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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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## Ride takes discipline, adrenaline

BY CRAIG HOWARD

Team Parkinson's is a group that does some physical activity to raise funds for Parkinson's disease and the Northwest Parkinson's Foundation. Some people ride bicycles, some run marathons, others even climb mountains. But primarily it is a group that rides from Seattle to Portland in a 200-mile bike event that most complete in two days. (Some actually do it all in one day.)

It all started nine years ago, when we had a rider who wanted to raise money for Parkinson's. So she signed up for the annual Seattle-to-Portland Bicycle Classic—with 8,000 other people. But she alone rode for the Northwest Parkinson's Foundation and established a tradition. The following year half a dozen did it, and now we have more than 120 people who do the ride each year.

So what's it like to ride from Seattle to Portland? It has literal and figurative ups and downs.

The hardest part is maintaining the discipline to train for months beforehand. This simply means doing 10-, 20- and 30-mile rides a couple of times a week, with a few longer ones thrown in. It's getting your legs and lungs ready, and the hardest part of all: where the bike meets the rider. Sore butts are only cured one way, and that's by riding. A lot.

This year there were nearly 9,500 riders in the "STP," as the ride is called for short. People start out at the University of Washington anywhere between 5



Photo by Pat Donohue

From left, Sam, Chris and Frank Jewell, their friend Frank Vitolo, and Pat Jewell (lying down) are all smiles at a rest stop along the 2008 Seattle-to-Portland Bicycle Classic route in July. The Jewell family and friends ride in the STP each year, raising money for the Northwest Parkinson's Foundation.

and about 7:30 a.m. Waves of riders start along the route in great whirring herds, with the hardest work early in the ride being simply not hitting other riders.

You make the first 25 miles or so on adrenaline and maybe some caffeine. But then you roll into the first rest stop in Kent, WA, where lines for bike repairs, food and porta-potties are long. But by then you've found your rhythm, and you really want to get back on the road.

After Kent comes The Hill, which everyone talks about leading up to the ride. And it is quite a hill, but after two

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## Rotigotine patches recalled

Schwarz Pharma recalled Neupro (rotigotine) transdermal patches in April. These patches are used to treat early-stage Parkinson's disease.

The problem is that rotigotine, the active ingredient, may crystallize in the patch. If that happens, less drug is available to be absorbed through the skin and so the efficacy of the products may vary. The crystallized drug may cause a patch to have snowflake-like patterns. The more snowflakes, the greater the chance the patch won't work properly.

Because of this, new patients should not be started on Neupro. Patients already using the patch should be slowly titrated off it and started on an alternative treatment as needed. Patients should not abruptly discontinue treatment with Neupro. The down-titration should proceed according to guidelines in the labeling, using patches that are unaffected or minimally affected by the crystallization.

Patients should be told to look at their patches and only use those that have a minimal number of crystals. For more information, contact the company at 800.477.7877.

## FDA OKs generic ropinirole

The U.S. Food and Drug Administration in May approved the first generic versions of Requip (ropinirole hydrochloride) for the treatment of moderate to severe restless legs syndrome.

Ropinirole hydrochloride tablets have been approved in a range of dosages, from .25 to 4 milligrams.

Roxane Laboratories Inc., Teva Pharmaceuticals USA, Par Pharmaceuticals Inc. and Mylan Pharmaceuticals Inc. have received approval to market ropinirole hydrochloride tablets.

The labeling of the generic versions of ropinirole hydrochloride may differ from that of Requip because some uses of the drug are protected by patents.

In addition to treating restless legs syndrome, Requip is also FDA-approved to treat symptoms of Parkinson's disease. But the generic products are *not* approved for treatment of Parkinson's disease because this indication is protected by patent. Manufacturers of the generic drugs may seek approval for that use once the patent for the Parkinson's disease indication expires this year.

