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A B O U T U S

The **Parkinson's Post** is published by the Northwest Parkinson's Foundation, a 501(c)(3) charitable organization.

**Our mission is to establish optimal quality of life for the Northwest Parkinson's community through awareness, education, advocacy and care.**

We welcome your comments on this newsletter and all our activities.



# Choosing a life better lived

BY CRAIG HOWARD

There's an interesting fellow named David Heydrick. He's a doctor—a neurologist, in fact—and an engineer. He's also a writer and a speaker in his work advocating for people to live healthier lives. And he was brought to this advocacy because he has Parkinson's disease.

Heydrick's largest work on Parkinson's-related things is the "Parkinson's pyramid," pictured here. This framework for living a healthy life has led to a lot of other thinking about good health for everyone, Parkinson's or not.

Recently Heydrick shared that he'd had a daydream, and it turned into a line of inquiry that has him very excited about raising general health.

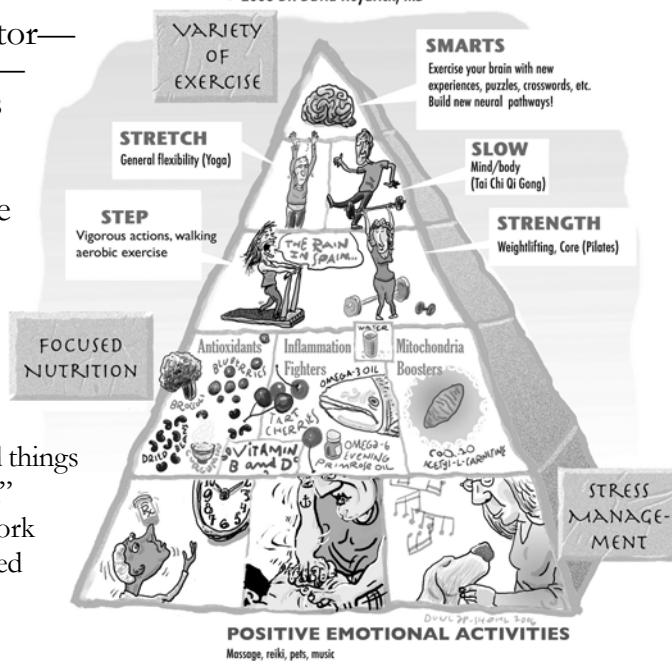
His idea was that we have the capacity to live not just lives, but very healthy, happy lives, just by paying attention to the ways we live—the way we eat, exercise, work, and even sleep.

If we can make just a few changes here and there, he reasoned, they will add up to a longer, healthier life.

Heydrick found some books he hadn't read in years, and a few new ones, and they've opened his mind to a sort of unified theory on living better.

## THE PYRADIGM OF HEALTH

© 2008 Dr. David Heydrick, MD



These include books by John Robbins, *Diet for a New America* (1987) and *Healthy at 100* (2006); T. Colin Campbell, Ph.D.'s book, *The China Study* (2004); and the widely published, pioneering works of Dean Ornish, M.D.

This reading led to a distillation of interesting facts about groups of people, whole societies, with remarkably long, healthy lives—lives that appear free of “Western diseases” such as cancer, adult-onset diabetes, heart ailments, and osteoporosis; lives apparently free of chronic afflictions we're all familiar with, such as multiple sclerosis, lupus, dementia

# HOPE conference to focus on living well

The third-annual HOPE Conference is set for Nov. 1 at the Seatac Hilton Hotel and Conference Center.

Some 700 attendees are expected at the conference, among the nation's largest gatherings of patients, carers and health professionals.

To learn more about the HOPE conference or to register, call 877.980.7500 or email [info@nwpf.org](mailto:info@nwpf.org).

Jointly presented by the Washington chapter of the American Parkinson Disease Association and the Northwest Parkinson's Founda-

tion, the conference will feature national and local experts on a range of topics related to living well with Parkinson's.

