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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.



NORTHWEST
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Getting by with a little help from my (guy) friends

BY RICK HERMANN



From left: Dan, Rodd, the author, Chris and Matt

In April I went out on a limb in an email to a group of my male friends. These are guys I know from playing music and through our once-a-month “philosophy on tap” gatherings. We meet to have a pint or two and try to solve the world’s problems. I know... we’re not doing a very good job.

Although I’m about a decade older than most of these guys, we have several common interests and we all know a little about one another. For example, they all know I have Parkinson’s disease, which I was diagnosed with in 1998, but until recently most didn’t really know exactly what Parkinson’s entails for me.

My email started out: “Hi guys. My life is kind of messed up right now.” I went on to ask for their help.

It had been a pretty rough patch for me. I’d been experiencing bouts of depression and was concerned because my wife and caregiver, Lee, had two out-of-town trips scheduled. These trips meant I’d be by myself for about two

weeks out of a two-month period.

Instead of gritting my teeth and telling Lee I’d be fine, I acknowledged my concerns and reached out.

I told my friends I needed help with meals during my wife’s absence because I tend not to eat well, or much at all, when she’s away. (I’m already underweight and can’t afford to lose more.)

I’m also susceptible to feelings of isolation, and I wanted to make sure I’d have companionship for evening meals.

I told my friends I couldn’t manage to organize a schedule and asked them to do what they could.

The response surprised me—not just my friends’ overwhelming desire to help.

I was also bowled over when I learned that a group of men can create the kind of support structure women are so good at in times of need.

One of the guys set up a schedule and shared it with the group. Others filled it in, committing to a meal or two.

It turned out to be enlivening and enlightening. Over dinner, and sometimes

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beers, I got to know a couple of the men I hadn't really known well prior.

Two or three of my "support team" members told me they really admired me for asking for help, something they said would have been hard for them to do.

It amazed me how, in one of my darker hours, I had inadvertently touched something in these men—a desire to help. And in helping, they told me, they found a level of joy. This certainly runs contrary to the view of men not being nurturers.

How was the food, you ask? It was great. And while the food was important, what I remember most about these two weeks is the enjoyment of spending time individually with my friends—each of them busy raising kids, working and trying to carve out time for themselves, but then making the time to bring me dinner.

One effort I especially admired was Matt's variation on a chef's salad. It was delivered in an aluminum lasagna pan. "I hope it's okay," Matt said. "I've never made a salad before." Matt, a soft-spoken teacher, was really working outside his comfort zone. The salad was delicious.

Another evening I was picked up by Chris, who drove me across town to have dinner with his family—his wife, two sons and his wife's parents. It was a joy and a privilege to spend time with these lovely folks. As Chris was driving me home, we agreed it had been a wonderful night.

Dan, in the midst of a job change, was having difficulty keeping up with the daily demands on his time and energy and forgot to sign up for a meal.

He called me after my wife returned, feeling bad about not helping

Need some support, gentlemen?

A new support group has been established for men with Parkinson's, multiple sclerosis and other neurological conditions. The group, led by Jeff Shaw, Psy.D., a staff neuropsychologist with Evergreen Healthcare, will deal with topics relevant to men's lives. The free group will meet from 3 to 4 p.m. the second Tuesday of the month in the Rainier Room (second floor) of the DeYoung Pavilion, 12039 NE 128th St., on the Evergreen Healthcare campus in Kirkland, Wash. Call 425.899.3140 for details.



out. I told him not to feel bad—I was just glad he'd called.

The next evening we went out for pizza and conversation, touching on some of the issues that run deep for men but that mainly go not talked about. I feel that this episode strengthened our friendship.

I learned that men can create the kind of support structure women are so good at in times of need.

These guys are all great, and I am thankful that Dan, Paul, Don, Chris, Rodd and Matt are men I can call friends. It was "only" dinner and a bit of conversation, but it made an enormously positive impact on my outlook while I was alone.

Maybe at the next "philosophy on tap" meeting at one of our several favorite local pubs, we will actually solve one of the world's problems as we linger over pints of microbrew. But for now, I just want to say, "Thanks, guys! I love you!"

Rick Hermann, 59, lives in Bellingham, Wash. His stories have appeared several times in the Parkinson's Post, including in the March/April 2006 and November/December 2008 issues, which you can revisit at our online archive (mwpf.org).

Boxing great's wife to speak on caregiving

An upcoming caregiving conference will feature Lonnie Ali, wife and caregiver to boxing legend Muhammad Ali, who will share how she stays grounded and healthy while caring for a partner with Parkinson's disease.

The free conference runs from 9 a.m. to noon on Sept. 11 in Bellevue, Wash. (location to be determined).

Call the Northwest Parkinson's Foundation at 877.980.7500 for more information.