*Source of these two articles: FDA: [www.fda.gov](http://www.fda.gov)*

## Take a few minutes to help out the helpers

**By Greg Anderson**

Help me solve a problem I've encountered frequently in my 15 years as a Seattle firefighter: There's something vital I need to know about you, but you can't tell me what it is. For a variety of reasons—perhaps it's unconsciousness, or maybe it's a fall or stroke or seizure that has caused a lapse in memory—sometimes a person in trouble is unable to give me information that might help me save a life: medical history and emergency contacts.

There are several simple programs and ideas that can help you help emergency responders provide timely and appropriate assistance.

Once is called ICE. Invented by a British paramedic, ICE stands for "in case of emergency" and is a simple way to enter emergency contacts into your cell phone address book. You can enter multiple contacts by naming them "ICE 1," "ICE 2," "ICE spouse," and so on. In this age of digital connection, the cell phone becomes a way for firefighters, paramedics and police officers to contact your loved ones and get emergency information from them that you aren't able to provide.

Another excellent idea is to make a simple, wallet-sized card containing your emergency information and tuck it into the see-through folder in your wallet next to your driver's license. If you want to maintain some privacy, fold it and put an "ICE" sticker on the outside.

The Vial of Life Project is another great idea. "Life" is an acronym for "lifesaving information for emergencies." It's simple—a plastic baggie with a Vial of Life decal on your refrigerator door alerts emergency responders to information inside about your medical condition. The website [www.vialforlife.com](http://www.vialforlife.com) will get you started—and it will cost you nothing but your time.

An honest reporting of your medical conditions, including any allergies you have and medications you take, will help firefighters and paramedics make decisions that are in your best interest.

Beyond these simple ideas, it's also important to talk with your loved ones and let them know what your wishes are, as well as to be clear who will make life-and-death decisions for you in the case of an emergency.

These "advance directives" include living wills, durable powers of attorney for health care, do-not-resuscitate orders, and your organ donor status.

# Hardest part of exercise? Sticking with it

**Q:** I have read that exercise is helpful for both movement and thinking abilities. But I have trouble sticking with exercise, even though I know it's helpful in the long run. Do you have recommendations to help a person with Parkinson's maintain an exercise program?

**A:** Exercise is an important part of your health and wellness with Parkinson's disease. It promotes physical endurance, flexibility, good posture and balance. And exercise may play another positive role in the health and well being of people with Parkinson's: neuroprotection.

Recent studies suggest that exercise may reduce the risk of developing Parkinson's in the first place; others are investigating the possibility that exercise is neuroprotective even for people with the disease. That is, exercise may "put the brakes" on disease progression by protecting existing neurons.

Regardless of the outcomes of this line of research, there's enough evidence *right now* of the benefit of exercise for people with Parkinson's.

For readers who are just getting started, a physical therapist can help you tailor your exercise program to target the areas affected most by Parkinson's.

As the question suggests, though, most people find the challenge is not so much beginning but *continuing* to exercise. Group exercise classes can help. The social reward, commitment to others, and group energy will bolster your motivation.

Yoga, tai chi and the Alexander technique are particularly helpful group exercises for people with Parkinson's. Each technique uses both the mind and the body to enhance movement.

Even if you are exercising alone, it can help to commit to a regular sched-



Ask the Expert is a regular column featuring questions from readers and responses from Parkinson's specialists. Got a question? Email it to [questions@nwpf.org](mailto:questions@nwpf.org) or mail it to 400 Mercer Street, Suite 401 / Seattle, WA 98109-4641—or just give us a call toll-free at 877.980.7500.

This month's question was answered by **Sierra Farris, MPAS, PA-C**, pictured at left, physician assistant at the Booth Gardner Parkinson's Care Center in Kirkland, WA.

ule. Choose the time of the day when you typically feel most energetic and that isn't likely to conflict with meals or social activities.

And while it is more convenient to exercise at home, you are much more likely to procrastinate and be distracted by other activities.

Another way to stay motivated is to do varied exercises, focusing on those that improve your ability to perform important or favorite activities. For example, if walking is important to you, ensure that some of your exercise involves walking longer distances.

On the flip side, riding a stationary bicycle may be rather boring if you have no intention of going bike riding.

