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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.



NORTHWEST
PARKINSON'S
FOUNDATION

Finding hope on 3 wheels

BY RICK HERMANN AND LEE WILLIS

The husband-and-wife team of Rick Hermann and Lee Willis describe the friendship and hope they discovered along the path toward living better with Parkinson's disease.

Rick: Somewhere between my Parkinson's diagnosis in 1998 and June 2008, I had forgotten what hope felt like. It didn't just disappear one day. It crept slowly, soundlessly away in the smallest increments over the past 10 years.

The realization came a couple of days after my first deep brain stimulation (DBS) surgery, while I was out walking with my wife. I noticed that my legs were springier and felt alive for the first time in years. I was told I might experience something like this after implantation of my electrodes.

The effect didn't last longer than a day, but it gave me hope that I would get back to the way I felt that day. And I dreamed of riding a bike again.

Lee: Rick has been riding bikes all his life, for commuting and for pleasure. In 1992, as he was commuting on his bike, he was broadsided by a car. It was after that that he first experienced neurological symptoms. In 1998 he was finally diagnosed with Parkinson's disease. I suspect the accident triggered the Parkinson's.

Rick: I'm uncomfortable when people tell me how brave I am to deal with



Courtesy photo

Rick Herman on his new recumbent trike.

Parkinson's disease in an active, upbeat way. The truth is, I am largely motivated by fear of disease progression and will do anything I can to stay otherwise healthy until the Next Great Thing in treatment comes along.

Lee: We happened into our friend Marilyn Williams, who is an avid cyclist and understands Parkinson's well. Her husband was diagnosed in 1996. She was telling Rick about her plans to ride with some friends to Glacier National Park in Montana in July. Rick was truly excited

> CONTINUED ON PAGE 3

Insufficient vitamin D linked to Parkinson's

A majority of Parkinson's patients had insufficient levels of vitamin D in a new study from Emory University.

The fraction of Parkinson's patients with vitamin D insufficiency—55 percent—was significantly more than patients with Alzheimer's (41 percent) or healthy elderly people (36 percent).

The finding adds to evidence that low vitamin D is associated with Parkinson's, said one of the study's investigators, Marian Evatt, M.D.

Evatt and her team compared Parkinson's patients to Alzheimer's patients because they wanted to evaluate the possibility that neurodegenerative diseases in general lead to vitamin D insufficiency.

Most Americans get the majority of their vitamin D from exposure to sunlight or by dietary supplements; fortified foods such as milk, and packaged cereals are a minor source. Only a few foods in nature, such as salmon and tuna, contain substantial amounts of vitamin D.

The body's ability to produce vitamin D using UV-B radiation from the sun decreases with age, making older individuals at increased risk of vitamin D deficiency.

"We found that vitamin D insufficiency may have a unique association with Parkinson's, which is intriguing and warrants further investigation," Evatt said. The connection could come partly because some people with Parkinson's have mobility problems and are seldom exposed to the sun, or because low vitamin D levels are somehow related to Parkinson's onset or progression.

Evatt said the study results are striking because the research subjects came from the Southeast, where, given the short winters, vitamin D insufficiency is not thought to be a factor.

In addition, the study found that

the fraction of patients with the lowest levels of vitamin D, described as vitamin D deficiency, was higher (23 percent) in the Parkinson's group than in the Alzheimer's group (16 percent) or the healthy group (10 percent).

The study examined 100 people in each group, who were recruited between 1992 and 2007. Every fifth Parkinson's patient from Emory's clinical neurology database was selected, and healthy controls and patients with Alzheimer's disease were matched on age and state of residence.

Doctors have known for decades that vitamin D plays a role in bone formation, Evatt said. More recently,

scientists have been uncovering its effects elsewhere, including producing peptides that fight microbes in the skin, regulating blood pressure and insulin levels, and maintaining the nervous system. Low vitamin D levels also appear to increase the risk of several cancers and autoimmune diseases such as multiple sclerosis and diabetes.

Previous studies have shown that the part of the brain affected most by Parkinson's, the substantia nigra, has high levels of the vitamin D receptor, which suggests vitamin D may be important for normal functioning of these cells, Evatt said.

Source: ScienceDaily

Studies, trials offer way to get involved

Here are three Northwest clinical trials seeking volunteers. Clinical trials are opportunities to get involved in the search for better therapies and for a cure. A full list of clinical trials across the United States, along with details on those highlighted here, can be found at www.pdtrials.org.