Focusing on practical tools patients and caregivers can use to enhance quality of life, the symposium will include sessions on medications, self-care practices, mental health and caregiving. Attendees will come away with coping tools and a new sense of optimism.

The keynote address will be given by **Dave Iverson**, producer of an upcoming PBS Frontline documentary on Parkinson's disease. Iverson, who has Parkinson's, will discuss his journey in making the documentary and address key questions Parkinson's raises for science and an aging society.

Other conference presenters will include:

- **Jeff Shaw, Psy.D.**, of the Booth Gardner Parkinson's Care Center in Kirkland, WA, who will present "Playing to Keep Your Brain Working, Art, Recreation, and Technology"
- **Laurence Elmer, M.D.**, director of the Parkinson's Disease and Movement Disorder Program at the University of Toledo, OH, who will present "The NEXT Revolution in Parkinson's Therapy."
- **Becky Farley, Ph.D., PT**, and **Cynthia Fox, Ph.D., CCC-SLP**, of the University of Arizona, who will present "Explaining the Principles Behind 'Big and Loud.'"
- **Julie Sacks**, director of APDA's National Young Onset Center, who will present "The Importance of Reaching Out and Making Connections Within Your Community."
- **Sheryl Jedlinski** and **Jean Burns** of PDPlan4Life, who will present "How Humor, Exercise, and Personal Expression Inspire Others to Live Well Longer with Parkinson's."

## Scientists to present latest advances in surgery, gene therapy

Two Parkinson's organizations will jointly host "Surgical Advances in Parkinson's Disease," an educational symposium set for Oct. 11 at the Doubletree Hotel in Spokane, WA.

The event, hosted by the Northwest Parkinson's Foundation and Parkinson's Disease Foundation, will provide patients, caregivers, and health professionals with the most up-to-date information about surgical techniques—those available and those in development—to treat Parkinson's disease.

Symposium presenters will include **Monique Giroux, M.D.**, and **Sierra Farris, M.P.A.S., PA-C**,

of the Booth Gardner Parkinson's Care Center in Kirkland, WA; **Jaimie Henderson, M.D.**, of Stanford University School of Medicine; and **Jeffrey Kordower, Ph.D.**, of Rush Presbyterian Medical Center in Chicago, IL.

Giroux, Farris, and Henderson will discuss various aspects of deep brain stimulation (DBS), the most commonly performed surgery for Parkinson's, including details on the surgery itself and how people with Parkinson's can care for themselves before and after surgery. Kordower will address the ongoing research and potential of gene therapy.

"We are pleased that this event will feature leaders in Parkinson's surgery, research, and clinical care," said Bill Bell, Northwest Parkinson's Foundation executive director.

Robin Elliot, Parkinson's Disease Foundation executive director, added that, in addition to being informative, "the symposium will also be interactive, by bringing together those at the forefront of finding a cure for Parkinson's and those living with it on a daily basis."

Registration is open to those who wish to attend in person. The program will also be available free on the Web. To register for this event, visit [www.nwpf.org](http://www.nwpf.org) or call 877.980.7500.

The event is the third in a series of four educational symposia and webcasts titled *Parkinson's Science: Innovations and New Perspectives*. Visit [www.pdf.org](http://www.pdf.org) to view the first two webcasts on genetics, nonmotor symptoms, and potential treatments in the pipeline for Parkinson's.

# Try techniques to tame restless legs syndrome

**Q: My legs bother me and feel restless at night. What causes this and how do I treat it?**

**A:** People with Parkinson's can have nighttime discomfort in their legs for several reasons. Muscle pain, especially in the calf muscles, is thought to be related to muscle stiffness. Muscle contraction, called dystonia, can lead to toe flexion—or a pulling sensation in the foot or leg muscles.

Movement disorder specialist Pinky Agarwal, M.D., describes a common leg problem called restless legs syndrome (RLS).

