, webcasts and more.

Such a resource would be used by people with Parkinson's at any age and any stage of the disease and by their families, friends and care partners.

PPAC member Rhona Johnson noted, "As people live with Parkinson's, the questions they have vary tremendously — whether it's wondering how to deal with the diagnosis, deciding when to tell an employer, considering joining a clinical trial, or finding home healthcare. Now the *Parkinson's Disease Resource List* will help people find answers to all of these questions."

You can order the *PD Resource List* by calling (800) 457-6676, emailing info@pdf.org or visiting www.pdf.org. Healthcare professionals and support group leaders are welcome to order multiple copies. The online *Resource List* is available at www.pdf.org/resourcelist.

The print and online versions of this publication have been made possible through an unrestricted educational grant from Novartis Pharmaceuticals.

SPOTLIGHT

on Research

Supported by PDF

Yvette M. Bordelon, M.D., Ph.D.

For decades, the Parkinson's Disease Foundation (PDF) has sponsored a clinical fellowship program at Columbia University to train young doctors for careers in Parkinson's disease (PD) and other movement disorders. They come to the highly competitive program after completing a residency in neurology.



Dr. Yvette M. Bordelon

PDF funds six to eight such awards each year. One "graduate" of the program is Yvette M. Bordelon, M.D., Ph.D., who is now an Assistant Professor-in-Residence at University of California, Los Angeles (UCLA) Medical Center. Her training in clinical care and research under the supervision of Stanley Fahn, M.D., helped put her on the path to become a Parkinson's-focused clinician and researcher.

It was the work with patients she found most valuable in her term as a fellow at Columbia. She says, "My doctoral work was primarily basic research, so the clinical work I was exposed to at Columbia led me to better understand the reality of Parkinson's and, therefore, develop better research questions. For example, I came to focus on developing biomarkers, which I knew could make a difference for my patients." Biomarkers, such as brain scans or blood tests, are measures of the presence or progression of a disease. There are cur-

rently no definitive biomarkers for PD, which makes it difficult to track its progression over time.

At UCLA, Dr. Bordelon now splits her time between seeing patients and conducting research focused on biomarkers. While at Columbia, she had begun studying the use of brain imaging as a biomarker for Huntington's disease, another movement disorder. She continues this line of research in Huntington's and now also pursues it in Parkinson's disease. She is investigating the use of a specific brain imaging technique, known as PET scan, to measure the clumping of the protein alpha-synuclein that occurs in the brain of a person with Parkinson's disease.

Dr. Bordelon believes that the development of biomarkers is a crucial step in finding new treatments that can actually slow the course of PD. And while her research in this area evolved from her direct work with patients, she finds that this research, in turn, informs her clinical practice — giving her a unique ability to tell people with PD firsthand about the latest scientific advances in the field.

It is clear from Dr. Bordelon's work, that Parkinson's specialists have a unique perspective and leadership to bring to patient care...and to science. The clinical fellowship program remains committed to training more young doctors who can share such skills with people living with PD.

Dr. Bordelon is Assistant Professor-in-Residence at UCLA and an investigator for the Parkinson Study Group. In FY2009, PDF's \$2.7 million grant to Columbia University included \$650,000 to support the Fellowship Program. Most graduates of the program return to their home states and countries to lead — in many cases, to create — exemplary programs in movement disorders.

PDF HELPLINE

DO YOU HAVE QUESTIONS ABOUT PARKINSON'S DISEASE?

We can help.

Call Monday through Friday,
9 AM to 6 PM ET

(800) 457-6676

The Parkinson's Information Service (PINS) is managed exclusively by the Parkinson's Disease Foundation and is supported by Boehringer Ingelheim.

pdfchampions

You can help fight Parkinson's!

Our grassroots fundraisers, PDF Champions, have raised...

- \$80,000 by organizing golf tournaments
- \$5,000 by running marathons
- \$3,000 by planning parties
- Immeasurable awareness about Parkinson's in local communities throughout the US!

Learn how **YOU** can become a Champion!

www.pdf.org/en/pdf_champion

(800) 457-6676 | info@pdf.org

PDF staff advises all Champions on fundraising tips and practices.

Mid-Stage Parkinson's: Managing the Movement Symptoms

Like most aspects of Parkinson's disease (PD), the "mid-stage" is very individualized. During this phase, symptoms become less easy to suppress using medications, and new problems, some related to PD and others provoked by the medications themselves, may develop. The term mid-stage has more to do with these changes than it does with the length of time since diagnosis. Some people experience mid-stage issues soon after diagnosis, while others may not encounter them for five or more years.

In this article, the first in a series of four, we discuss the impact that mid-stage PD has on your movement symptoms and ways you can address them.

Movement Symptoms of Mid-Stage PD

In mid-stage Parkinson's, your medications may begin to "wear off" substantially before it's time for the next dose, leading to "off" periods, which occur when the beneficial medication effect quickly drops off. When this happens, movement symptoms that formerly remained hidden for hours, such as tremor or stiffness, may become more troublesome than they were in earlier years.

