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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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## Simple card could make difference in a crisis

Take a moment to look in your wallet. You likely have credit cards, some form of identification, maybe an insurance card, some family photos, and a little cash—right?

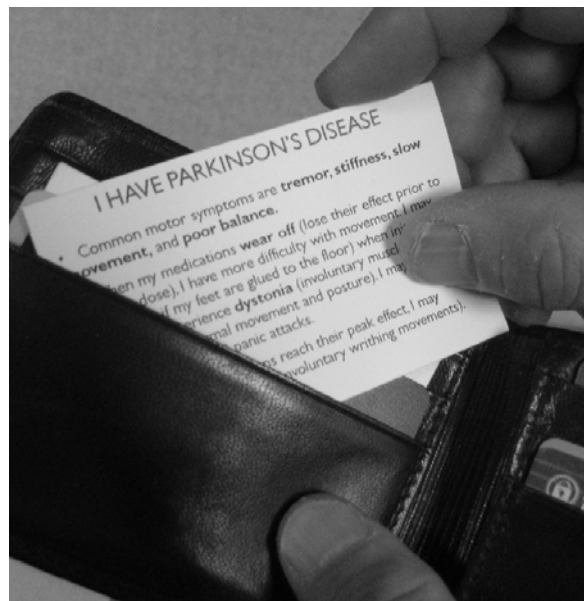
There's one more thing people with Parkinson's disease should consider carrying in their wallets—an emergency medical alert card.

You can get one free of charge through the Northwest Parkinson's Foundation.

Because our mission is to advocate for the Parkinson's community, we designed this card to help you—and emergency medical care providers—by supplying critical information about your health in case you are ever unable to communicate verbally.

The card contains room for you to list the medications you take and their side effects, any allergies you have, and the names and phone numbers of your physician and emergency contact person.

The card also spells out some of the



most common symptoms of Parkinson's disease and provides a place for you to indicate whether or not you have a deep brain stimulation device.

The latter is important for emergency personnel to know about because certain imaging tests should not be performed in those with a DBS device. Importantly, the card provides contact information for the device manufacturer, in case medical personnel have questions about appropriate treatments.

The emergency medical alert card folds to the size of a credit card and fits neatly in your wallet.

The Northwest Parkinson's Foundation has distributed the cards to Parkinson's support group facilitators in our network. You can also receive a card directly by calling us toll-free at 877.980.2500 or by emailing [info@nwpf.org](mailto:info@nwpf.org).

# Good ideas (including yours) are worth sharing

OVER MORE THAN 10 YEARS of working with the Parkinson's community we've picked up some great insights for living well with Parkinson's disease.

Now here's a good idea: We decided to create an online "tip jar"—a place where we, and our readers, can contribute quality-of-life tips for everyone's benefit.

If you visit the virtual tip jar, you'll see we've started things off by contributing a few of those helpful hints and strategies we've been collecting from people like you. Others



are beginning to post their good ideas directly.

A great feature is you can comment on other people's contributions. Some fruitful conversations are bound to result

as the Parkinson's community begins to connect in this new way. So don't be shy!

Visit [nwpf.org/submissions/default.aspx](http://nwpf.org/submissions/default.aspx) to access our virtual tip jar.

## 10 years later, we're still in this together

**By Craig Howard**

As chairman of the Northwest Parkinson's Foundation board, I can tell you it's the most rewarding affiliation I've ever had. People with Parkinson's are different. I've never quite put my finger on it, but there is just something about the character (and the characters) of the Parkinson's community.



A little more than 10 years ago the concept of the Northwest Parkinson's Foundation was hatched. Bill Bell thought there needed to be a center, a physical place, where people like our mothers could go to get the best care. From that idea, the Booth Gardner Parkinson's Care Center was born at Evergreen Healthcare in Kirkland, WA.