RLS is a sensation of restlessness and discomfort in the legs that worsens when sitting, lying, or resting and improves with movement, such as walking. Some patients describe the sensation as a creeping, crawling, gnawing, or boring sensation, or an urge to move.

People with this condition commonly experience trouble falling asleep.

RLS is present in up to 10 percent of the population but may be slightly more common in Parkinson's. The cause of RLS is not clear, but it may be related to an alteration in brain chemistry and dopamine changes in an area of the brain called the diencephalospinal region. Studies suggest a possible genetic link in some people.

Other conditions such as peripheral neuropathy, kidney disease, pregnancy, and iron deficiency can worsen RLS. Blood tests for iron deficiency and other metabolic conditions are available.

Certain medicines can worsen RLS. Antihistamines like Benadryl (an ingredient in Tylenol PM, which is often used for sleep) and certain antidepressants can worsen RLS in Parkinson's.

Conversely, medications that replace dopamine can treat RLS.



Ask the Expert features questions from readers and responses from **Monique Giroux, M.D.**, medical director of the Booth Gardner Parkinson's Care Center in Kirkland, WA. Got a question? Email it to [questions@nwpf.org](mailto:questions@nwpf.org), mail it to 400 Mercer Street, Suite 401 | Seattle, WA 98109-4641, or call us toll-free at 877.980.7500.

In responding to questions, Dr. Giroux seeks advice from other specialists to make readers are aware of the range of providers available to address the various aspects of Parkinson's. For this month's response, Dr. Giroux sought input from Center colleagues **Pinky Agarwal, M.D.**, **Kay Ballen, OTR/L**, and **Martha Glisky, Ph.D.**

Two dopamine agonists, ropinirole and pramipexole, are approved for treatment of RLS. Carbidopa/L-dopa is also helpful. These medicines can be used throughout the day to treat the movement symptoms of Parkinson's or taken at night for RLS.

Other helpful medicines include benzodiazepine drugs such as clonazepam, though its use may be limited because of its sedative effects. Opioid medications such as propoxyphene, codeine, and oxycodone can be tried in more severe cases. Side effects from opioids can include dependency, constipation, and itching.

In some cases the antispasticity medicine baclofen and the antiseizure medicine gabapentin are effective in addressing RLS.

RLS can significantly affect sleep, especially the ability to fall asleep. Lifestyle changes can reduce the severity of RLS and improve sleep. It is recommended that RLS sufferers avoid caffeine, alcohol, and over-stimulation during the evening hours.

Occupational therapist Kay Ballen,

OTR/L, offers a few suggestions to improve your nighttime sleep. She recommends developing a sleep ritual that helps you unwind an hour or so before going to bed. Try gentle stretching or a warm bath to help you unwind, relieve minor aching from muscle tightness or stiffness, and alleviate RLS.

Neuropsychologist Martha Glisky, Ph.D., notes that sleep deprivation from RLS can make patients feel irritable, stressed, and depressed. She offers tips to help people deal with the daytime effects of sleep problems from RLS. Reduce stress by simplifying your life when possible, she says, and find time for relaxation and pleasurable activities.

She recommends avoiding multitasking after a poor night's sleep and choosing activities that aren't too demanding. In addition, give yourself extra time to complete activities if you have had poor sleep the night before, Glisky recommends.

Simple changes in medicine or medicine timing can also make a difference. Most importantly, talk to your provider about options for treating RLS.

# Patience pending

BY PETER DUNLAP-SHOHL

We people with Parkinson's are mavericks. We not only march to the beat of a different drummer, sometimes we don't march at all. In fact our theme song should be "I Ain't Marching Anymore" by Phil Ochs. Go with the flow? Not us. No flow, no go.

As members of a culture so manic that it has been forced to slice time into nanoseconds too small for any human to even perceive, we are the dissenting minority. While others multitask all around us, texting their overfilled to-do lists to their partners while crashing their cars, we struggle to single-task, spending the morning buttoning our shirts or not tying our shoes.

