## What's New in Parkinson's Research? An Interview with Dr. Beck

What's new in Parkinson's disease (PD) research? At the Parkinson's Disease Foundation (PDF), this is the question we are often asked by people with Parkinson's and their loved ones. How soon and in what ways will scientific research help my life with PD?



Recently, we sat down with James Beck, Ph.D., PDF's Vice President of Scientific Affairs, to ask him some of the questions that you, our readers, most frequently ask us about the

state of Parkinson's disease research.

## Q. How has Parkinson's research evolved over the past ten years?

A: The focus of the field has shifted in new and exciting ways. When I first came to PDF, scientists were very focused on the idea of using antioxidants to treat Parkinson's disease. In fact, there were several large clinical trials underway to test whether compounds such as

creatine and Coenzyme Q10 could treat the disease by stopping a process called oxidative stress. To everyone's disappointment, these clinical trials failed. But there remains hope for one potential treatment of this kind that works by raising blood levels of an antioxidant called urate. As we go to press, a phase III clinical trial for that potential drug is getting underway.

At about the same time as the antioxidant trials were going on, two independent lines of research changed the focus of the field. Both were led by scientists at PDF Research Centers: Jeffrey Kordower, Ph.D., at Rush University Medical Center, and David Sulzer, Ph.D., at Columbia University Medical Center. Their results both pointed to the protein alpha-synuclein as a likely culprit in the development of PD.

Alpha-synuclein is a protein that is found naturally in the brain and body. But in Parkinson's disease, it clumps together abnormally. We have known about the protein for quite some time, but the research of Drs. Kordower and Sulzer changed our understanding of its early role in PD, and in turn, shifted the attention of many PD researchers. >> Read more on page 6

## Science News

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## Decades-Old Exposure to Pesticide-Contaminated Milk May Be Associated with Early Parkinson's Brain Changes

In the early 1980s, the pesticide heptachlor, which was used on pineapple crops in Hawaii, was found in the local milk supply. A new study published in *Neurology* on December 9, 2015, shows that men who lived in Hawaii and drank a lot of milk at that time, yet did not smoke, had fewer neurons in the area of the brain where cell loss occurs in Parkinson's disease (PD), than men who drank less milk. Researchers led by Robert D. Abbott, Ph.D., at >> Read more on page 8

#### Aspirin Targets a Pathway to Cell Death in Parkinson's

Researchers at Cornell University have found that the main ingredient in aspirin may stop the process leading to cell death in Parkinson's disease (PD), according to a study published in the November 25, 2015, edition of *PLOS ONE*. The compound is called salicylic acid and is found naturally in plants. Scientists were studying it when they noticed its similarities to a medication called selegiline, that is used to treat PD. But the researchers, led by Daniel F. Klessig, Ph.D., at Cornell University, had only studied the compound in plants. >> Read more on page 8

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## **Letter from Leadership**

Dear Friends:

It gives me great pleasure to share with our readers the news of an exciting development for the Parkinson's disease (PD) community: in late January, my own or-

"[This merger] will create a genuinely comprehensive national not-forprofit that will pursue the cure and care of PD." **Robin Elliott** 



ganization, the Parkinson's Disease Foundation (PDF), and the National Parkinson Foundation (NPF) signed a letter of intent (LOI) to merge our two not-for-profit organizations.

What will the merger mean for readers of the PDF News and Review and the Parkinson's disease community as a whole? In my view, it will be a game-changer, in more than one way.

First, it will create a genuinely comprehensive national not-forprofit that will pursue the cure and care of Parkinson's disease — by funding scientific research and enhancing patient care.

Second, it will greatly improve opportunities for planning within the Parkinson's disease community, making it easier to identify areas of unmet need — programmatic as well as geographic — and to design initiatives and assemble resources to fill those needs.

Third, it will reduce by one the total number of national PD organizations, thereby generating efficiencies and reducing frustrations among constituents — especially among our donors.

I want to emphasize that the merger will be one of those rare creations: a marriage of equals, comparable in age (we were both founded in 1957), in size (we each have an annual budget of about \$10 million), and in commitment to service to a common and treasured community. It is an important and exciting moment for us all.

One important immediate task will be identifying new leadership for the combined PDF-NPF. After more than two decades in the saddle at PDF, I have informed my own Board of Directors at PDF of my intention to step down in June 2017. A merger at this time will leave the new Board of Directors free to appoint a CEO of stature befitting the importance of the challenge. In the meantime, I intend — working with my colleague Paul Blom (the interim CEO at NPF) — to assure the merged organization a smooth transition to its new life and mission.

In future editions of News and Review, we will report on developments as they occur. Please feel free to share any questions or feedback with me or other members of the PDF team at (800) 457-6676 or info@pdf.org.