Way beyond that, however, the Northwest Parkinson's Foundation developed into an organization reaching deep into the Northwest and beyond. Into places where people may only have access to a family doctor—a professional tasked with trying to understand all aspects of any number of afflictions. We all owe a great deal to these doctors. But intricate conditions like Parkinson's require we take charge for ourselves and learn all we can.

Through the work of the Northwest Parkinson's Foundation, tens of thousands of people every month are given information, resources, possibilities, and hope. Individuals with Parkinson's gain power, and their family and friends gain understanding. By diminishing the unknown, everyone can move ahead with a more confident stride.

We have always believed a cure is coming. There are many millions being spent each year with that goal, and the promise grows with each new discovery. We decided our job was to help people live better with Parkinson's until that cure is found.

This includes reaching out with our newsletter six times a year, with our weekly email update, and with our annual symposium in Seattle,

which is one of the largest of its kind in the world. There are also telehealth talks every month, where support groups in 20 communities connect and learn across a network.

To help keep you up to date on our programs and the many people we meet throughout the year, we've compiled a *Report to Contributors* that summarizes our achievements during 2008. You can view it online at [www.nwpf.org](http://www.nwpf.org), and we encourage you to share it with anyone in the Parkinson's community who might be looking for hope and inspiration.

There are so many opportunities to have an impact in the Parkinson's community, and I hope when you see them you'll contact us.

Our best ideas have always come from people just like you—people eager to make a difference for themselves and for others.

My great hope is that 10 years from now this will all be a memory because the cure has been found, rendering this organization obsolete.

But know that until that time, we'll be here to connect each of you to our Parkinson's family, and to spread the word of living well today.

*Craig Howard chairs the Northwest Parkinson's Foundation board. His mother has had Parkinson's for 25 years.*

# Team Parkinson's cyclists take on cross-country trek for the cause they love

## By Sue Peterson

This year my husband and I will not be riding the 206-mile Group Health Seattle-to-Portland Bicycle Classic, as we've done for the past 18 years. Instead, Mark and I will be riding 4,300 miles across America—from Anacortes, WA, to Bar Harbor, ME.



We're doing this for the Northwest Parkinson's Foundation, as members of Team Parkinson's. This is our way of reaching out and supporting this organization in its mission to be a resource for the Parkinson's community.

Our amazing journey to Maine started in our heads a couple of years ago. We were at a Christmas party at the home of two of our biking buddies. One of them, acknowledging he's not getting any younger, said he'd like to bike across America.

It was a light bulb moment for us. Several friends shared our enthusiasm for the idea, and we all talked about it for weeks. Then we put the planning wheels into motion.

Now, two years later, I can't believe it's actually time.

There will be seven of us riding and three driving. Even 11-year-old Cole, our friends' grandson, has decided to join us for the drive.

Our drivers have their marching orders. They will "walk across America" while we ride. That is, they each plan to walk a mile a day and keep a ledger in the truck to measure their progress.

We'll leave on June 7 and our timeframe is approximately 68 days. Since we're all retired except for Mark, who is a teacher, we have until September to complete the ride. Our goal is to average 68 miles a day—terrain and weather conditions will dictate the actual miles we log each day. Every six days we'll take a break to freshen up, sightsee, and rest.

As we pedal up one hill and down the other, you can keep track of us through our blog at [powc2c.wordpress.com](http://powc2c.wordpress.com). (This stands for Pendleton on Wheels Sea to Sea, named for the town where we live.)

*Sue and Mark Peterson of Pendleton, OR, have been Team Parkinson's members for six years. To learn more about Team Parkinson's, visit our website at [mpf.org](http://mpf.org).*

## Patient programs offer opportunity to learn

Mark your calendar if you're in the Idaho Falls, ID, or Bozeman, MT, areas. Two patient-education programs slated for the summer target people with Parkinson's disease. These informative sessions are free of charge, so don't miss them!

♦ Lauren C. Seeberger, M.D., medical director of the Movement Disorders Center at the Elks, will present on July 31 in Idaho Falls.