■ Study of Tai Chi Exercise and Balance in People with Parkinson's Disease

This study will examine how tai chi affects balance, gait, muscle strength, and general physical performance. The trial comprises three groups: tai chi, conventional strength training, and a low-impact exercise control group. Randomized participants in each group take part in a 60-minute exercise program twice a week for 26 weeks.

■ Examination of Motor and Cognitive Planning in People with Parkinson's Disease

This study will examine how the brain gets ready to give a response. The study involves three sessions. Participants are asked to complete one reaction-time session while off their Parkinson's medications. Participants also complete tests of language, memory, and other functions.

■ Study to Reduce Off Time and Uncontrolled Movements Caused by Levodopa in People with Parkinson's Disease

The purpose of the study is to assess the efficacy and safety of a range of doses of an investigational drug, SCH 420814, used together with a levodopa decarboxylase inhibitor. Researchers are gathering data that would allow them to gain approval from the FDA for SCH 420814 to be used to treat Parkinson's.



Courtesy photo
Rick Hermann
 zips along on his
 recumbent trike.

> CONTINUED FROM PAGE 1

for her and also, frankly, jealous.

Rick told her that he had given up biking, but Marilyn asked, “What would it take to get you back on wheels?”

Rick: Things had been going in the wrong direction for a few years. In June, I had an epiphany: There was only one viable choice if I wanted to have a life. For me, DBS surgery was the leap I had to make.

Lee: A couple of days later, Rick received a copy of an email from Marilyn to Bill Bell, executive director of the Northwest Parkinson’s Foundation. Here’s what it said:

Bill—Rick has researched what it would take to start riding again. I will commit to rejoining Team Parkinson’s and doing a serious job of fundraising if you will commit to getting Rick back on a bike.—Marilyn

With tears in his eyes, Rick shared this news with me and before we knew it, Marilyn had set up a page on the Team Parkinson’s website.

I got busy and sent this information out to friends and family. There was an immediate and overwhelming response. We were thrilled and really blown away!

Rick: On July 21 I had the first of two surgeries at Swedish Medical Center in Seattle, both performed by neurosurgeon Peter Nora, M.D. At the same time, we were fundraising for the recumbent trike, using the online Team Parkinson’s fundraising format. The response was amazing: We hit our \$2,000 goal within a month.

Lee: By the time Marilyn headed to Mt. Rainier for her chosen Team Parkinson’s fundraising ride, the fund had grown enough for Rick to shop. He found

Mike Libik, who owns Easy Street Recumbents in Austin, TX. Rick chose a Sun X3 recumbent trike. The trike is a stable design, and Mike adapted it by installing a front-wheel hub motor and a lithium-ion battery pack.

The trike arrived by coincidence on the day we came home from Rick’s second programming appointment to activate his DBS hardware.

Rick: Lee was the heart of the fundraising campaign, and she worked hard on it. My mood flagged occasionally, but our anticipation was keen.

I rode the trike home from the shipping dock, about a mile uphill. I panicked at first when my legs painfully seized up, but once I figured out the motor-assist function, I relaxed and just accepted the extra power. The motor is virtually silent, and I peddled and glided along the forest trail to our home near Lake Whatcom, WA.

I know cycling and DBS aren’t for everyone. But it’s been a miraculous time for me as I’ve recaptured the hope I’d slowly lost. I’m looking forward to a great 2009—much of it in the saddle of the new trike. Thanks to everyone who made it happen.

Patient fills plate, makes connections with support group

Tori Kelly keeps very busy with three foster teens, a part-time job, and four or five hours volunteering each week.

She recently added another role to her list: facilitator of a new Parkinson’s support group in Stanwood, WA.

“My life has become quite full since I was diagnosed with Parkinson’s,” Kelly said, noting that keeping busy

“takes my mind off my disease and on to helping others.”

The group met for the first time in mid-October, and an amazing commonality—beyond the Parkinson’s, that is—was discovered: The group boasts three accordion players! Other members include a cartoon sketch artist, a singer, and a former model.

The members of this new group spent two hours getting to know each other, providing encouragement, lending support, and exchanging insights about medications, health care, and day-to-day challenges.

The group welcomes patients, family members, and caregivers to join. It meets from 9 to 11 a.m. the second Monday of every month at the Warm Beach Free Methodist Church in the Upper Wesley Building, 20815 Marine Drive, Stanwood.

To learn more, contact Tori Kelly at 425.422.1067 or tkelly.2@juno.com.

For a listing of support groups in your area, visit www.nwpcf.org/supportgroups.aspx. Can’t find a support group nearby? Consider starting one! Call us at 877.980.7500 for guidance on getting started.