Sincerely,

Roborn Anthony Kelish Robin Anthony Elliott

President

# www.pdf.org

### In Our Inhox

#### HelpLine Callers Share Feedback on **Educational Resources**

I appreciate the science news and educational seminars on the PDF website. It is nice to have all this information to help understand my mom's experience with Parkinson's.

#### Anonymous, via HelpLine

We were hungry for information after my husband was first diagnosed. I am so thankful for PDF's help and now being able to share its educational pamphlets at health fairs with others who need it.

#### Peggy Scripture Woodson, via Facebook

[Note from the editor: Contact our HelpLine at (800) 457-6676 or info@pdf.org to ask questions about PD, find local resources (including PD specialists and support groups) or order free educational materials.]

#### Viewers React to Latest PDF Online **Seminars**

Anxiety in PD

I learned a lot and realized I need to talk to my doctor about how I can better manage my anxiety in PD.

#### Anonymous, via survey

The seminar not only provided helpful information; it also emphasized that there are others "out there" with anxiety in their family. Anonymous, via survey

#### Cognitive Issues: Advice for PD Care **Partners**

As a Certified Health Education Specialist, I find PDF's PD ExpertBriefings incredibly helpful to my work, and love how CEUs are available.

#### Anonymous, via survey

Members of our online advanced PD caregivers support group, many from around the globe, shared rave reviews on the practical tips shared in this seminar.

#### Elaine Casavant, via Facebook

[Note from the editor: If you missed these PD ExpertBriefings, view them anytime at www.pdf.org/parkinsononline.]

Share comments and suggestions with the Parkinson's Disease Foundation at 1359 Broadway, Suite 1509, New York, NY 10018, info@pdf.org or (800) 457-6676.

## PDF Leads the Charge to Find Out How Many People Have Parkinson's

Imagine trying to drive across country with a map from the 1970s. How can you plan for the journey ahead with outdated information? That is the problem we face in Parkinson's disease (PD) when it comes to figuring out how many people are living with it.

Forty years ago, scientists gave us initial estimates of how many people live with Parkinson's. They range anywhere from 600,000 to one million. But those numbers are imperfect and out-of-date. And it is important to the future of research and care that we update them. It's possible, for example, that there are dramatically more people living with Parkinson's disease than we realize. That knowledge may, in turn, increase research investments from government and industry.

To make this happen, PDF is investing \$250,000 in a project we call P4 — the PDF Parkinson's Prevalence Project. We are funding six groups of epidemiology experts who are using different sets of data (i.e., medical records, clinical trial data) to help us understand who has Parkinson's in the US and Canada. Here's a quick update:

- Connie Marras, M.D., Ph.D., is mining a database of 11 million health records from Ontario, Canada (that's one-third of the entire Canadian population!) to understand how many people in Ontario live with PD. The results could be helpful for the US too, as the demographics of Ontario are very similar to those in states like Kansas, Indiana and Missouri.
- G. Webster Ross, M.D., and Caroline Tanner, M.D., Ph.D., are analyzing data from the Honolulu-Asia Aging Study, which followed Japanese-American men living in Oahu, HI (born between 1900-1919) for 47 years. Because the men were followed for such a long time, the results will help us understand how prevalence of PD changes with age.
- James Bower, M.D., and Rodolfo Savica, M.D., M.Sc., are examining all electronic medical records of residents of Olmsted County, MN, which were collected as part of the Mayo Clinic's Rochester Epidemiology Project. By analyzing such high quality records for evidence of PD, they may capture a complete picture of the disease in a community.
- Stephen Van Den Eeden, Ph.D., is probing the electronic medical record database for Kaiser Permanente Northern California to determine the prevalence of parkinsonism in California's Greater San Francisco Bay and Sacramento metropolitan areas. Because Kaiser's 3.8 million members represent 25

#### PD Prevalence: Current Estimates

1,000,000 people live with PD in the US 60,000 people are diagnosed each year in the US Four percent are diagnosed before age 50 Seven to 10 million people live with Parkinson's disease worldwide



Learn more at <a href="www.pdf.org/en/parkinson\_statistics">www.pdf.org/en/parkinson\_statistics</a>

to 30 percent of the population in these regions, this may give a fairly accurate picture of PD in that area.