Finally, even if you don't have the energy to exercise on a particular day, make the commitment to go to the gym or usual exercise location for the time you would normally exercise. Make a rule that you will not turn on the television or computer until after you exercise for the day. It's amazing how often the energy kicks in once you get started, and how much better you will feel for the rest of the day.

I use my experience as an exercise trainer to help motivate people to exercise. I tend to follow four tenets.

First, I ask people to examine the value they place on exercise. It's not easy to exercise a body that feels stiff or slow, but recognizing why exercise is of value is very important. If you don't find value in exercising or understand how exercise can help, you probably won't stick with a program.

Second, it's important to evaluate your current abilities then set reasonable goals. Physical therapists who specialize in Parkinson's can assess your level of fitness and help you establish goals. Goals must match your abilities and be attainable. If a goal is too high, you may become frustrated and give up. If a goal is too low, you will likely see little benefit and feel you're wasting time.

Third, you need a way to monitor your "compliance" with your exercise program. For some, it's rewarding to jot down on the calendar that you walked a mile today.

Last, don't overdo it. You want to advance your exercise program as you become more fit. What you don't want is to wake up and not be able to sit on the toilet because your legs are sore—or worse, not be able to get out of bed at all. The old adage, "no pain, no gain," is *out*. Eating a small bowl of ice cream because you made progress is *in!*

# Shipwrecked by Parkinson's disease

Following is the June 30, 2008, post from "Off & On," cartoonist Peter Dunlap-Shohl's blog about life with Parkinson's. The author is pictured here with his wife, Pamela Dunlap-Shohl (far right) and Jan Shilling of Teva Neuroscience at an Alaska educational event.

BY PETER DUNLAP-SHOHL

As a cartoonist, I carp for a living. One of the hazards of my job is that the first thing I do each day (after the ritual swallowing of pills and a trip to the bathroom) is look to see what the worst news is in our paper. From the Supreme Court to the lowliest local pol, I begin my day with the malefactor who did the most damage since the last time I checked. (By the way, did you notice that I'm *already* carping here? I'm a natural!)

This is like startin' your mornin' with a steamin' hearty bowl o' hot, nutritious worms. After a while it colors your attitude toward humanity. God only knows how the reporters who cover the courts and child welfare avoid becoming misanthropes, and I suppose many do.

Paradoxically, Parkinson's disease has been the antidote for my case of mild misanthropy. While I loathe having this disorder, it has provided a mirror-image alternate to the viewpoint brought on by watching the bozo parade.

Instead of dwelling amid the latest creative disasters of the inept and the evil, I'm a Gulliver in reverse. Being shipwrecked by Parkinson's has fetched me up gasping and coughing on the Island of the Caring and the Competent.

It is another world. The inhabitants there are the likes of our friend Betty. Betty lost her husband to Parkinson's disease. As far as I am concerned, enduring that earned her a free pass on ever having to face Parkinson's again. Betty disagrees. She has volunteered for years as the voice of experience to care partners who need light on their lonely road. She often leads separate sessions for them during our monthly support group meetings. It is one of the most



important services our little Parkinson's club offers.

It is the world of Dr. Dave Heydrick, a neurologist with Parkinson's who has put his intelligence, humor, charm and discipline into the mission of uncovering all he can about coping with Parkinson's and passing his learning along to the rest of us. Dave provides those of us drafted into this battle with the precious and indispensable commodity of credible hope.

It is the world of Bill Bell. When Bill's mother got diagnosed, Bill became her advocate. On finding so little support for area people with Parkinson's and their families, he went on to become an advocate for everyone in the Pacific Northwest. Smart, and an unusual combination of the good-natured and the hard-nosed, Bill put his talent and energy into running the Northwest Parkinson's Foundation. His newsletter now goes around the world, but he still seems to know and take an interest in every person with Parkinson's in the Northwest.

It is the wider world of researchers and doctors who devote amazing creativity, skill and discipline to taking care of patients and taking this disease down. To read about deep brain stimulation or gene therapy is to glimpse what seems like science fiction come alive.

I can't say I'm happy about the circumstances that brought me to this place where the people are busy trying to make the world better, and succeeding at it. But I'm amazed and grateful that it exists.