I only pass out in the best places

BY PETER DUNLAP-SHOHL

I am under strict orders from my son never to do this again. We were dining with family, and I was enjoying a beer and a well-prepared meal in a sunlit restaurant in exotic Kirkland, WA. As conversation wafted around I became distracted by an odd sensation in my stomach, a feeling akin to what you might experience if you'd swallowed a live and angry badger.

My initial Badger Pacification Strategy (BPS) was denial. Skip this tack should this happen to you. It's useless. As the situation rapidly deteriorated, I adopted BPS #2:

Lowering my head to the table in an attempt to control the mounting nausea. You might want to skip BPS #2 as well. No help.

It became clear that I was down to two choices. Release the "badger" in our cozy booth



This is the June 13, 2008, post from "Off & On," the writer's blog about life with Parkinson's disease.

(BPS #3) or make for the restroom and return the little guy to the wild via the porcelain porthole (BPS #4). Clearly there is no scenario under which #3 could be defined as successful, which left only a desperate attempt at #4.

Thinking quickly, I enlisted my wife Pam as my handler, the better to spread the inevitable blame when the doomed mission went grandly awry. I rose decisively to my feet, and then (I'm told) crumpled decisively to the floor (BPS #5)

Miraculously, BPS #5 worked great. At least on the badger. But one doesn't crumple to the floor in the middle of a restaurant discreetly. A hullabaloo followed. People were summoning help via their cell phones before I hit the carpet. When I came to, I looked up into a circle of unfamiliar and concerned faces. They assured me that the paramedics would arrive soon, and hovered close until they arrived.

I was still gathering my wits when the team showed. They lost no time in festooning me with wires connected to machines that read vital signs. I was feeling much better and, after explaining about the hazards of rising too quickly when on Parkinson's medications, which can lower blood pressure and cause fainting (see related story on the next page), I managed to talk them out of taking me to the hospital.

This moment of helplessness paradoxically granted a measure of hope. We are bound to one another by our frailty. Confronted by my small catastrophe, strangers responded with swift compassion.

I wobbled out of the restaurant under my own power but with my family arrayed in close formation around me. As we wound our way to the door, I carried a new intimacy with the anonymous throng returning to their dinners.

The barriers had been breached, and as we left it was possible to sense a common thought that ran through the minds of many: "Damn, I hope I didn't order what *he* had!"

Cartoonist Peter Dunlap-Shohl, 49, blogs from Anchorage, AK, where he lives with his wife and son and leads the Anchorage Parkinson's Disease Support Group. You can enjoy more of his posts at offandonakpdrag.blogspot.com.

Wired communities connect to expertise

The Parkinson's Telehealth Program broadcasts live, interactive, educational talks to a network of rural communities in the Northwest.

On the third Monday of each month, a guest speaker presents a topic

geared toward the interests of Parkinson's families. The information is designed to help participants improve their knowledge of Parkinson's disease and, in turn, their quality of life.

All sessions start at 2 p.m. PST.

The Parkinson's Telehealth Program is jointly presented by the Spokane Parkinson's Resource Center, the Northwest Parkinson's Foundation, and

INHS/Northwest Telehealth.

Visit our website at www.nwpcf.org/telehealthnet.aspx to find out if your community is connected, where to go to view the programming, and to see a list of upcoming presenters and topics.

If you have questions, email us at info@nwpcf.org or call us toll-free at 877.980.7500.

Dizziness and its relationship to Parkinson's

Q: I get dizzy and lightheaded when I stand. Is this related to Parkinson's disease and what can I do about it?

A: Dizziness is sometimes used to describe a feeling of imbalance or insecurity when standing. Dizziness on standing can have multiple causes. Most commonly, however, it is due to a condition called *orthostatic hypotension*, which is a drop in blood pressure that occurs when you move from a lying or sitting position into a standing position.

"When we stand, blood pools in the lower legs, our vessels work to squeeze the blood back to the heart, and the heart rate increases so that our blood pressure does not drop," said cardiologist Rachael Wyman, M.D., of Eastside Cardiology Associates in Kirkland, WA. "If one of these steps does not work adequately, blood pressure will drop when standing."

Orthostatic hypotension can be caused by heart problems, problems in blood circulation, or problems with neurologic control of these functions, referred to as *autonomic dysfunction*. Orthostatic hypotension secondary to autonomic dysfunction is not uncommon in Parkinson's, with more than half of patients experiencing this problem at one time or another.