- Dr. Tanner (mentioned earlier) is examining the prevalence of PD in four California counties (Santa Clara, Kern, Tulare, and Fresno) as part of the California Parkinson's Registry Pilot Project. She is examining health records from nearly 300 medical practices collected from 2008 to 2010. Because the records are from both urban and rural populations, she can analyze any differences in PD prevalence between the two types of communities.
- Allison W. Willis, M.D., M.S., and colleagues are extending their previous research into data from the Centers for Medicaid and Medicare Services (CMS). The CMS provides health coverage for about 30 million people in the US — nearly 95 percent of people over the age of 65. Dr. Willis previously studied neurology-related insurance claims from the CMS database related to PD, to estimate how many people among those 30 million might have the disease. But, because PD is so difficult to diagnose, she is taking a harder look at those claims — and diagnosis records — to see if they are accurate.

#### Conclusion: What's in a Number?

PDF's hope is that with P4, we will not only have better estimates of Parkinson's disease prevalence, but also greater assurance that these numbers are more meaningful. Our scientists are studying rural and urban communities, men and women, and people of different racial and ethnic backgrounds. Their findings will help us to understand prevalence in general, and how it might vary in different communities. And when we have better information — how many people have Parkinson's disease and who they are — we'll have a much better roadmap to the cure.

## How Exercise Can Improve Life with Parkinson's

#### By Margaret Schenkman, P.T., Ph.D., F.A.P.T.A.

Research demonstrates the importance of maintaining an active lifestyle for people who live with Parkinson's disease (PD). We know, for example, that certain exercise programs can improve strength, balance, flexibility and

"[E]veryday activity is just as important to living well with PD as are structured exercise regimens!"

Margaret Schenkman, P.T., Ph.D., F.A.P.T.A.



aerobic capacity — all of which are important in PD. We also have early, though not conclusive evidence from animal studies that vigorous exercise may actually pro-

tect against the death of brain cells that underlies PD.

But which type of exercise is best, and how intensive and frequent should it be? There's no standard "exercise prescription" for PD; the right program may be different for each person, and should be adjusted as PD progresses. The good news is that many types of activity are beneficial, so people with PD can choose the ones they enjoy and that best meet their needs. The single most important piece of advice is to get active, and stay active!

#### What Changes as PD Progresses?

People who are in the early stages of PD tend to be just as strong and physically fit as healthy individuals of the same age. But as PD progresses, so do the physical challenges. In addition to the movement symptoms of the disease — tremor, slowness, freezing of gait — people with PD commonly lose some of their range of motion, especially in the neck and back. This can interfere with their ability to twist and look over the shoulder (when driving, for example), and can affect balance.

It is also common for muscle strength to decrease in the course of PD. In one study, people with moderate PD symptoms — that is, those who scored higher than 30 on the standard Unified Parkinson's Disease Rating Scale — exhibited just one-half of the strength exhibited by a group of healthy individuals in their quadriceps (the thigh muscles that are important to walking and to standing up).

Other common consequences of PD are declines in cardiovascular conditioning, which supports a person's physical endurance, and in the ability of the nervous system to get the body going. This can mean that even in the early stages of Parkinson's disease, a person may need to breathe more oxygen when walking — that is, he or she may need to put in more effort than the average person to go for a walk. One question is whether this

inefficiency in oxygen use contributes to the fatigue that is so common in Parkinson's disease.

The good news is that exercise can help to lessen the impact of these changes. People with PD who stay active and exercise feel better, and do better, over time.

#### **Organized Exercise vs. Physical Activity**

When it comes to physical activity in PD, we are really talking about two things — structured exercise, and general physical activity. Each provides its own benefits, and people with PD need both. What's the difference?

One difference is that structured exercise programs. such as cardio or strength training regimens, are often carried out under the supervision of a physical therapist or other health professional. General physical activity, on the other hand, is a matter of how we move around throughout the day, whether walking, gardening or dancing, typically without supervision. Recent studies indicate that everyday activity is just as important to living well with PD as are structured exercise regimens!

#### The Benefits of Structured Exercise

Exercise is still a fairly new area of research in PD, and we are only now beginning to understand its effects.

Structured exercise, research shows, can ease the movement symptoms of PD that put people at risk of falls. For example, programs focused on improving flexibility, aerobic endurance and strength, can help with balance; some studies also show benefits for fall prevention. Additionally, programs involving physical therapy, treadmill exercise, dance and martial arts can help a person with PD to take bigger steps, walk more quickly, extend the arms farther, rise more easily from a chair and improve balance. In addition, exercise in general can lessen the severity of nonmotor symptoms such as depression, coqnitive changes and sleep difficulties.

Even when the benefit is small, exercise can improve the daily life of a person who lives with PD. Considering that PD is progressive, such improvements are even more remarkable; simply maintaining the same level of strength requires making gains against the advancing disease.