Mid-stage often includes the onset of dyskinesias. Dyskinesias are involuntary writhing movements that are caused by dopamine medications, and tend to occur at the peak of the medication effect and taper off when the medication effect wanes. Many people experience both "on-off" fluctuations and dyskinesias: when their medications are working, they are mobile but experience dyskinesias, and when their medications wear off, dyskinesias subside, but Parkinson's symptoms are more pronounced.

Dystonia — an often painful, sustained cramping and twisting motion — can be provoked by medication, but more likely occurs in the "off"

unmedicated state. A common form is toes that curl under or upwards, often first thing in the morning.

Two additional symptoms are important to address because they can increase the risk of falls. The first is postural instability, or impaired balance and coordination. The second, freezing, happens when a person feels stuck to the ground and finds it difficult to start walking. It often occurs when a person launches forward after rising from a chair, after he or she is standing still, or while walking, in which case the body continues its forward motion, but the feet stay planted.

Tips for Managing These Symptoms

Manage Your Medications

The first step in addressing mid-stage movement symptoms is to ensure that your medications are well managed so that they last longer, symptoms are better controlled and dyskinesias are minimized. Unfortunately, postural instability and freezing do not respond to most available medications, and supplementary strategies involving physical therapy and fall prevention are needed.

The timing of medications can impact how you feel, so a key part of good management is sticking to a schedule. It is also a good idea to go through a complete list of symptoms and problems with your doctor, and to be certain about the role, dosage and timing of medications. If your symptoms fluctuate, it is helpful to keep a detailed record of your response to medications throughout the day, indicating meals, sleep and daily activities, for one week prior to your next appointment with your doctor. Some neurologists and support groups have preprinted sheets for you to use. Doctors use these reports to make informed adjustments, e.g., adding a new class of medications or adjusting

the dosages or timing of them.

Work with a Physical Therapist

For postural instability, it may be helpful to work with a physical therapist (PT). With a referral from your neurologist, a PT can perform an evaluation and develop a program that may include fall prevention, balance training and the proper use of assistive devices such as canes or walkers.

Break Your "Freeze"

There are a few strategies that may help with freezing. Try marching in place until you feel the freeze break. Rocking side to side can also be effective. Another tip is to try singing out loud — preferably a song with a marching beat. Lastly, some people find that if they drop a string or piece of paper on the floor, and then step over it, this can break the freeze. Different tips may work at different times. So, if one doesn't work, try another.

Seek a Second Opinion

Don't be afraid to seek a second opinion from a movement disorder specialist (MDS), a doctor who specializes in Parkinson's. If you are already being treated by one, another may offer fresh insight. PDF's helpline staff — available at (800) 457-6676 — can help you locate one who is close to you, where available.

Talk to Your Doctor about DBS

When you or your loved one has tried these solutions and problems persist, it may be time to consider deep brain stimulation surgery (DBS). DBS is not for everyone, but recent research indicates that when it is done on appropriate candidates, it offers symptom control superior to that which is obtained with the best medication management. (See PDF's booklet: *Deep Brain Stimulation for PD*.)

Conclusions

These are just a few ways to cope with the motor challenges of mid-stage PD. In future issues, we will examine additional aspects of the mid-stage Parkinson's experience.

PDF Commits \$700,000 to Promising Parkinson's Scientists

The Parkinson's Disease Foundation (PDF) has just announced a series of grants amounting to \$700,000 to support the work of 11 research scientists. The grant recipients were chosen from a group of nearly 160 applicants by a scientific review committee led by Stanley Fahn, M.D., PDF's Scientific Director.

PDF has traditionally awarded one-year grants to promising scientists through two of its larger research programs: the International Research Grants Program (IRGP) and the Research Fellowship Program. Both programs enable investigators with novel "high risk/high reward" proposals to demonstrate the feasibility of their ideas, while generating the critical preliminary data that will lead to future funding from major institutions such as the National Institutes of Health.

This year, upon the recommendation of the scientific review committee, PDF expanded the award parameters of both programs. Specifically, IRGP grants this year reached a maximum of \$75,000 for each of two years (following a successful first year) — up from \$50,000 for a single year.

Among the awardees are two from the University of Washington, Seattle — Cyrus Zabetian, M.D., M.S., and Jonathon Burman, Ph.D. — who plan to answer questions about genetic variants and Parkinson's disease (PD). Although the number of people whose Parkinson's is determined by genetics

is very small, most scientists agree that the study of genetics is crucial to understanding classic PD.

Dr. Zabetian will create the first South American genetics consortium on Parkinson's. In collaboration with five other institutions in four countries (Argentina, Brazil, Peru and Uruguay), he will collect DNA and clinical, demographic and environmental exposure data from over 1,700 people living with Parkinson's for two years. With his colleagues here and abroad, he will analyze the

regions of the world. This will increase our chances of discovering new PD genes, which could lead to important breakthroughs in our understanding of the disease."

Dr. Burman will conduct research in the laboratory of Leo Pallanck, Ph.D., studying PINK1 and parkin, two genes implicated in causing early-onset PD. The project will focus on the role that PINK1 and parkin play in maintaining and recycling mitochondria, the energy-producing apparatus of the cell. He proposes that PINK1 may play a part in sensing when mitochondria are damaged and ensuring that they are recycled, thus keeping the brain cell

healthy and fully powered. He will test his hypothesis by studying how these genes affect the mitochondria, using the fruit fly as a model system. His hope is that a better understanding of the mitochondria in PD will point to new therapies.