As Parkinson's advances, the risk of orthostatic hypotension increases. And some medications used to treat the motor symptoms of Parkinson's can worsen the problem. Your doctor can tell you which drugs lend to orthostatic hypotension, as well as those that can be taken to increase blood pressure.

Another common cause of orthostatic hypotension is low blood volume, which can stem from dehydration.

"Many people with Parkinson's don't drink enough fluids, or they limit



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, mail it to 400 Mercer Street, Suite 401 | Seattle, WA 98109-4641, or call us toll-free at 877.980.7500.

In responding, Dr. Giroux seeks advice from other specialists to make readers 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 **Rachel Wyman, M.D., FACC**, of Eastside Cardiology Associates, and **Marilyn Ward, R.D., CDE**, of Evergreen Hospital Medical Center, both in Kirkland, WA.

the amount they drink because of swallowing problems," said nutritionist Marilyn Ward, R.D., CDE, of Evergreen Hospital Medical Center in Kirkland. "As we get older we can't rely on our thirst as a reminder to drink. By the time we feel thirsty, we may already be dehydrated," Ward said.

One way to increase fluid intake is to drink a large glass of water or juice every time you take your pills or urinate. Put water where you can easily see it to remind yourself to drink regularly, Ward advised.

Increasing salt intake can also help. Drinks with high levels of salt include electrolyte beverages like Gatorade and vegetable juices like tomato and V-8. (Keep in mind that many electrolyte or sport drinks are high in sugar and should be avoided if you have diabetes.) Soups are also a good source of both fluid and salt.

Eating smaller, more frequent meals can also help, as the symptoms of orthostatic hypotension can be worse after large meals.

See a nutritionist or swallowing

specialist if you are having trouble or need guidance with diet. And always speak to your doctor before making any changes to your diet or fluid intake.

If orthostatic hypotension is severe and not explained by these conditions alone, a cardiac evaluation or testing for other problems such as diabetes may be needed. Heart-pumping function can be evaluated with an echocardiogram or ultrasound, and an EKG can be done to assess heart rate and rhythm.

Here are a few additional things you can do to reduce the effects of orthostatic hypotension:

- Use compression stockings to reduce blood pooling in your legs.
- Stand slowly and wait a few moments before starting to walk.
- If possible, elevate the head of your bed by 5 to 20 degrees.
- Ask your doctor or physical therapist for exercises for balance.
- Avoid alcohol and high-temperature environments like hot tubs.

If serious problems continue, see your primary care doctor or a cardiologist for additional testing.

Event raises spirits, funds for Foundation programs and services

About 125 guests ate, drank, and made merry at **Take a Bite Out of Parkinson's** on October 28 at Pike Brewing Company in Seattle. The fundraiser generated \$21,000 for Northwest Parkinson's Foundation programs and services.

The event was hosted by Ron Post and Ilyse Rathet of RITROVO Italian Regional Foods; Charles and Rose Ann Finkel of Pike Brewing Company; and Karen and Dick Hadley and Paula Rose of the Northwest Parkinson's Foundation board of directors.

Post, along with Craig Howard, president of the Foundation board, made welcoming remarks. The Hon. Daniel J. Evans, former Washington state governor and founding board member of the Foundation, kicked off the raise-the-paddle portion of the evening. The Hon. Booth Gardner, also a former Washington state governor, shared some personal anecdotes as well.

Participating chefs and restaurants were Seth Caswell of emmer; Walter Pisano of Tulio; Holly Smith of Cafe Juanita; Heidi Gates of Poco Carretto Gelato; Ethan Stowell of Union, Tavolata, and How to Cook a Wolf; John Sundstrom of Lark; and Matt Williams of Beato Osteria & Wine Bar. Participating vendors were Matt Carter of Carter's Chocolates; Stephanie Cuffel of Washington Wine Company; Connie Rizzo of DeLaurenti; and Garagiste.

"I appreciate the tremendous support of our sponsors, chefs, and vendors and the generosity of our guests," said Bill Bell, executive director of the Foundation. "It was a fantastic evening all around."

Dear Friends,

THE NORTHWEST PARKINSON'S FOUNDATION was born out of the need to create a single, centralized location for people to find information and resources on living well with Parkinson's. To ensure that everyone touched by Parkinson's would have access to relevant information on treatment and care, we made the commitment from the start to provide all of the resources we publish free of charge to anyone who requests them.