♦ Monique Giroux, M.D., medical director of the Booth Gardner Parkinson's Care Center, and Sierra Farris, MPAS, PA-C, neurostimulation program coordinator with the Evergreen Neurological Institute, will present on August 28 in Bozeman.

For event details and to register, contact Alecha Newbern at [alecha@nwpf.org](mailto:alecha@nwpf.org) or 877.980.7500.

## Get connected through weekly email update

Do you like to read upbeat, inspiring stories about people with Parkinson's? How about the latest innovations in Parkinson's research? Encouragement, opinions, ideas, events, the quest for the cure, and much, much more—all to remind you that you aren't alone with Parkinson's disease.

This is only a sampling of what you'll find in your email inbox each Friday—when you subscribe to our Parkinson's News Update.

Subscribing is easy—not to mention free. Just go to [nwpf.org/ParkinsonPostSubscribe.aspx](http://nwpf.org/ParkinsonPostSubscribe.aspx) and check the second box ("I would like to receive the free weekly email, the Parkinson's News Update"). You'll start receiving your weekly email shortly.

# Clinical trials may be right for many with Parkinson's

**Q:** Why should I participate in research, and what kinds of studies can I participate in?

**A:** People with Parkinson's participate in research for various reasons. Some do so with the hope of finding a new treatment for themselves. Some want to contribute to knowledge that will benefit others in the future.

When deciding if a research trial is for you, it's important to understand that, although everything is done to insure the safety of research subjects, the true safety and benefit of experimental treatments are not yet known.

Prescription drugs would not be available without volunteer research subjects. Every prescription drug used to treat Parkinson's disease has been tested in clinical trials prior to approval by the Food and Drug Administration (FDA).

There are many research hurdles a potential drug must clear before being approved for use. It must first undergo rigorous testing for safety and benefit in pre-clinical studies, those that involve animals or take place in laboratory settings.

Only drugs that pass this rigorous safety test are made available for clinical trials, which are studies involving humans.

There are four phases of clinical trials. Phase I tests the drug in a small number of individuals to evaluate its safety, identify side effects, and determine the best dose for study.

Phase II extends this work to include a larger number of people.

Patients most commonly participate in Phase III and IV clinical trials. In these trials, the medications have been tested for safety in a small number of volunteers. Their benefits and side effects have been documented and compared to existing treatments.



**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, Dr. Giroux seeks advice from a variety of specialists. For this month's response, Dr. Giroux sought input from Pinky Agarwal, M.D., her colleague at the Booth Gardner Parkinson's Care Center.

The FDA serves as the governing body that approves a treatment if efficacy and safety outcomes are reached in Phase III trials.

Phase IV studies continue to monitor treatment effects in a more general population after a drug has been approved and released for prescription use.

Many research trials include a placebo control. In such trials there

is the chance you will not be given the active medicine but will instead receive an inactive pill or treatment.

In "double blind" studies, neither the researcher nor the volunteer knows whether or not the active pill or treatment

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Every prescription drug used to treat Parkinson's disease has been tested in clinical trials prior to approval by the FDA.

has been administered.

A strong "placebo effect" is well-documented in Parkinson's studies. Simply expecting that a medicine will help can increase the chance of experiencing an improvement to symptoms.

Placebo-controlled trials, then, help insure that any benefits experienced are the result of the medication or treatment being tested, rather than the influence of positive expectations.

Many placebo-controlled clinical trials are followed by an extension trial that allows all patients to receive the active drug.

There are plenty of good reasons to participate in clinical research, beyond the obvious benefits to science. Knowing you're making a difference can feel empowering to patients, suggests neurologist Pinky Agarwal, M.D., of the Booth Gardner Parkinson's Care Center.

"By participating in a clinical trial, patients are able to play a more active role in their health care," Agarwal says.