Dr. Fahn says that PDF's decision to increase the size and duration of grants has, "encouraged applica-

tions from the brightest international scientific talent, which has ensured that only the best ideas are supported by the available funds. These grants will promote innovative research with a high potential to significantly advance the knowledge of Parkinson's."

In FY2009, PDF contributed more than \$5.9 million to support Parkinson's research. Since 1957, PDF has funded over \$75 million worth of scientific research in Parkinson's, supporting the work of leading scientists throughout the world.

FY2010 PDF Grant Awardees

International Research Grants

David Park, Ph.D.
University of Ottawa

Hardy Rideout, Ph.D.
Biomedical Research Foundation,
Academy of Athens

Antonio Strafella, M.D., Ph.D.
Centre of Addiction and Mental Health

Christian Wider, M.D.
Mayo Clinic

Cyrus Zabetian, M.D., M.S.
University of Washington

Learn more at:
www.pdf.org/en/results_funded

Research Fellowship Grants

Jonathon Burman, Ph.D.
University of Washington

Alessandra Chesi, Ph.D.
University of Pennsylvania School
of Medicine

Navneet Ammal Kaidery, Ph.D.
Johns Hopkins University

Stefan Sandberg, Ph.D.
University of Washington

Pedro Soldado, Ph.D.
University of California, San Francisco

Ryan Walsh, M.D., Ph.D.
University of Alabama at Birmingham

genome in search of genetic abnormalities unique to that population.

Dr. Zabetian says the project will build on some of the progress already made by genetic studies in developed countries, such as the discovery of the gene LRRK2 in Ashkenazi Jews, which have revealed that the genes for PD vary across different populations. He notes, "We lack a sufficient number of large-scale PD genetic studies from developing nations. With this funding from PDF, we will be able to expand our research to understudied

Where Are They Now? Profiles of 2008 Learning Institute Graduates

The strength of the Parkinson's disease (PD) movement, like many other causes, rests primarily in the advocacy efforts of the people who live with or are affected by the disease. And one important use of advocacy is to spread awareness of the importance of participating in clinical studies. These were the ideas behind PDF's first Clinical Research Learning Institute, held last July on Long Island, New York.

In the past year, Learning Institute graduates have been actively working to increase knowledge of clinical studies throughout the PD community and to advocate for a "patient perspective" in the clinical research process.

Here are some highlights from four of last year's 25 participants.

Sister Mary C. Daniel, O.P., M.Ed., M.Th., brought to the Learning Institute her experiences as a leader of a local PD support group and as a teacher, administrator and regional superintendent of schools for the Archdiocese of New Orleans, LA.

Already an active Parkinson's educator previous to the Learning Institute, Sr. Mary has continued her PD community outreach, but now emphasizes to others how important it is to be willing to participate in clinical studies. Her message seems to have had an impact: at least 15 people with Parkinson's who have heard it have gone on to sign up for a trial for the first time.

In May, Sr. Mary was one of the first individuals to represent people with Parkinson's at the annual meeting of the Parkinson Study Group (PSG), a nonprofit, cooperative group of 400 investigators, coordinators and scientists who conduct clinical trials at 126

sites throughout the US and Canada.

Susan J. Foster, R.N., B.S.N., M.A., has more than 25 years of experience in clinical research, sales training and product marketing in the pharmaceutical industry.

Ms. Foster is now a patient advocate for a Stanford University affiliated Stem Cell Re-

search Oversight committee. In this position, she will review stem cell research projects for nonprofit groups that may not have the resources to do so themselves, providing the studies with the vital patient perspective. Ms. Foster also provided this patient perspective in May, when she joined Sr. Mary as one of the first people with PD to attend the annual PSG meeting.

Israel Robledo, an elementary school reading specialist in Midland, TX, previously worked for the Texas Department of Human Services.

In his new role, Mr. Robledo has given presentations about clinical study involvement to local support groups, community groups and health fairs. He will soon be featured in a two-part special on Parkinson's produced by a CBS affiliate television station. Mr. Robledo has a special interest in raising awareness about clinical research within minority communities and has spoken to the Black Ministers Alliance about this issue.

Stanley Wertheimer, B.Ch.E., M.S., Ph.D., is Professor Emeritus of Mathematics at Connecticut College and both co-facilitator and co-founder of the Connecticut Parkinson's Working Group (CPWG) in New Haven, CT.

Since the Learning Institute, he has used CPWG's print newsletter and website to educate his community

about clinical research and has also led information sessions at the Institute for Neurodegenerative Disorders. In collaboration with local research groups, he is planning an annual CPWG meeting that will be devoted solely to clinical research. The CPWG also recently became a partner of *PDtrials*, a collaborative initiative led by PDF and supported by many other PD organizations that is dedicated to increasing awareness about clinical studies.

The Next Class

After just one year, these four graduates and their 21 colleagues have done much to spread the word about Parkinson's clinical studies. To build upon the foundation laid by this group, PDF is in the process of organizing the Second Clinical Research Learning Institute, to be held in fall 2009.