Now in our 10th year, we reach more than 25,000 people through the *Parkinson's Post*, weekly email news updates, the Parkinson's Telehealth Network, patient-education programs, our toll-free help line, and more. Clearly there is an urgent and growing need for these services as we continue to receive requests for information from

across the country and around the world.

This year alone we have seen our subscriber base grow by more than 6,000 people, dramatically increasing our printing, postage, and distribution costs. That number will continue to rise as we weather these uncertain times and as many of the people we serve, especially the elderly and those on fixed incomes, find their expenses rising beyond their limited means. The free resources that the Northwest Parkinson's Foundation provides are often the only source of information about treatment and care available to those touched by Parkinson's and are crucial in helping them regain the strength and hope they need to live meaningfully with Parkinson's.

As the holidays approach and we pause to celebrate another year of service to the thousands of people touched by Parkinson's disease, we hope you will consider a donation to the Northwest Parkinson's Foundation as part of your year-end giving.

If every one of the 19,500 households that receive this newsletter were to give just \$15, we would reach our funding goals and ensure that all of the publications we produce will continue to be available free of charge to anyone who requests them.

Individually we may not have the means to make a large contribution, but together we can have a tremendous impact on the patients, families, and caregivers who need our help the most.

Thank you for making the *Parkinson's Post* a part of your year, and best wishes for a new year of good health and good cheer.

Happy holidays,

Bill Bell, Executive Director
Northwest Parkinson's Foundation

Team Parkinson's raises \$115,000 to date

The board and staff of the Northwest Parkinson's Foundation extend their warmest thanks to everyone who has participated in this year's Team Parkinson's effort. The 2008 effort has raised more than \$115,000 to date to support the Northwest Parkinson's Foundation mission.

As part of this extraordinary effort, 98 people from throughout the region participated in the Group Health Seattle-to-Portland Bicycle Classic in July—and 14 of them, led by capable cheerleader and rider Pat Matson, completed the 200-mile ride in a single day!

Each team member who raised more than \$150 was entered into a drawing to win one of our fantastic prizes.

Bruce Pederson won an overnight stay from Worldmark by Wyndham. Lynne Birmingham won a custom-fit bicycle valued at \$2,500. Stephen Berg won a weekend stay at a Lake Chelan, WA, cabin. Congratulations, prize winners!

To the more than 25,000 patients, family members, and caregivers we serve, *all* team members are winners. It is through your ongoing support that we are able to continue providing hope and inspiration to the Parkinson's community.

We hope you will continue this work with us next year by signing up for Team Parkinson's 2009. Visit the Team Parkinson's section on our website—at www.nwpcf.org—to register and start spreading the word among your friends, family, neighbors, and co-workers. You can even make Team Parkinson's a part of your holidays by mentioning your participation in your greeting cards or by inviting people to make pledges in lieu of gifts this year.

We'd also love to have your feedback on this year's Team Parkinson's effort. Email your comments to Keri Kellerman at keri@nwpcf.org, putting "Team Parkinson's feedback" in the subject line. We'll be sure to consider your thoughts and ideas as we plan for next year.

Please join us in thanking our Team Parkinson's 2008 sponsors for their generous support:

- **Hos Brothers Construction**
- **Legacy Roofing**
- **Pro-Build/Lumbermens**
- **Mid-Mountain Contractors**
- **Teva Neuroscience**

And please share in our appreciation of those who provided in-kind goods or services:

- **Cameron Catering**
- **Horton, Lantz & Low**
- **Alaska Airlines**
- **Alpine Hut**

Lastly, we extend special thanks to Shelly Tolo, who stepped in and coordinated the effort with humor and grace.

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.

We list tribute contributors in each issue of the *Parkinson's Post*. However, *all* donors are recognized in our *Report to Contributors* each year. Listed here are those who made tribute gifts between **September 11 and October 9, 2008**.

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Parkinson's insights, updates are just a click away

Did you know that this edition of the *Parkinson's Post*, as well as all past editions, can be viewed online? You can help connect friends, family, and anyone else you think might benefit from the content by directing them to our *Parkinson's Post* archive at www.nwpf.org/ParkinsonPost.aspx.

If you'd prefer to read the *Parkinson's Post* online only, thus helping us reduce the cost of printing and postage, please send us an email making this request to post@nwpf.org. Be sure to include your full name and the address to which we currently mail your printed newsletter.

Each Friday we also send the *Parkinson's News Update* by email. This electronic publication includes the latest hopeful and helpful Parkinson's news from around the world. Stories include insights on research, therapies, and wellness. If you'd like to receive the *Parkinson's News Update*, please drop us an email at subscribe@nwpf.org.