HOPE is on the way

Mark your calendar for the 2010 HOPE Conference on Parkinson's on Nov. 6, at the Hilton Seattle Airport and Conference Center.

Join the Northwest Parkinson's Foundation and the American Parkinson Disease Association Washington Chapter for an uplifting day of information and resources on living your best with Parkinson's today.

The conference will include four presentations by national experts in Parkinson's, a lunch-hour panel discussion and an array of community resources and vendors.

Look for registration details in the next *Parkinson's Post*.

Twelve years ago I established the Northwest Parkinson's Foundation with the help of Craig Howard and countless others.

While great strides were being taken to find a cure, almost no one was focusing on those in our community living with Parkinson's every day. To help fill that need we established a goal to open a center for Parkinson's disease with a focus on *care rather than cure*. Today, the Booth Gardner Parkinson's Center at Evergreen Healthcare is entering its 11th year and is recognized as a national model of comprehensive care.

The Northwest Parkinson's Foundation is a fundamentally positive organization, with an upbeat yet realistic message about living well with Parkinson's today. We champion both specialized clinical care and the self-care tools that are so vital to one's optimal quality of life—either as a person with Parkinson's, or as a family member or caregiver. We offer tools, resources, coaching and extensive web content to help all who are touched by Parkinson's get answers quickly.

Over the years I've met some of the most courageous and inspiring people who walk the journey with Parkinson's. My mother Tina, the inspiration for this effort, was certainly one of them. I have become close to many hundreds of families, and feel myself lucky to have become their friend, champion and advocate. I'm inspired by and learn from this tribe every day.

Last year was the most successful year in our history. More people were reached and helped by our programs than ever before. With these structures solidly in place, the time has come to move to the next stage of organizational growth. As the Northwest Parkinson's Foundation charts this course, I am stepping down from my position as executive director. I initiated this change because of my passion for the community—

you've all proven to me the profound strength of the human spirit, and I'm certainly not going to let that go. I will continue to serve passionately on the board of directors and remain deeply dedicated to the philosophy, mission and our shared cause. I know you'll continue to be involved, too.

The board was actively engaged in a search process and is pleased to announce that Colleen Crowley, J.D., CFRE, joined our organization on Aug. 1 as the new executive director. Before joining the Northwest Parkinson's Foundation, Colleen served as executive director for Washington Women in Need, where she helped that organization grow from a small start-up to a mature and thriving social service organization. Most recently she worked as a nonprofit consultant with the Collins Group. Colleen brings a wealth of experience to the position and we look forward to starting a new chapter of growth and opportunity under her skilled leadership.

It has been a true honor, privilege and pleasure to have served at the helm of this wonderful organization for these past 12 years. We're looking to the next decade as one with even greater visibility for the programs and services people have come to rely on from us, and I will remain deeply involved in this community that has become my family.

Please join me in welcoming Colleen. With her leadership, we are starting a new chapter for our Parkinson's community, and I look forward to my part—and yours—in the years ahead.

Thank you for all your support. The best is yet to come.

Bill Bell

Join us for Be Well Washington events

Mark your calendar for **Be Well Washington** Family Health Week from Aug. 2 to 7.

From Aug. 2 through 6, you're encouraged to make healthy choices for your physical and mental well being

through complimentary health screenings, informative lectures with health experts, and healthful cooking demos at Washington neighborhood clinics.

The week culminates on Aug. 7 at Qwest Field with the Be Well Health Fair. Bring your family and learn the benefits of health, wellness and an active lifestyle. You'll find interactive wellness displays, health-focused

exhibits for women and seniors, a kids' corner full of fun and healthful activities, a cooking stage, entertainment and more!

Be sure to stop by the Northwest Parkinson's Foundation booth to learn more about our wellness programs and resources for caregivers and families.

For full details, visit Be Well Washington online at bewellwashington.com.

Simple strategies help you stay positive, active

Q: How do people diagnosed with neurological conditions like Parkinson's remain positive despite their difficulties?

A: Realistically, it is often challenging to be optimistic and positive in light of the difficulties common to Parkinson's disease and other significant medical problems. For all people, life involves adversity and struggles. We all feel down or upset from time to time.

Some of these life issues resolve after time passes, and we can move on. Parkinson's, unfortunately, has a way of sticking around.

The key to coping well is to accept the changes over which we have no control, and to take control over the aspects of our life we can change. (The "Serenity Prayer" reminds us that we have to be wise to know the difference.)

Many people give Parkinson's too much power and succumb to losses too quickly. Some abandon their fantasies and their plans for the future, ultimately giving in to the self-fulfilling prophecy of decreasing ability.

The biggest losses are associated with relationships, although most people most fear the loss of independence.