Based on these findings, how can a person with PD find the right exercise program? The right type of structured exercise for a person with PD will depend on his or her goals and symptoms. A key component is finding a physical therapist who can tailor a program to meet your needs. If you struggle with balance, for example, a therapist might develop a program aimed at improving it, through flexibility and strength training as well as activities to challenge balance such as dance, boxing and/or pos-

	Exercise	Activity
Early PD	Prevent future falls with the following types of training: aerobic, flexibility and strength	Find fun activities that challenge balance, aerobic conditioning and multi-tasking
Moderate PD	Review PD-related issues with a professional, and target training to address them	Pursue a vigorous activity that is fun and safe, like walking, dancing or kick-boxing
Advanced PD	Supervised exercise to help balance and walking, if appropriate	Stay active within your abilities

tural control exercises. But if your balance is steady, other types of exercise — such as aerobic conditioning and lower extremity strengthening — might be more useful in improving overall cardiovascular and strength fitness.

Activities such as boxing, martial arts, tai chi, challenging hiking and vigorous dance can provide a combination of improvements in balance, strength, flexibility and cardiovascular fitness. Yoga can be helpful for improving range of motion and flexibility of certain muscle groups.

One important note: in order to maintain the gains made from exercise, a person with PD needs an ongoing, long-term program. Just as you lose the benefits of a PD medication if you stop taking it, you lose the effects of exercise if you stop the regimen.

#### The Benefits of Staying Active

Research shows that people with PD become more sedentary as the disease progresses. According to one study, people with PD were one-third less active than older adults generally. Yet studies also suggest that staying active is critical as we age, whether or not we live with PD. Sitting less, doing household chores, or taking a stroll in the neighborhood might all significantly improve life with PD. Staying active can also help people with PD maintain the gains they achieve through organized exercise. So how can people with PD change their habits?

In addition to physical therapy, researchers have found that setting goals can be helpful. What is your current level of activity? Can you set a goal to walk a bit more, or move more during the day? Even modest goals — for example, getting up to take a pill rather than asking someone to bring it to you, or taking a stroll around the neighborhood after dinner — can improve well-being.

It also helps to get encouragement. You might want to ask family and friends to join you in an activity or to supp<mark>ort you by asking about you</mark>r progress.

Lastly, be sure to monitor your activity levels. There are many tools available to measure activity, including

how many steps you take each day. When I started wearing a simple pedometer, I was amazed to find that I had increased my own steps per day from 3,000 to 10,000! Many of these tools also offer apps for mobile devices, which allow you to share your progress with friends and family, providing a social aspect to the experience that can keep you motivated.

#### The Big Question: Can Vigorous Exercise Slow PD?

We all would like nothing better than to find a way to slow or reverse the progression of PD. Recent research suggests that vigorous exercise may be one of these ways. In one small study, overall PD symptoms improved remarkably among participants who were pushed to bicycle 30 percent more intensely than usual. Animal studies suggest that intensive exercise can protect the brain. And we know that regular exercise reduces cognitive difficulties among older people.

The jury is still out, however, on whether exercise can protect the brain cells that are lost in PD. Studies are under way to determine the best "dose" of exercise, and how effective it can be early in PD. It may be, for example, that in early-stage PD, certain types of exercise can be as effective as medications in reducing symptoms.

#### **Conclusion: Keep Moving!**

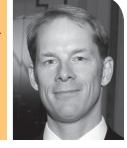
Getting into the habit of exercising and being active, and cultivating those habits over the long term, are important for anyone, but are especially important for someone who has PD. We are still learning about the effects of exercise on PD, and we know that there is no "one-size-fits-all" prescription. For sedentary people, just getting up and moving is beneficial. More active people can build up to regular, vigorous activity. But there is no doubt that many approaches to exercise work well. So choose ones that you enjoy, and keep moving!

Dr. Schenkman is As<mark>sociate</mark> Dean for Phy<mark>sical</mark> Therapy Education, and Director, Physical Therapy Program, University of Colorado School of Medicine.

Running parallel to this research, there has been an increased focus on the genetics of Parkinson's. We now know that for many people, small genetic variations may combine with other factors to increase the risk for, but not directly cause, Parkinson's disease. Closer to the clinic, we have seen increased focus on research to

"I am hopeful that we will soon discover how PD progresses and how we can interfere with this progression."

James Beck, Ph.D.



ease the disabling nonmotor symptoms of PD, such as cognitive issues and fatigue.

Another exciting development is an increased focus on something

that PDF has long believed to be central to the effectiveness of PD research: the role of people living with PD. Listening to the concerns of the community has played an important role in the development of medicines to address some of the disabling daily aspects of PD, such as dystonia, fatigue and dyskinesia.

The result of these advances is that the PD pipeline is strong, solidly based upon basic research and likely to address unmet needs in the community.