PDtrials

You can play a part in moving
Parkinson's research forward

Browse Clinical Trials

Find up-to-date information on Parkinson's disease studies currently enrolling participants in the US

All Trials:

View all clinical trials

By Location:

Locate clinical trials in your area

By Trial Type:

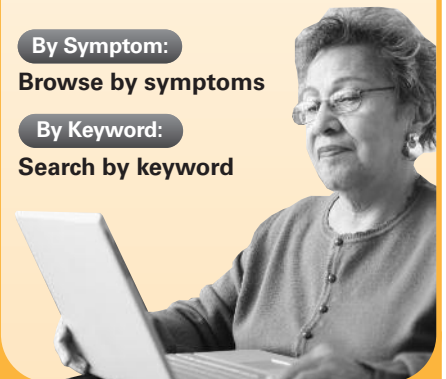
Browse by clinical trial objectives

By Symptom:

Browse by symptoms

By Keyword:

Search by keyword



(800) 801-9484 | www.PDtrials.org | info@PDtrials.org

Clinical Research Learning Institute

Sharing Stories

Writing, the Little Monster and Me

By Sherri Woodbridge

When, at the age of eight, I was teaching school to my students — my monkey, Pinkie, my life-sized doll, Brenda and my Raggedy Ann doll, Annie — English and creative writing were our prime subjects. I read many stories to my class and critiqued the stories “they” wrote.



Sherri Woodbridge

As far back as I can remember I have loved to write. One of my life mottos has become “I live to write, and I write to live.”

Years later, when I was in my mid-30s, I began to notice that my favorite activities, including writing, were becoming more difficult. For example, writing by hand was becoming challenging for me, so I began to type out my articles, stories and lists. After an hour or so of this, I found that my right fingers would begin to cramp up badly and refuse to work.

At first, because my symptoms were advancing slowly, I tried to continue life as usual. Then, after I found myself tripping constantly and returning home from work too exhausted to spend time with my family, I knew it was time to go to the doctor. Two days before Christmas in 2004, I was diagnosed with Parkinson’s disease (PD).

A year and a half later, with my doctor’s support, I decided to leave my job. With the free time I had, I began writing again. It was something I could still do that did not drain all of my energy. Besides, I loved it.

I started writing about my experiences living with young onset PD

(YOPD) in an online journal, or blog, which I now call Parkinson’s Journey (www.parkinsonsjourney.com). It began much like a diary, but one that could be read by anyone who found it on the Internet. It was my wish that if anyone were to read it, they might be encouraged by knowing that they were not alone with this ‘little monster’ called PD (or, in my case, YOPD). I soon found that many people were reading and responding to my entries, sharing their experiences and letting me know they found solace in the words.

I still write several times a week and the blog has become my best therapy. They say that if you are struggling with something, you may not necessarily need a professional counselor if you have a good friend who listens. Writing became my good friend. As I have written more, I have come to believe that maybe there is something to this disease, other than the aches and pains, the difficulties and the uncertainties it brings.

The blog has generated for me a supportive network of friends. Writing openly about Parkinson’s seems to affirm to other people with PD that they are not alone in their struggles, which in turn inspires me. The more transparent that I have been in ex-

pressing my struggles with the ‘little monster,’ the larger my online family has grown. I have even recruited a friend to work with me on Parkinson’s Journey.

I realized recently that this arena of PD patients and caregivers has blossomed into a beautiful family and support group. There is such a deep level of bonding that occurs when you share a chronic disease such as PD. We look out for each other, try to encourage one another, check up on each other and cheer each other on. Sometimes, it seems as if we are all able to leave all our little monsters outside the Internet chat room doors, leaving us free to enjoy each other’s company.

There are days my fingers still refuse to do what I want them to do, so I carry a small recorder to capture new article ideas. Plus I look really important! Whenever I start feeling down about having to drag this little monster around with me the rest of my life, I like to remind myself of one important fact: Parkinson’s does not have me. I have Parkinson’s. I am still me and I am still able to write. For that, I am grateful.

Sherri Woodbridge lives in Southern Oregon, where she enjoys spending her time with her husband, children and granddaughter. In addition to writing frequently for her blog, www.parkinsonsjourney.com, she is also currently working on a book about people with Parkinson’s.



Share YOUR Story

Visit PDF’s website to read more from people living with Parkinson’s or to share your story with the community.

www.pdf.org/en/personal_stories

Improving Brain Function

Continued from page 1

creativity — may not only be therapeutic for Parkinson's symptoms, but may actually change the brain.

One real life demonstration of this theory in practice is my patient, John, who has had PD for 20 years. John remains very active by walking and hiking, maintains flexibility through Pilates, plays golf to practice hand-eye coordination and agility, memorizes and writes poetry, finds a creative outlet in his garden and helps other people with PD to develop individualized exercise routines.

His physical abilities have certainly changed over time because of Parkinson's disease, but his habits of keeping physically active, remaining involved in his community and staying intellectually challenged have helped him to maintain a high quality of life and have potentially changed the way in which his brain works.

How can others follow John's example? It is important to remember that not everyone's response will be the same as John's. With that said, let's walk through a three-part plan for taking charge of Parkinson's and discuss the research that is helping us to better understand its impact on the brain.