This is a role none of us are cut out for these days. Patience cannot be ordered over the Web and then delivered the next day in a brightly colored Express envelope. Instead, we must learn it. And how do we do that?

Slowly.

Fortunately, we have many opportunities for practice. We spend countless minutes waiting for our meds to kick in. Dopamine brings a rush, but you can't rush dopamine.

Crossing a room can take on the quality of a major expedition, complete with danger. You may be in a hurry, but your feet are on their own schedule, and frankly, they're tired of being ordered around. They will get you there in their own sweet time. Push them too much, and you're going down hard, pal. They'll stick to the floor and you'll topple to their level with a thud that frightens everyone in the vicinity—with the exception of the mutinous extremities them-



*This is the Sept. 8, 2008, post from "Off & On," cartoonist Peter Dunlap-Shohl's blog about life with Parkinson's disease.*

selves. They're already safe on the floor. It won't be them that feels the pain. I don't know a single person with Parkinson's who has injured a foot in a fall.

So you learn not to rush your feet. They have the upper hand.

You want to practice patience? Try removing the cap from the bottle that holds the pills that enable you to take the caps off bottles. Hours of fun. The irony alone will amuse you for eons. Which is how long it will take to get to the pills.

The ultimate exercise for developing patience is the marathon wait for the cure. I remember a friend who bitterly observed that he had been assured that a cure was no more than a decade away. That decade has passed, and so has he.

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You want to practice patience? Try removing the cap from the bottle that holds the pills that enable you to take the caps off bottles.

But bitterness sours the present for the sake of an uncertain future. So we need something to do instead of waiting.

We have to work in the present to advance the progress toward the day when we can get back in the rat race with everyone else.

I'd love to just stop and smell the flowers, but ever the pranking poltergeist, Parkinson's even takes your sense of smell.

*Peter Dunlap-Shohl, 49, blogs from Anchorage, AK, where he lives with his wife and son, works as a cartoonist, and leads the Anchorage Parkinson's Disease Support Group. You can enjoy more of his posts at [offandonakpdrug.blogspot.com](http://offandonakpdrug.blogspot.com).*

## Will work for PD

There are so many ways to play a role in improving quality of life in the Parkinson's community. One way is to get involved with the Northwest Parkinson's Foundation.

People across the region—and beyond!—are getting creative in supporting our quality-of-life mission. They're joining Team Parkinson's, starting bowling and golf tournaments, and hosting parties, concerts and recitals to benefit North-

west Parkinson's Foundation programs and services. They're also volunteering to assist us with events, mailings, and projects around the office.

Want to help? Give us a call at 877.980.7500 to share your ideas or volunteer your time.

## Pesticides linked to Parkinson's in results of new research

A recent study by researchers at the University of Texas Health Science Center and East Texas Medical Center indicates that use of pesticides such as rotenone may increase risk of Parkinson's disease.

Pesticide use has long been linked to Parkinson's, but this is one of the first studies to show a possible correlation between a specific pesticide and Parkinson's disease in humans, according to the researchers.

"It shows what we all have been suspecting but had no proof of," said George Plotkin, M.D., one of the researchers. "It is an obvious connection that there are things in our environment that increase Parkinson's disease dramatically."

Study participants responded to a survey that asked about their habits, demographic information, occupational history, and mental history. Those with Parkinson's were 10 times as likely to have been exposed to rotenone than those in the control group.

Rotenone comes from the roots of tropical plants and is highly toxic to fish and insects but mildly toxic to humans and other warm-blooded animals. It is used in gardens and in fisheries to remove unwanted fish species.

Amon Dhillon, M.D., M.S., a co-investigator in the study, said Parkinson's is likely the result of two factors—genetics and exposure to environmental toxins.