#### What is the one single thing you find most exciting about PD science right now?

A. The focus on alpha-synuclein. The protein was first discovered to play a role in PD by Roger Duvoisin, M.D., whose career was launched with PDF support. Twenty years later, it has become a major target in the search for game-changing PD therapies.

The research is still at an early stage, but it is exciting. Scientists are already studying several types of drugs that would target the protein in the brain in different ways. Some of these aim to change how much

alpha-synuclein is made; others, how it folds; still others, to stop it from spreading in the brain. For all of these, the goal is the same: to slow or stop PD.

The result is that we have more drug targets for anti-PD therapies than we had 10 years ago, and today's targets are better. The PD drug pipeline is strong, and that's exciting news for future therapy development.

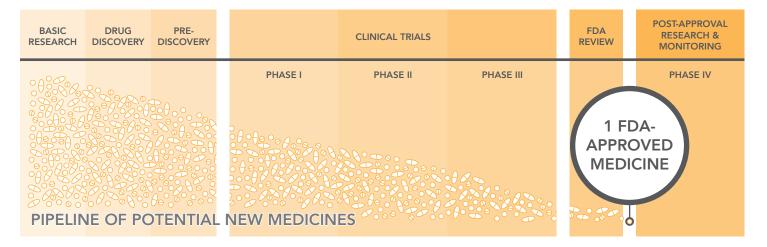
#### O. It is still a mystery as to how Parkinson's begins and develops. Which theories are most intriguing to you? Are we closer to solving the mystery?

A. These are two critical unanswered questions. The first, understanding how PD begins, is difficult to answer. We have made progress; for example, we have discovered rare individuals who have certain inherited genetic mutations that cause PD. But even in these cases, we continue to struggle to determine just how PD starts.

The second question, understanding how PD progresses, may be easier to answer. One intriguing theory is called the prion hypothesis, which suggests that alpha-synuclein, by spreading throughout the brain, may be responsible for the progression of PD. The theory states that alpha-synuclein becomes damaged in PD and folds into an abnormal shape. This damaged form wreaks havoc on brain cells, causing them to die.

Here is where it gets interesting: the misshapen alpha-synuclein escapes the brain cells it has damaged, enters new healthy cells and damages (or infects) them too. The theory says that this cycle continues, with the protein slowly spreading PD throughout the brain, leading to disease progression and worsening symptoms.

I am hopeful that we will soon discover exactly how PD progresses and how we can interfere in this progression. It is possible that understanding this process may give us enough information to find better treatments for PD without having to understand or eliminate its root causes.



#### O. You said the PD drug pipeline is stronger than ever. Among the experimental treatments that are now in development, which is closest to market?

A. There are several potential new drugs in clinical trials that we hope will soon be up for approval by the US Food and Drug Administration (FDA). Of these, the one with the best chance of becoming available soon is called pimavanserin (Nuplazid<sup>TM</sup>). If it is approved, this drug will be the first to specifically treat the hallucinations that are experienced by many people with PD (also known as PD psychosis). Hallucinations are the number one reason for which people with PD are placed into nursing homes, and better medications are sorely needed.

In addition, there are several drugs in development that are designed to ease more well-known PD symptoms (such as tremor and stiffness) and several designed to improve upon the effects of levodopa. Time (and clinical trials) will tell how well each may help in PD.

#### Our community urgently needs better treatments and a cure. What are the main obstacles to getting there and how can we confront them?

A. There are two types of obstacles: those related to our limited scientific understanding of PD and those related to how research gets done. We have already discussed several in the first category. In the second, a major obstacle is the erratic nature of funding for science. In today's environment, support for research is hard to come by even for the most worthy projects. And when it is available, it can be difficult to keep. This means that researchers spend too much time and energy looking for funding, and not enough focused on research.

This unreliability in funding has several serious consequences, which in turn, slow scientific progress. The first is that scientists leave the field of PD. Think for a moment about typical young scientists — smart and dedicated thirty-somethings. What will they do if they cannot depend on their jobs? Unfortunately, they often take their talents elsewhere. The second is that for scientists who do stay in the field, erratic funding hampers their ability to conduct long-term projects — the type that are crucial to solving a chronic disease like Parkinson's. This is why PDF provides long-term, stable support to teams of scientists at our two Research Centers - allowing them to focus the bulk of their energy on doing research, instead of on writing grants.

A second related obstacle, which leaves us in danger of drying up the PD pipeline, is a lack of sufficient support for basic science. Basic science is the foundation upon

which all discoveries are based. It studies the building blocks of PD (the brain, neurons and chemical reactions), to provide clues that help us better understand PD. Basic science is also critical to finding new therapies. We often hear that drug research is a pipeline (see image on page 6). At the beginning of that pipeline is basic research and at the end are clinical trials, where new drugs are tested before getting approved by the FDA. We need to keep the beginning of the pipeline well-stocked with ideas. But funding often focuses on the end of the pipeline.