So how do we stay positive when we see the threats to our future functioning and plans? Here are my five top recommendations to prevent the losses and remain positive.

◆ **Maintain your support system** by dedicating quality time with the people you are close to, and be appreciative of the time and energy they spend with you. Reward them by sharing stories, words of appreciation, hugs and thoughtful notes. Your support system will be part of the wisdom helping you determine what should be changed or accepted.

(It is much easier to keep a friendship than start a new one, and as we get older it is more difficult to make friends.)

◆ **Become or remain passionate** about something. Set a challenging goal that requires involving others, improving a skill, gaining strength, improving coordination or learning more about a topic of interest.

Resume a sport, even if it means adapting it. Some people switch from a bicycle to a recumbent tricycle to

continue cycling. Consider going to the golf course with friends, even if you don't play any longer.

Use some of that spare time to experiment with art, and develop new hobbies.



ASK THE EXPERT features questions from readers and responses from various Parkinson's experts. Got a question? Email it to questions@nwpf.org, mail it to 400 Mercer Street, Suite 504, Seattle, WA 98109-4641, or call us toll-free at 877.980.7500. Jeff Shaw, Psy.D., is a clinical neuropsychologist with the Booth Gardner Parkinson's Care Center at Evergreen Healthcare in Kirkland, Wash.

◆ Have a reason to **get out of the house**. Every day, schedule something that gets you out of doors.

Consider a volunteer position (check out volunteerwashington.org for ideas). The best way to improve your outlook on your own problems is to help others.

◆ If you don't **control your thoughts**, who does? Identify the thoughts that take the wind out of your sails. These thoughts are often hopeless, negative, dark, critical images or self-statements that encourage you to give up.

Replace those negative thoughts with new thoughts that are supportive and encouraging and that coach you along rather than criticize.

◆ **Keep track of your successes and move!** Set goals you can achieve, and celebrate accomplishments.

Note the difference that movement and exercise makes on mood. Remember that *emotion* is mostly about *motion*. The same areas of the brain that control our body's movement control our feelings. We feel better when we move. Find excuses to move more often.

In combination, these strategies can have a powerful effect on your well being. They take effort, determination and practice, but they're worth the work.



Statin schizophrenia

BY PETER DUNLAP-SHOHL

Okay, I'm a pillhead, a bulwark of the vast international pharmaceutical conspiracy, er, industry. You got the pill? I got the ill. I take three kinds of pills for my Parkinson's disease. Two of these I take every few hours. I also take a multivitamin, and a vitamin D supplement, and, what the heck, throw in some salmon-oil gels while you're at it. Even my dog takes a tranquilizer before a trip to the vet. It would be depressing, but I'm on a pill for that as well.

Still, when my wise old internist announced a year ago that he wanted to put me on something for my high level of "bad" cholesterol, I balked. He gravely showed me the lab report numbers that said "HEART ATTACK COMING." But the thought of more pills, pills, pills was just too much. He reluctantly agreed to let me try to cope with the problem by modifying my diet.

A year passed. Leaves turned to gold and fluttered to the ground, snow fell only to be pierced by the green shoots of spring. Birds returned with their raucous calls, as buds swelled and then burst into leafy glory etc., etc. And with the same majestic inevitability, my bad cholesterol numbers got worse.

So I went back to my wise old internist. While waiting for him in the examining room, I dimly remembered some controversy about Parkinson's and statins, the commonly prescribed remedy for evil cholesterol. I whipped out my cell phone and Googled "statins" and "Parkinson's disease" and was rewarded by the following: **Statins+PD=BAD**. But, what's this? I also got **Specific Statin+PD=GOOD**.

The first article, from *Science Daily* in January 2007, warns: "Researchers are sufficiently worried by new study results

that they are planning clinical trials involving thousands of people to examine the possible link between Parkinson's disease and statins, the world's biggest selling drugs, reports Patrick Walter in *Chemistry & Industry*."

While the second, from a July 2007 edition of the same online publication, heralds one particular statin as a significant hindrance to both Alzheimer's disease and Parkinson's: "Researchers from Boston University School of Medicine have found that the statin, simvastatin, reduces the incidence of Alzheimer's disease and Parkinson's disease by almost 50 percent. This is the first study to suggest that statins might reduce the incidence of Parkinson's disease."

For a brief moment I became more concerned about schizophrenia in science than the question of whether or not I should begin statins.

I informed my wise old internist of my findings, and he asked me where I came down on the issue, and what I wanted to do.

Really what I wanted was for him to stop treating me like an intelligent adult and tell *me* what I wanted to do. After all, he's the one with a medical degree, and all I have is a smart phone. But this is the day of the empowered patient, and my responsibility to be the master of my fate and the captain of my pills was clear.