Exercise

First, there is compelling scientific evidence demonstrating that exercise improves both the symptoms of PD and quality of life and suggesting that it may help the brain. Given the wide

range of motor symptoms that can occur with Parkinson's — slowness, rigidity, having a narrow base of body support, freezing, sequencing movement, trouble turning, instability and difficulty doing two things at once — we are still learning what particular types of exercise are most helpful for which symptoms and why.

Already, we have learned that exercise is important for people with PD in maintaining and improving mobility. In one study, people with PD who did high-intensity training on a treadmill — 30 minutes a day, four days a week

trunk rotation; an agility course, to help anticipate and prevent freezing; lunging, to practice taking bigger steps; and simple Pilates exercises. The difficulty of each routine is increased over time. A recent report on this program suggests that not only does it improve motor problems; it may even prevent them.

In addition to improving strength and agility, exercise — especially when it involves learning new motor skills — may increase the connections between neurons and improve blood flow in the brain. Experiments about these connections with people have been inspired by animal studies,

where research has shown that in mice with Parkinsonian symptoms, exercise helps retain dopamine neurons and may allow neurons to use dopamine more efficiently.

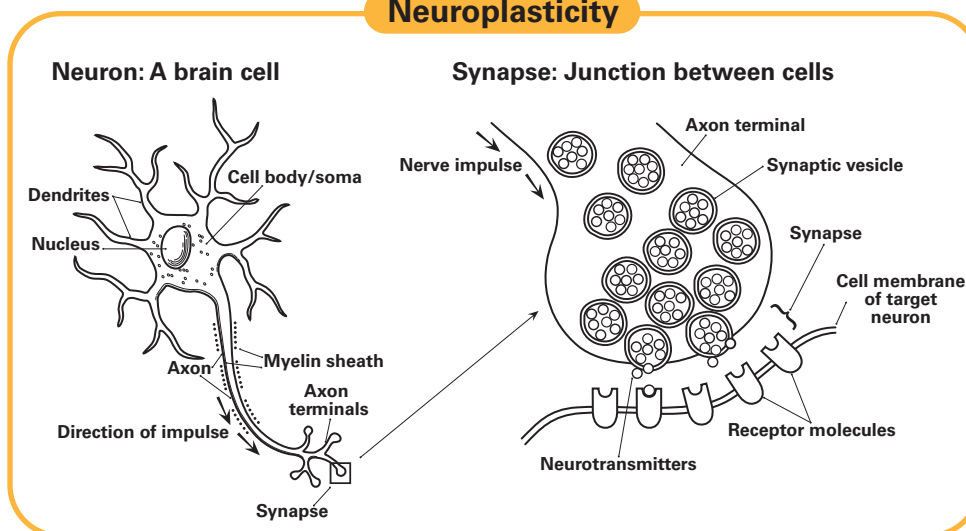
Another study looked at Parkinsonian mice who exercised in an "enriched environment" — one that is stimulating both cognitively and to the senses. For the mice, this meant new toys and exercising with other mice. This group had better

motor function after three weeks and more dopamine neurons in their brains than the mice that exercised in a nonstimulating environment.

The results are preliminary, but the bottom line for people with Parkinson's disease who want to stimulate their brains may be this: *do your exercise in an enriched environment and try to exercise with others!*

If you do begin to exercise, consult with your doctor first...and remember that exercise does not have to be strenuous. Activities such as walking and stretching can be quite beneficial.

Neuroplasticity



We now know that the brain can change and adapt to new circumstances, an ability called "neuroplasticity." One way the brain can change is that it can form new synapses, the pathways of communication among neurons. In one report, researchers found that musicians who performed with symphony orchestras experienced increased communication between the right and left sides of the brain as well as increased visual spatial function. The research needs to be replicated, but along with other studies, it suggests that we may be able to change cognitive function through our creative activities.

— could walk more quickly and with improved stability after six weeks than they could before starting the regimen. They also improved their scores both on a standard motor exam for PD (the Unified Parkinson's Disease Rating Scale, or UPDRS) and another scale that measures quality of life.

Is this type of repetitive aerobic exercise sufficient to address the complex issues that occur in PD? In another ongoing study, people with PD are participating in a program that includes a variety of exercises: Tai Chi to increase limits of stability; kayaking to improve

Stay Connected

It is not a new idea that social connectedness — knowing that one is loved, esteemed and belongs to a network of mutual obligation — may affect the brain and our health. For years, scientific evidence has pointed to the health benefits of social networks, such as the capacity to improve the immune system and to decrease stress. By contrast, people with few social ties seem to have higher mortality rates.

We don't yet have much evidence to show how connectedness changes the brain, but we do know that the mind-body connection may affect neuroplasticity. Researchers studied the brain activity of Buddhist monks with electroencephalogram tests (EEGs) and found that those who meditated had more “gamma-wave synchrony” — an indication of neurons communicating across different areas of the brain — than people who were not trained in advanced meditation. The monks had, in effect, changed their brains. If changing the way we feel affects our brains, then increasing social connectedness could do the same. Yet many people have barriers that limit social interaction and, as we age, we are all at increased risk for becoming isolated.