Without investment in basic science, we will have nothing to test in clinical trials. PDF invests most of its annual \$4 million research budget on basic science to fill the gap and keep the new ideas coming.

In addition to funding, a third but equally important obstacle is finding ways to engage people with PD in research. Over the past decade, PDF has led the way in ensuring the patient community is a part of research. We have done so in part through a program known as Parkinson's Advocates in Research, which brings together patient advocates and researchers. In a related program, known as Community Choice Research Awards, PDF funds research based on the priorities of the community. Both of these initiatives are designed to ensure that the insights of people with Parkinson's are shared with the researchers who are developing their new treatments. It is a powerful concept. Already, PDF has invested in four conferences to study issues the community has identified as important, including fatigue, constipation, dystonia and dementia. This will help to speed research and improve treatments.

#### O. How confident should people feel about the state of PD science?

A. Very. Over the past ten years, progress may have been difficult to see — there were only a handful of new drugs approved. But behind the scenes, scientists have made progress in understanding how PD develops and how to stop it. More importantly, we have built a strong pipeline, filled with novel compounds that tackle PD symptoms and some that may even halt the disease itself. The future is bright.

## THE JAMES PARKINSON LEGACY SOCIETY

WHEN YOU MAKE A PLANNED GIFT TO PDF AS I DID, YOU SUPPORT THEIR MISSION TO END PARKINSON'S FOR THE NEXT GENERATION.

Jean Dewdney, member

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Milk and Parkinson's\* | Continued from page 1 the Shiga University of Medical Science in Japan analyzed health data from 449 Japanese-American men without Parkinson's, originally collected for the Honolulu-Asia Aging Study. They analyzed health information collected in the 1960s when the men were on average 54 years of age, and the results of brain autopsies which took place decades later after their deaths, for signs of neurological changes, including Parkinson's disease.

#### Results

- The 12 nonsmokers who drank more than two glasses of milk a day had 40 percent fewer brain cells in their substantia nigra (the brain area where loss of cells leads to PD) than those who drank less milk.
- Among the 10 participants who drank the most milk, the researchers found pesticide residues in the brains of nine. Among the 41 participants who did not drink any milk, researchers found some pesticide residue in the brains of 26.

 Among participants who were smokers at any time in the 30 years, there was no association between brain cell death and drinking milk.

#### What Does It Mean?

In this study, high milk consumption in midlife is associated with neuron loss in PD-related areas of the brain 30 years later. While it is possible that contaminated milk contributed to brain cell loss, there is no way to know for certain. The milk consumption took place decades ago, and it's impossible to know that it was contaminated. Not to mention that there are other explanations — milk can lower urate in the blood, which might increase Parkinson's disease risk. An important note: this study should not cause concern because the pesticide in question has been banned and the US milk supply is considered safe. Besides which, dairy products can be an important source of protein and calcium for people with PD. Check with your doctor before you cut back on dairy products.

#### Aspirin and Parkinson's\* | Continued from page 1

To understand its potential to treat Parkinson's, the team knew they would have to study it in human cells. They used a laboratory screening technique to see whether three forms of salicylic acid (plant-derived, synthetic, and a form derived from the Chinese medicinal herb licorice) had a similar effect in human cells. They also tested whether any of the formulations could prevent cell death in human cells.

#### Results

- All three forms of salicylic acid acted similarly to selegiline — they attached to an enzyme called GAPDH and stopped it from damaging brain cells.
- The synthetic forms of salicylic acid, and those derived from medicinal Chinese licorice, were more effective than salicylic acid itself.

#### What Does It Mean?

This study illustrates that the main ingredient in aspirin, salicylic acid, may interact with an enzyme linked to Parkinson's disease to stop cell death in laboratory conditions. However, evidence from epidemiology studies do not suggest aspirin itself is beneficial in Parkinson's disease.

Nevertheless, the results could open the door to development of compounds that are similar to, but more effective than, aspirin. Clearly, more research is needed. In the meantime, eating licorice for therapeutic purposes is not recommended (the form used in this study is a specific form derived from Chinese medicine), and people with Parkinson's disease should check with their doctors before taking aspirin as it can have negative side effects.

#### More Science News on PDF.org

- Rivastigmine May Reduce Risk of Falls in PD
- Elevated Urate Associated with Lower Parkinson's Risk

www.pdf.org/science\_news

<sup>\*</sup> To read the full summaries of these two stories, visit <a href="www.pdf.org/science\_news">www.pdf.org/science\_news</a>.