"You have some genes that make you more susceptible to Parkinson's disease," he said, "and, on top of that, there are things in the environment that will make it more pertinent."

Parkinson's surfaced around 1817, at the peak of the industrial revolution—a fact that bolsters evidence that Parkinson's is linked to the environment, Plotkin said.

He said that while some harmful pesticides may still be available on store shelves, people can avoid exposure by using care. "Life has to go on, but we have to understand right now the way we handle these pesticides," he said. He recommended wearing masks and gloves when handling pesticides and other toxic products.

The study also revealed links between other pesticides and Parkinson's disease. People in the study with Parkinson's disease were twice as likely to have used pesticides with chlorpyrifos, such as Dursban, than those in the control group.

Dursban and similar pesticides were banned by the Environmental Protection Agency in 2000 because they may potentially harm the developing brain and nervous system in children.

"I would not be overly concerned until we have more substantial evidence," Dhillon said. "This study is the first step. I think we will have to have more substantial research before we can make any conclusions."

*Excerpt printed with permission from the Tyler Morning Telegraph, of Tyler, TX.*

## Advanced Parkinson's subjects are sought for treatment trial

The Booth Gardner Parkinson's Care Center in Kirkland, WA, is seeking participants for a national study of a new experimental treatment for advanced Parkinson's disease. The study evaluates the safety and effectiveness of delivering an investigational medication through a new delivery route directly into the digestive system.

The study requires a short stay in the hospital to evaluate whether the new method is beneficial for the patient. If the method is effective and tolerated, a

small tube is placed into the stomach with an extension tube into the small intestine for continuous delivery of the study medication for up to 12 months.

Who qualifies?

- Men or women 30 or older
- Those with advanced

Parkinson's disease who experience wearing off with Parkinson's medications

- Those who are able to keep a diary of "off" time
- Those who have had treatment with available Parkinson's medications that are not providing optimal treatment of symptoms.

What can you expect while participating in this study?

- You will receive close medical

follow-up at no cost from physicians who have expertise in Parkinson's.

- Physical and neurological exams
- Laboratory assessment
- Evaluations to assess your mental and physical symptoms of Parkinson's and your ability to perform daily activities.

Participation in this study does not affect the treatment of other medical conditions, and participation in any research study is confidential and voluntary.

For more information, call the Center's research coordinator at 425.899.3126 or 425.899.3115.

*Source: Booth Gardner Parkinson's Care Center*

and Parkinson's. And it turns out these groups had some core similarities.

### Features of societies with long lifespans

- *Manageable stress.* When present, the stress is handled by support from the community. There is an abundance of love and respect for one another, a love and respect that includes children and the elderly.

- *Little or no medication use.* There is no need because they don't experience Western or chronic diseases. They also do not experience sleep disorders!

- *A low-calorie, nutrient-dense diet,* about 1,500 calories per day, primarily from plant-based (i.e., vegetarian) sources, with a focus on fresh and unprocessed whole foods and only occasional small amounts of meat (usually fish) and dairy.

- *An active lifestyle* that is naturally aerobic and strength-building, with activity occurring *outdoors.*

Some will immediately say, "Probably just good genetics." But it's clear it goes way beyond that.

There are societies with very similar genetic histories living near each other, with very different lifespan and health histories.

There is a lot to be learned from these groups of people without Parkinson's and other diseases.

For the better part of a century, scientists have been documenting a great deal about the relationship between lifestyle and disease. But, as Robbins states, "... since there is comparatively little profit to be made from encouraging lifestyle changes, the wider public has little idea of the extraordinary benefits such changes can bring."

When it comes to lifestyle, evidence is accumulating that what's good for the brain are the same things that have long been shown to benefit other organs, such as the heart.

Ornish, for example, has demonstrated in clinical trials a reversal of heart disease and decreased need for medication through lifestyle changes.

The reality for most of us, however, is a culture that prizes achievement and busy-ness, and this adds to stress, poor eating habits, and disturbed sleep.