The first steps in expanding and maintaining social ties are to identify what keeps you from feeling comfortable in social interactions and then to figure out what type of connectedness might work for you. Some people with PD have found that a support group provides a sense of community. Others prefer meeting peers who share their interests, such as art, community service or music. Perhaps you feel that a support group isn't right for you, or you find it difficult to get out of the house. In these cases, an online community may provide a good alternative.

To sum up social connectedness, I remember the words a patient once shared with me: *find somebody to love, find something to do, and have something to look forward to.* Connections to social

support can change the way we feel and perhaps in doing so, can help change our brains for the better.

Be Creative

One other way that you may be able to change your brain is through creativity, an area of study which is now gaining interest among neuroscientists. Contrary to what many think, creativity is neither restricted to artistic genius nor to extraordinary talent. It is within reach for all of us.

Creativity involves a cognitive brain process in which ideas first diverge and then come back together in a new way — also known as “think-

the brain, the disease does not hinder a person's creative abilities. Actually, exercising them may improve the experience of living with it.

In one report, researchers found that musicians who performed with symphony orchestras experienced increased communication between the right and left sides of the brain and increased visual spatial function. It needs to be replicated, but along with other studies, it suggests that we may be able to change cognitive function through our creative activities.

Perhaps if we engaged each day in a brain fitness program in the same way we do our bodies (as my patient John does by reading and writing poetry), we could help strengthen the connections in our brain and delay some of the cognitive changes that occur in Parkinson's.

Take Charge

Exercising, staying socially connected and being creative require a lot of motivation. To become and remain motivated, you have to have self-confidence, to feel like you have some control over your life and have connections to other people. When you are living with Parkinson's, all of these areas can take a hit. What we know now is that empowering yourself in these areas can enable you to live a fuller and richer life. This three-part plan we have reviewed here isn't a cure for Parkinson's. But it gives you a chance to be in charge. You can make a difference.

Julie H. Carter, R.N., M.S., A.N.P., is a Professor of Neurology at Oregon Health & Science University, and Associate Director at the OHSU Parkinson Center of Oregon. For a full list of the research studies referenced in this article, visit www.pdf.org or contact PDF at (800) 457-6676 or info@pdf.org to request a copy.

This article was adapted from Dr. Carter's presentation at a recent PDF symposium, now available at www.pdf.org/en/edu_events_texas.

7 Tips for Staying Socially Connected

1. Identify what is stopping you from interacting with others
2. Commit to something
3. Join a support group
4. Explore a new activity
5. Find people who inspire you
6. Be a support to someone else
7. Express yourself artistically

ing outside the box.” It is not limited to the arts — there can be creativity in science, for example, or in any kind of problem solving. For an activity to be creative, there needs to be an end product — a musical score, a painting or a solution to a problem — that displays the process to others.

Creative problem solving uses the frontal and parietal parts of the brain. The frontal lobe is an area that is also affected by Parkinson's, often causing issues with problem solving, multi-tasking and divergent thinking. In a recent preliminary study, however, scientists showed that despite the association between PD and this portion of

AROUND & ABOUT THE COMMUNITY

Spring Festivities Raise \$800,000 for Parkinson's Research

The Parkinson's Disease Foundation's (PDF's) two recent New York City-based events — *Bal du Printemps* and *Celebrate Spring* — raised \$800,000 to support Parkinson's disease (PD) research. The success, in light of a challenging economic atmosphere, has been attributed in large part to PDF's generous volunteers, who remain steadfast in their commitment to fighting Parkinson's.

Bal du Printemps Celebrates Philanthropists and Movement

On May 12, PDF welcomed over 300 guests to its annual gala, *Bal du Printemps*, at New York City's Pierre Hotel, raising over \$725,000 for Parkinson's research. Themed a 'Cel-

ebration of Movement,' the event honored longtime PDF supporters, Evan and Sandra Stern and family.



Stephanie Goldman-Pittel (left) and Margo Catsimatis (second from left) present the Page and William Black Humanitarian Award to Sandra and Evan Stern.

The evening began with remarks by David Leventhal, Founding Teacher of the Mark Morris Group's Dance for Parkinson's Program. He spoke about

the program's exploration of the power of dance to alleviate the movement-related symptoms of Parkinson's. He noted, "As one of our Brooklyn participants says, 'When I'm in dance class, I don't have Parkinson's'...It's a wonder that we don't have more research about what actually happens to us when we dance...Of course, PDF is at the forefront of exploring this kind of research...the answers will no doubt provide rich benefits for all of us, but particularly for people with PD."

The Stern family was then presented with the 2009 Page and William Black Humanitarian Award. Ms. Stern, a member of PDF's Board of Directors, along with her husband Evan and their children — Mark, Russell, Doug, Kyle and Anna — have

News In Brief

Continued from page 1

the level of calcium was also protective. And cells that lacked alpha-synuclein were more resilient against elevated dopamine than those that contained the protein.

Researchers concluded that it takes a combination of biological factors all happening at the same time in order to cause dopamine neurons to die. Therapies aimed at interfering with any one of these processes could, in theory, be neuroprotective.

Drs. Mosharov and Sulzer are both supported through PDF's annual Center Grant to Columbia University.