# PD Take

#### Tips & Tools from the PD Team:

## How can I ease dystonia in Parkinson's disease?

The Movement Disorders Specialist





Blair Ford, M.D., Professor of Neurology, Columbia University Medical Center, PDF Scientific Editor, New York, NY.

Leverage Levodopa. The key to alleviating dystonia is to figure out whether it is caused by or relieved by levodopa. Do this under your doctor's care. When dystonia occurs in the morning or as levodopa wears off, it may be caused by PD. In this case, it may help to take a small, earlier dose. When dystonia is mixed with dyskinesias, it may be caused by levodopa. In this case, it can help to reduce levodopa and avoid drugs that prolong its effects.

Add New Medications. If levodopa adjustments are not sufficient in easing dystonia, your doctor may recommend additional medications such as amantadine (Symmetrel®), botulinum toxin injections (if dystonia is limited to one body part), muscle relaxants, pain medications or, if dystonia is intractable, deep brain stimulation.

Get Active. There are many effective non-drug strategies that can ease dystonia in PD. Ask your doctor about occupational therapy, physical therapy, yoga and tai chi.

#### The Physical Therapist

Don't let the frustration and discomfort of dystonia stop you from living your life. Learn how to manage your symptoms and keep moving.



Heather J. Cianci, P.T., M.S., G.C.S., founding therapist, Dan Aaron Parkinson's Rehabilitation Center, Good Shepherd Penn Partners, Philadelphia, PA.

Get a Physical Therapy Assessment. Physical therapists have intimate knowledge of where muscles are located and what functions they perform. Your therapist can help you learn which muscles are specifically affected by dystonia, which will help you understand how to better stretch, strengthen and relax. Your therapist can also show you new ways of moving during dystonia episodes to help prevent injury and possibly limit pain.

Try Massage. Depending on the muscles affected, a therapist can teach you self-massage, partner massage, or how to use devices to provide temporary relief. Massage helps make muscles and surrounding tissue more pliable. Some people find that massage after exercise can make future dystonia episodes less severe.

Become Physically Fit. An inactive lifestyle makes PD more challenging. Being sedentary leads to slower and smaller movement, worsening posture and weak muscles. These changes can worsen dystonia and make it difficult to manage. Learn a fitness routine and feel more in control of dystonia, and your life.

#### The Occupational Therapist

Even if you cannot eliminate your dystonia, there are things you can do to reduce its impact on your daily life.



Erin R. Foster, O.T.D., M.SCI., O.T.R./L., Assistant Professor of Occupational Therapy, Neurology and Psychiatry, Washington University School of Medicine, St. Louis, MO.

Relax. Many people report that being relaxed helps with their dystonia. Find stress-reducing activities that you can incorporate into your daily routine to promote general physical and mental relaxation, or to use on-the-spot when you experience dystonia. Examples include yoga, tai chi, mindfulness/meditation, diaphragmatic breathing, progressive muscle relaxation and guided imagery/visualization.

"Trick" It. Some people use "sensory tricks" involving gestures, positions or touch to temporarily relieve dystonia. Examples include touching the chin for neck dystonia or holding the pen differently for writer's cramp. While sensory tricks do not work for everyone, you may find it worthwhile to try some out. If you are working with an occupational therapist, ask them for additional ideas that might work for you.

Plan Around It. If you have predictable periods of dystonia, organize your day around it. Plan your "must-do," more challenging, or social activities for when you do not have dystonia, and take the opportunity to rest or engage in more sedentary activities when you do.



## Join the Newest PDF PD ExpertBriefings

Find practical tips for taking charge of PD. Available online or by phone.

What's in the PD Pipeline? Gene & Cell Therapies

Tuesday, April 5, 2016 Roger Barker, Ph.D. University of Cambridge **Apathy or Depression:** Which One Is It?

Tuesday, June 14, 2016 Dawn Bowers, Ph.D. McKnight Brain Institute

Each PD ExpertBriefing takes place LIVE online from 1:00-2:00 PM ET and then becomes a recording on PDF's website. Pre-registration is recommended; phone participants can access each LIVE seminar by dialing (888) 272-8710 and when prompted, entering code 6323567#. CEUs are available for some professionals via PDF's sponsorship of the American Society on Aging.

This series has been made possible by educational grants from AbbVie, Inc., Acadia Pharmaceuticals Inc. and Lundbeck LLC.

www.pdf.org/parkinsononline

## WHAT'S YOUR **PASSION?**

See how PDF Champions are putting their passion to work for PD.