*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 [offandonakpdrag.blogspot.com](http://offandonakpdrag.blogspot.com).*

# Foundation welcomes new volunteer, staff

The Northwest Parkinson's Foundation welcomes **Elizabeth Bacher** to its board of directors. Elizabeth brings broad experience in public and media relations, marketing and sales.



She began her career as a news writer, assignment editor and producer for television stations in Portland and Seattle. After a stint working in public relations in Chicago, she returned to Seattle as media relations director for a public policy firm. It was there that she met Northwest Parkinson's Foundation board member Booth Gardner and learned about the organization.

"My dad was diagnosed with Parkinson's about 10 years ago," Elizabeth says. "I was eager to learn as much as I could about the disease."

Elizabeth loves animals and these days works at Seattle's Woodland Park Zoo, where she creates cause-marketing campaigns for a variety of programs.

Outside work, Elizabeth enjoys hiking, traveling, antique hunting, reading, and keeping up on politics and current events.

**Keri Kellerman** joins the Northwest Parkinson's Foundation as development director. She replaces Dav'ne Stahley, who recently began a new position at Seattle Opera.



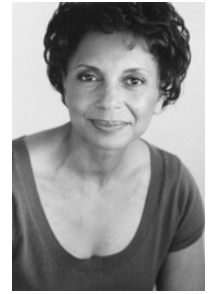
Keri is thrilled to be joining the Northwest Parkinson's Foundation, to which she brings more than a dozen years of development experience.

She previously worked as development director for Seattle Youth Garden Works, leading and launching a significant capital campaign, and for On the Boards, where she helped the performing arts organization eliminate its debt and build a financial reserve.

Keri has held positions at several other arts organizations, including Pacific Northwest Ballet and Seattle Repertory Theatre, and has broad experience leading annual campaigns, major gifts, corporate and foundation relations and special events.

In her spare time, she is a professional freelance photographer and active member of Seattle's art, fashion and music communities.

**Alecha Newbern** recently joined the Northwest Parkinson's Foundation as program manager, a brand new position for the organization. She will plan educational and community events and patient and caregiver programs.



Alecha joins the Northwest Parkinson's Foundation after a long career with US Airways and a position organizing events for World Trade Center Seattle.

"I'm honored to be joining the Northwest Parkinson's Foundation team," Alecha says. The organization's mission—to establish optimal quality of life for the Northwest Parkinson's community through awareness, education, advocacy and care—is one that resonates with Alecha, who has lived these principles in caring for her son, who has severe epilepsy. "He is turning 32 and doing well," she reports.

Outside work, Alecha enjoys acting and theater, decorating, gardening, cooking, entertaining, dancing and biblical study.

## HOPE is on the way

Mark your calendar for the 2008 HOPE Conference, set for Nov. 1 at the Seatac Hilton Hotel and Conference Center.

Jointly presented by the Washington chapter of the American Parkinson Disease Association and the Northwest Parkinson's Foundation, 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 the upcoming Frontline documentary on Parkinson's. Iverson is himself a Parkinson's patient.

Other confirmed speakers are:

- Jeff Shaw, Psy.D, of the Booth Gardner Parkinson's Care Center in Kirkland, WA
- Laurence Elmer, M.D., director of the Parkinson's Disease and Movement Disorder Program at the University of Toledo, OH.
- Becky Farley, Ph.D., PT, and Cynthia Fox, Ph.D., CCC-SLP, of the University of Arizona
- Julie Sacks, director of APDA's National Young Onset Center
- Sheryl Jedlinski and Jean Burns of PDPlan4Life

Go to [www.nwpf.org/Events.aspx?Event=53](http://www.nwpf.org/Events.aspx?Event=53) to register or learn more.



Photo by Pat Donohue  
**Two riders pose by a Team Parkinson's 2008 sign at an STP rest stop in July. Some 9,500 riders took part in the STP this year, including about 120 members of Team Parkinson's.**

miles of huffing and puffing, you roll out on top and realize it's just one of the many achievements that go into making the STP a great ride.