Pesticide Exposure Tied to PD

Prolonged exposure to two widely-used pesticides — maneb and paraquat — may put a person at a higher risk of developing Parkinson's disease. This risk is elevated if the exposure occurs earlier in life, according to a report in the April 15 issue of the *American Journal of Epidemiology*.

Authors Beate Ritz, M.D., Ph.D., and her colleagues from the University of California, Los Angeles (UCLA) performed a study involving residents of California's Central Valley, an area known for its wide

exposure to agricultural pesticides. Little research has been conducted on how pesticides affect people because it is difficult to accurately estimate exposure. To solve this problem, her team developed a "geographic information systems" tool that allowed them to correlate pesticide use from 1974-1999, locations of farmland, residences of people with PD and controls, and more, onto a single map for analysis. Using the tool, they identified residential areas that would have been exposed to maneb and paraquat over the 25 year period.

Of the 709 people who were enrolled in the study, 368 had been diagnosed with PD within the past three years and had lived in one of three counties in Central Valley for at least five years. The remaining 341, who served as a control group, did not have PD, but had also lived in the same geographic area for at least five years.

Researchers found that when people were exposed to *both* maneb and paraquat within 500 meters of their homes, their likelihood of being diagnosed with PD was substantially increased as compared to those without exposure. The majority of the risk for being diagnosed with PD was attributed to those individu-

als exposed between 1974 and 1989 — all of whom were children, teenagers or young adults at the time. This group of people, who had younger-onset PD — meaning that they were diagnosed before the age of 60 — were up to four to six times more likely to develop PD if they were exposed to both pesticides.

For years, there have been anecdotal observations that Parkinson's is found in higher rates among farmers and in rural populations. This study provides epidemiological support for an association between pesticide exposure and Parkinson's, and fits with previous scientific models in animals, in which pesticides cause a loss of dopamine brain cells. Epidemiological studies of this type, however well designed, are based on retrospective estimates of toxin exposure and are subject to error. While most individuals who are exposed to pesticides will *not* develop PD, this study is important because it is the first to suggest that two pesticides can work together to increase a person's risk for PD, and to demonstrate that those most at risk are people with younger-onset PD who were exposed at a young age.

For more news, visit www.pdf.org.

AROUND & ABOUT THE COMMUNITY

long been generous contributors to PDF's fundraising efforts and consistent champions of its mission.

PDF thanks this year's gala leadership for making this event possible: Honorary Co-Chairs, Page Morton Black, Amy Goldman and Judith Sulzberger, M.D.; Gala Co-Chairs, Karen Burke Goulandris, M.D., Ph.D., Isobel Robins Konecky and Arlene Levine; Dinner Co-Chairs, Margo Catsimatidis and Stephanie Goldman-Pittel; Master of Ceremonies, Len Berman; and the Drury Design Group.

Young New Yorkers Celebrate Spring

On April 23, more than 425 guests joined PDF and the Young New Yorkers for the Fight Against Parkinson's committee for the second annual *Celebrate Spring* event in New York City.

Guests enjoyed cocktails, dancing and clear views of the Manhattan skyline from the rooftop of Hudson Terrace. Co-Chairs G. Pennington Egbert III, Missy Egbert Sheehan and

many lives are touched by this disease," noted Mr. Egbert.

The event raised \$75,000, which was directed to a research program identified by Lucien Côté, M.D., a Parkinson's specialist at Columbia University. PDF thanks its co-chairs and the Young New Yorkers for the Fight Against Parkinson's committee for their support of this event.

PDF Pacers Join the Annual Unity Walk

The 15th Annual Parkinson's Unity Walk took place on April 25 in



Two enthusiastic members of the PDF Pacers Team were Fia Talbot and Judith Sutphen, daughter and wife of PPAC member and team Captain Bruce Talbot.

New York City's Central Park, raising over \$1.5 million for Parkinson's disease (PD) research.

Hours before the Walk began, the Park filled with thousands of people with Parkinson's, their families and friends — many of whom formed "teams" to support a loved one. They wore festive team t-shirts and carried signs in support of the fight for the cure for PD.

Among the crowd was PDF's own team — the "PDF Pacers" — made up of staff members, board members and representatives of the People with Parkinson's Advisory Council (PPAC) and the Parkinson Pipeline Project. Led by Captain Bruce Talbot, the Pacers donned green and gold shirts bearing the PDF tulip — a symbol of hope — and joined the two mile walk.

The Pacers raised more than \$8,000, one-third of which was raised by a single PPAC member, Joanna Ste-

ichen. All proceeds from the Unity Walk are directed to the research programs of seven Parkinson's organizations, including PDF.

Team captain Talbot said of the event, "I've been attending the Unity Walk for about a dozen years, missing it only once. It gives me enough inspiration to stay upbeat and make it until the next year. Despite the economy, our team total represents a 60 percent increase over last year's. It's clear people really want a cure ...as soon as possible."

Award Presented to DBS Pioneer

On April 27, PDF partnered with the American Academy of Neurology (AAN) at AAN's Annual Meeting in Seattle, WA to sponsor the 9th Annual Academy Movement Disorders Research Award.