The only way for this to change is for an individual to consciously decide to change his or her own path. Heydrick refers to this new approach as "It's All Good!"

### The "It's All Good!" lifestyle approach

- *Take away excessive stress*—by meditation, laughter, and many long-term complementary therapies. The energy you spend stressing out over every little thing should be replaced with loving relationships and social connectedness.

Relationships have proven in study after study to have a profound positive influence on health.

- *Take away over-dependence on medication and supplements*—replacing them with wise use of medications and supplements at the lowest effective doses. Much of what we take medications and supplements for can be addressed as well if not better in the long run with nutrition and exercise.

- *Take away unhealthy, nutrient-poor, high-calorie foods*—like processed sugar- and fat-laden foods and excessive amounts of animal-based foods, and replace these with nutrient-dense, naturally low-calorie foods. This means organic fresh fruits and vegetables, nuts, seeds and legumes, herbs and spices, and whole grains, and occasional animal-based foods like wild Pacific salmon and free-range eggs. Some of this costs more than your average store-bought

foods, but what a great investment.

- *Take away excessive sedentary, indoor habits*—and replace with regular vigorous activity including stretching, strengthening, and mind-expanding activities. Use it or lose it, preferably outdoors.

This may sound a bit idealistic, and the reality is that with Parkinson's we can spend much of our time and resources just trying to make it through each day battling symptoms—symptoms that create their own stress.

What's more, all of us, with or without Parkinson's, battle many modern issues, including environmental toxins and the distractions that come

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Most of us live in a culture that prizes achievement and busy-ness. This adds to stress, poor eating habits, and disturbed sleep.

with modern conveniences, making it tougher to "eat healthy and exercise."

Making an entire lifestyle change is not easy, but starting or maintaining a healthy lifestyle will pay off.

Like most things we undertake, we can't expect to get a perfect score right away. But by choosing one small thing to improve in your life, getting that under control then moving to another, eventually you can make a significant impact on your health and well-being.

Try eliminating the bad stuff bit by bit. Eventually, the "It's All Good" approach might make a difference for you, and Heydrick's daydream might just become your reality.

*For more on this topic take a look at [www.parkinsonspyramid.com](http://www.parkinsonspyramid.com). Craig Howard is a founding Northwest Parkinson's Foundation board member.*



TRIBUTE GIFTS

Gifts to the Northwest Parkinson's Foundation support educational programs including our website, email updates, caregiver booklet, newsletter, patient-education programs, and conference. Donations also fuel outreach and advocacy efforts on behalf of patients and families.

We are privileged so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year in honor or memory of special friends and loved ones.

*Thank you, all, for your support.*

Listed here are tribute gifts made between **July 9 and September 10, 2008.**

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The Northwest Parkinson's Foundation is a cofounder and partner of the **Booth Gardner Parkinson's Care Center** (13030 121<sup>st</sup> Way NE, Kirkland, WA 98034). This comprehensive care facility is home to physicians, neuropsychologists, physical and occupational therapists, and speech pathologists, all specialists in working with Parkinson's patients. To make an appointment, call **425.899.3123**.

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## Staying informed has never been easier!

The Northwest Parkinson's Foundation offers more than one way to stay informed. In addition to our bimonthly *Parkinson's Post* newsletter, you can sign up for the *Parkinson's Email Update*, a weekly email containing the most helpful and hopeful news items we can find from around the world.

These articles, bundled into one email message and delivered to your inbox each Friday, include the latest information on wellness, treatments, and research discoveries, as well as insights into living better with Parkinson's disease. The *Parkinson's Email Update* is geared to patients and caregivers. And, like all our educational resources, it's free of charge to the Parkinson's community.

Speaking of free resources, don't forget our website—[www.nwpcf.org](http://www.nwpcf.org)—where you'll find a range of articles on Parkinson's disease, event listings, archived issues of the *Parkinson's Post*, and more.