Team Parkinson's has long been supported by Cameron Catering—volunteer Suzanne Cameron and her great crew. They make the rest stops a special affair for Team Parkinson's riders. Other riders get in long lines for bananas and sandwiches; our team member choose from a buffet of gourmet fare, with no lines!

There are other stops along the way, with terrific scenery (Mt. Rainier looms over much of the first 100 miles). The camaraderie is what you really notice—this is not a race, it's a ride. People chat, swap stories, share snacks, all while pedaling along averaging between 12 and 20 mph.

Team Parkinson's has its own bright cycling jerseys each year. And it's the greatest feeling to happen upon another Team Parkinson's jersey in the ocean of riders and realize it's someone you don't know. Yet. Because you'll certainly start talking to each other.

Who does this insane ride? You'd be amazed. Riders are 12 years old to 80. Most everyone on Team Parkinson's has a connection to Parkinson's, and some riders even *have* Parkinson's.

(My most inspirational ride ever was crossing the finish line in Portland

with a 70-year-old friend with Parkinson's.)

Team Parkinson's has become a cornerstone of fund raising for the Northwest Parkinson's Foundation. And because of our sponsors, every dollar donated in honor of a rider is a dollar that goes straight to the work the organization does.

## Most everyone on the team has a connection to Parkinson's, and some even *have* Parkinson's.

All the parts come together—sponsors, people willing to ride, and their friends and family supporting them with donations—to make this a great community effort for the cause.

Our thanks goes out to everyone involved, from the riders and their supporters, to our sponsors, and to the people who simply cheer us all on for riding for the cause.

If this sounds like fun, go to our web page. We're going to be doing this again next year!

*Craig Howard is cofounder of the Northwest Parkinson's Foundation. He did not, however, ride the STP this year. Instead, his Team Parkinson's goal is a 110-mile ride in Tucson, AZ, in November. You can push him on by making a donation at his team page at [www.nwcpf.org](http://www.nwcpf.org).*

## Vehicle donation is an easy way to give

Avoid the hassle of car lots, expensive ads and price haggling and get a charitable gift tax deduction instead!

Through the Northwest Parkinson's Foundation vehicle donation program, you can donate your car, truck, van, SUV, RV, motorcycle or boat using Northwest Charity Donation Service, which sells vehicles on our behalf.

Most vehicles are accepted. Northwest Charity Donation Service will determine if your vehicle qualifies.

Ready to help? Call Northwest Charity Donation Service at 800.961.6119 or visit [www.nwcds.com](http://www.nwcds.com) and say that you want the proceeds from your vehicle sale to go to the Northwest Parkinson's Foundation. Northwest Charity Donation Service will determine the market value of your car, pick it up free of charge, complete all title transfers, and provide you with a tax receipt.

## Volunteer skills

There are many ways to help us achieve our mission to improve quality of life in the Parkinson's community. People across the region—and beyond!—are getting creative in their support. They're joining Team Parkinson's, starting bowling and golf tournaments, and hosting parties and recitals to benefit Northwest Parkinson's Foundation programs. Want to help? Call us at 877.980.7500 to share your ideas.



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 **April 28 and July 8, 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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## Webcast to shed light on surgical advances

The third installment of the webcast *Parkinson's Science: Innovations and New Perspectives* will take place on Oct. 11. Offered by the Parkinson's Disease Foundation in collaboration with the Northwest Parkinson's Foundation, the event will discuss the newest surgical advances available to treat Parkinson's disease, including deep brain stimulation (DBS).

In addition to being available to a live audience in Spokane, WA, the program will be available to view live on the web. Go to [www.nwpcf.org/webcast/spokane.cfm](http://www.nwpcf.org/webcast/spokane.cfm) for registration and program details.

Visit [www.nwpcf.org/Events.aspx](http://www.nwpcf.org/Events.aspx) for a full listing of educational opportunities and Parkinson's-related special events.

To post a Parkinson's-related event or activity on our website, email the details to [info@nwpcf.org](mailto:info@nwpcf.org) or call us at 877.980.7500.