From left to right: On November 22, Nicole Lopen ran the Philadelphia Marathon in honor of her father, raising \$2,000 for PDF. Also on November 22, 120 guests attended the 13th annual Music for Parkinson's Research concert in Rye, NY, raising \$40,000. Pictured are Denny Jacobson, Eileen Lehrer, Francie Camper, Robert Mencher, Regina Schwarz, David Eger, Ph.D., Jane Eger, Martin Mintz and PDF President, Robin Elliott. On November 30, Pranamya Mahankali and the Liberty University College of Osteopathic Medicine - Student Osteopathic Medical Association raised \$446 for PDF at their Second Annual Pancakes for Parkinson's in Lynchburg, VA. On January 17, Lauren Mattioni ran the Arizona Rock 'n' Roll Half Marathon in Phoenix, AZ, raising \$350 to benefit PDF in memory of her grandmother.

## Will you join our Champions?

Make a difference during April, Parkinson's Awareness Month, with our top 5 tips:

Host a bake sale or car wash.

Turn happy hour into Helping Hours, by hosting a signature PDF fundraising event.

Learn more at www.pdf.org/helpinghours Wear the winning PD Awareness T-Shirt design.

For \$9.95 at www.pdf.org/shop

Get sporty to raise funds, whether through a 5k, a walk or a golf tournament.

www.pdf.org/marathon

Dress casual at work in exchange for \$5.00 donations.

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POFCHAMPIONS

## New Steps in Building Health Care Leaders in Parkinson's –

As part of its mission to end Parkinson's, the Parkinson's Disease Foundation (PDF) is investing \$600,000 in 2016 for training for health care leaders, who can improve lives of people with the disease. Meet this year's leaders.

#### Fellowships for Neurologists Specializing in PD

To date, PDF has funded two-year movement disorder fellowships for 150 neurologists who reach an estimated 12,000 patients every year. At right, are this year's fellows: Meagan Bailey, M.D., and Ian O. Bledsoe, M.D., of Rush University Medical Center; Miriam Sklerov, M.D.; Lan Luo, M.D., and Shabbir Hussan I. Merchant, M.D., of Columbia University Medical Center. Not pictured: Madeleine Sharp, M.D.





### **Training for Nursing Faculty Leaders**

To date, PDF has trained 170 nurse faculty leaders through its Edmond J. Safra Visiting Nurse Faculty Program, who have educated 11,000 nursing students. A new class of scholars completed training in November 2015 at the Fresco Institute for Parkinson's and Movement Disorders at NYU Langone. They are pictured with Gwyn M. Vernon, M.S.N., R.N., C.R.N.P., National Director of the program, and Amy Lemen, M.A., L.C.S.W., and Alessandro Di Rocco, M.D., both of NYU Langone.

#### Online Training for Physical & Occupational Therapy Practitioners (New!)

To date, more than 9,500 physical therapists have taken our online course, Parkinson's Disease: A Practical Approach to Evaluation and Treatment for the Physical Therapist. Since January, 100 occupational therapists have taken Occupational Therapy: Across the Parkinson's Disease Continuum. CEUs are available for both. At right, OT course faculty gather at the live taping in Dallas, TX, in December 2015. From left to right: Linda Tickle-Degnen, Ph.D., Eli Pollard, Sue Berger, Ph.D., Jay Phillips, Marilyn Phillips, P.T., Ingrid Sturkenboom, O.T., Sotirios Parashos, M.D., Ph.D., and Erin Foster, O.T.D., M.S.C.I.



Learn more about all opportunities for health professionals by visiting www.pdf.org/en/parkinson\_health\_professionals

## Community Events



Celebrate Spring New York Date: Thursday, April 7 Place: Marquee, New York, NY www.pdf.org/csny

Walk

Date: Saturday, April 23 Place: New York, NY www.unitywalk.org

**22nd Parkinson's Unity** *Ocelebrate Spring Boston* Date: Friday, April 29 Place: The Liberty Hotel,

Boston, MA www.pdf.org/csbos

O PDF Gala Bal du Printemps Date: Wednesday, May 11 Place: The Metropolitan Club, New York, NY www.pdf.org/gala

( ) PDF Event

Find more events or list yours on our website: <a href="https://www.pdf.org/event\_calendar">www.pdf.org/event\_calendar</a>

Photo Credits: Page 3: Watermarked map of Parkinson's prevalence in the US (Credit-Allison Willis, M.D.); Page 10, PDF Champions photo three (credit Shelley Andrews/Liberty University College of Osteopathic Medicine).



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# Are you on the team ENDING PARKINSON'S?

April is Parkinson's Awareness Month. Join our team, invite others! Launching April 1.

www.pdf.org/parkinson\_awareness



## Community | Commitment | Impact

Supporting the research and ideas that will improve the lives and futures of people touched by Parkinson's.

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