I opted for the simvastatin. I don't know if it helps with Parkinson's. I'm just hoping that if it actually prevents heart attacks, I'll live long enough to find out.

Peter Dunlap-Shohl, 51, leads the Anchorage Parkinson's Disease Support Group. Retired from the Anchorage Daily News, where he was a cartoonist for 25 years, he now works as a freelancer. This is reprinted from the Jan. 9, 2010, posting on his blog, Off & On (offandonakpdrag.blogspot.com).



Gifts to the Northwest Parkinson's Foundation support our educational publications and self-care tools, including the

Parkinson's Post newsletter, weekly emails news updates, a content-rich website, patient-education programs and the annual HOPE Conference on Parkinson's.

In addition to sustaining our existing programs, your thoughtful donations also support our efforts to develop and implement innovative *new* programs that respond to the changing needs of

the Parkinson's community. We are privileged that so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year.

In each issue we list contributions made in honor or memory of loved ones touched by Parkinson's. Those wishing to establish a permanent memorial may create a family fund with a minimum donation of \$2,500, either from a single gift or many. New family fund donors are listed below, and the donations page of our website (nwpf.org) lists all-time donors to these funds. Contact Keri Kellerman (877.980.7500 or keri@nwpf.org) to learn more.

Listed here are those who made tribute or family fund gifts from **April 17 to June 16, 2010.**

FAMILY FUNDS

**Alvord Medical Director Fund
in Honor of Roger Evans**

Mary A. Mitchell Memorial Fund

Brian Drake
Scott Harbers
Nancy Mitchell
Justin Peltzer
Chris Ruef
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Pam Whitelam

**Margaret (Martie) Philbrick
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Jonathan French
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Putting in the miles (thousands!) for Team Parkinson's

By Sue Petersen

For about 15 years I have ridden the STP—the annual 200-mile Group Health Seattle-to-Portland Bicycle Classic. During the STP several years ago, I noticed a group of riders wearing Team Parkinson's jerseys.

At one of the rest stops, I asked the group what Team Parkinson's was all about.

I learned that this team of some 100 cyclists was riding to raise awareness about Parkinson's disease and funds to support the programs of the Northwest Parkinson's Foundation.

They were the friends, family, neighbors and colleagues of people with Parkinson's—and a few were even people with Parkinson's themselves.

They were incredibly sincere about the cause, and I found myself wanting to join them.

There was another reason for my

interest: my brother-in-law has Parkinson's disease.

For the next four years my husband, Mark, and I rode the STP as members of Team Parkinson's, raising money for the Northwest Parkinson's Foundation, an organization we rely on for support and for information on this disease that has impacted our family.

A few years ago I started thinking about a different kind of Team Parkinson's undertaking—a cross-country bike ride with my Mark and our cyclist friends.

During the spring of 2007 planning for the ride began in earnest. Mark—who provided the trip as a wonderful retirement gift—and I were looking at it as a great opportunity to fulfill a dream, as well as a chance to support the Northwest Parkinson's Foundation since we'd be missing the STP that year.

On June 7, 2009, the journey became a reality. Mark and I, along with five friends, rode while three other friends drove with our gear. We embarked on a course across the northern tier of the country, with the goal of reaching Bar Harbor, Maine.



The Petersens on the Maine coast last summer, at the end of their 4,400-mile, cross-country trek.

The ride proved to be no picnic. We scaled steep mountain passes, experienced extreme weather conditions and dealt with rough road, gravel and aggressive drivers.

But it was worth it. The upside was viewing the extreme beauty of the changing landscape and experiencing

> CONTINUED NEXT PAGE

IN HONOR

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Bruce & Lynette Alber

Harvey Armintrout
Doug & Libby Armintrout

Bonnie Brainard
Brandon & Annie Johnston

Buck Buckman
Duke & Darlene Ralston

Zach Cross & grandfather
Raymond F. Jarris

Michael Crowell
Christine Crowell
Amie Parker

Tom Deutschlander
Patricia A. Tempinski

Heather Dooley
Taylor Hood & family

Kathy Dooley
Gary & Linda DeBoer
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the genuine goodness and graciousness of the American people.

After 72 days and 4,400 miles, we crossed the city limits of Bar Harbor.

The journey was completed, the dream fulfilled and we had raised money for the cause.

This year our Team Parkinson's event will be the Idaho 400—a ride that's a bit longer than the STP but a lot shorter than our last Team Parkinson's ride!

We'll still be part of the STP, though, this time as volunteers at the Portland finish line. Boy, do we have some great surprises for our Team Parkinson's comrades as they cross the finish!

Sue and Mark Petersen live in Pendleton, Ore. To learn more about Team Parkinson's and to sign up for the team, visit nwpf.org or call us at 877.980.7500.