This award is presented to a scientist who best represents the ideals of involvement in scientific research, clinical care of patients and training



Dr. Mahlon DeLong (second from left) following his lecture at AAN. He is pictured with Cynthia Comella, M.D., Chair of the selection committee for the lecture; Robin Elliott, PDF Executive Director; Stanley Fahn, M.D., PDF Scientific Director; and Lewis P. Rowland, M.D., PDF President.

of younger colleagues. This year, it was given to Mahlon R. DeLong, M.D., a pioneer of the surgical technical technique known as deep brain stimulation (DBS).

Dr. DeLong is currently Professor of Neurology at Emory University. In 2007, he was the recipient of PDF's 50th Anniversary Award for Exemplary Contributions to the Advancement of Parkinson's Science.



Celebrate Spring leadership and sponsors (left to right): William B. Sheehan, G. Pennington Egbert III, Missy Egbert Sheehan, Georgina B. Schaeffer, Greg Romero and John Romero.

Georgina B. Schaeffer led the event for the second year in a row, along with their committee, a group of nearly 100 New Yorkers dedicated to advancing a cure for Parkinson's.

The co-chairs, whose fathers both lived with Parkinson's, noted that their work over the past two years has involved more than raising funds for research. "The experience of having a loved one with Parkinson's is what brought our group together and *Celebrate Spring* makes us realize just how

Calendar of Events



10th Annual Carnegie Center 5K and One Mile Fun Run

Date: Saturday, September 26
Place: West Windsor, NJ

The Parkinson Alliance welcomes walkers and runners to join a 5K and Fun Run. Refreshments will be served and awards will be given to age-category and group team winners. All proceeds will benefit Parkinson's research.

For more information, visit www.parkinsonalliance.org.



16th Annual Morris K. Udall Awards Dinner

Date: Tuesday, October 20
Time: 6:00 PM - 11:00 PM
Place: Capital Hilton Hotel
Washington, DC

The Parkinson's Action Network (PAN) invites you to their annual fundraiser and awards ceremony. This year's leadership includes Dinner Co-Chairs, Diane and John Rehm, Honorary Chairman, Michael J. Fox, and Special Program Guest, US Senator Mark Udall.

For more information, call (202) 638-4101, email udalldinner@parkinsonsaction.org or visit www.parkinsonsaction.org.

APDA/NPF Young Onset Parkinson Conference

Date: Friday, October 23 – Saturday, October 24
Place: Dallas, TX



The American Parkinson Disease Association (APDA) and the National Parkinson Foundation (NPF) are hosting the first of four conferences geared specifically toward people living with young onset Parkinson's disease. The event will include presentations about the latest Parkinson's science and panel discussions regarding work/disability issues, managing stress and relationships and how to deal with the strains of being a caregiver.

For more information, visit www.youngparkinsons.org or www.parkinson.org.

PDF Casino Night

Date: Wednesday, November 11
Time: 8:00 PM
Place: Capitale
New York, NY



Parkinson's
Disease
Foundation

Join PDF for a night of casino games, raffles, prizes, cocktails and dancing. All proceeds from this event will be directed toward PDF's research programs.

For more information or to purchase tickets, call (800) 457-6676 or email info@pdf.org.

Add Your PD Event to PDF's Online Calendar!

Send PDF information about an event in your community and it may be featured on our website.

Submit today at:

www.pdf.org/en/event_calendar

The Parkinson's Disease Foundation® (PDF®) is a leading national presence in Parkinson's disease research, education and public advocacy. We are working for the nearly one million people in the US who live with Parkinson's by funding promising scientific research and supporting people with Parkinson's, their families and caregivers through educational programs and support services. Since its founding in 1957, PDF has funded over \$75 million worth of scientific research in Parkinson's disease, supporting the work of leading scientists throughout the world.

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice. This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.



Parkinson's
Disease
Foundation

Hope through Research • Education • Advocacy

SUMMER 2009

(800) 457-6676
info@pdf.org
www.pdf.org

Main Office

1359 Broadway, Suite 1509
New York, NY 10018
P: (212) 923-4700
F: (212) 923-4778

Columbia University Office

710 West 168th Street
New York, NY 10032

Midwest Office

833 W. Washington Blvd.
Chicago, IL 60607
P: (312) 733-1893

PDF BOARD OF DIRECTORS

Officers

Page Morton Black, *Chairman*
Lewis P. Rowland, M.D., *President*
Timothy A. Pedley, M.D., *Vice President*
Stephen Ackerman, *Treasurer*
Isobel Robins Konecky, *Secretary*
Stanley Fahn, M.D., *Scientific Director*

Directors

Constance Woodruff Atwell, Ph.D.
Karen Elizabeth Burke, M.D., Ph.D.
Margo Catsimatidis
Barbara Costikyan
Peter Dorn
Stephen B. Flood, Esq.
Sarah Belk Gambrell
Daniel Gersen, Esq.
Arlene Levine
Marshall Loeb
Howard DeWitt Morgan
Alma Rangel
Marie D. Schwartz
Domna Stanton, Ph.D.
Sandra Feagan Stern, Ed.D.
Melvin S. Taub
Martin Tuchman

Executive Director

Robin Anthony Elliott

Editor

Christiana Evers

Managing Editor

Melissa Barry

Scientific Editor

Blair Ford, M.D.

Layout & Design

Sharon Klein Graphic Design