## Center trials seek volunteers

A number of clinical trials are taking place at the Booth Gardner Parkinson's Care Center. These trials are helping researchers to develop the next generation of treatments for Parkinson's and other movement disorders.

Beyond contributing to medical advances, participation is a way to play a more active role in your health care, gain access to new drugs not available in the marketplace, and receive excellent physician care as part of the research at no cost.

If you'd like to learn more about participating in a clinical trial, call the center at 425.899.3126 or 425.899.3115.

Here are some current trials and the types of participants sought:

- ♦ Aplindore-211 / 30 or older; Parkinson's diagnosis within five years; no treatment with levodopa for at least two months before baseline visit; no dopamine agonist for at least one month
- ♦ Coenzyme Q / 30 or older; Parkinson's diagnosis within five years; no Parkinson's drugs for 60 days before baseline visit
- ♦ Droxidopa / 18 or older; diagnosed with primary autonomic failure, dopamine beta-hydroxylase deficiency, or non-diabetic neuropathy with orthostatic hypotension; not taking anti-hypertensive medications
- ♦ Levodopa-carbidopa intestinal gel (duodopa) / 30 or older; demonstrate severe motor fluctuations in spite of treatment with levodopa; minimum off time of three hours a day; Parkinson's diagnosis at least two years prior
- ♦ SP 953—rotigotine continued access program / taking no more than 6 mg a day of rotigotine patch over the past six months
- ♦ CD PROBE / diagnosed with cervical dystonia; new to botulinum toxin therapy or have not received botulinum toxin for 16 weeks or more
- ♦ Progeni study—collaborative study of genetic linkage / Parkinson's patients with family history of Parkinson's in the first-degree relative

## The role of bioethics in research

By Sierra Farris, MPAS, PA-C

Biomedical research ethics have greatly evolved over the past 60 years with the primary goal of protecting study subjects.

The Nuremberg Code, established in 1948, defined the importance of voluntary participation in research and the requirement of *informed consent*. Informed consent defines the purpose of the research and its potential benefits and risks—using simple, understandable language.

In 1962, after an unknown side effect of thalidomide became apparent, Congress passed the Kefauver Amendment, which required the Food and Drug Administration (FDA) to ensure that drugs are effective and safe before releasing them to the public.

In 1964 the World Medical Association set rules for doctors offering biomedical research to patients. These rules were known as the Declaration of Helsinki. They focus on both clinical and non-therapeutic research and form the backbone of the Good Clinical Practices guidelines used today.

Congress passed the National Research Act in 1974, creating the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. This commission produced the Belmont Report, which further defined and solidified ethical principles for research in the United States involving humans.

The Belmont report identified three principles that remain in high standing today:

*Principle of respect for individuals:* All individuals have the right to information and the freedom to decide their treatment. In research, this is ensured by using the informed consent document that outlines in very understandable terms the proposed treatment, stating the research is voluntary at all times. Individuals who cannot give consent must have a surrogate decision-maker who can best decide on their behalf.

*Principle of beneficence:* Individuals must be protected from harm. Research should minimize risks and maximize benefits with a clear, understandable explanation in the informed consent materials.

*Principle of justice:* The selection of research subjects must be fair.

In 1991 the majority of federal agencies that sponsored human research adopted policies regarding the protection of human subjects, known as the Common Rule, which is based on the Belmont Report and other FDA regulations. The Common Rule requires protection of vulnerable patients (i.e., prisoners, children, pregnant women), requires appropriate informed consent, and sets standards for institutional review boards, conduct of research institutions, and record keeping.

In addition to appropriate ethical conduct by researchers and physicians, patients must also follow through on *their* commitment to allow for the most accurate data collection when a new therapy is under consideration, in order to protect individuals who may use the therapy in the future.

*Sierra Farris is the neurostimulation program coordinator at Evergreen Neurological Institute in Kirkland, WA.*



**Gifts to the Northwest** Parkinson's Foundation support educational programs including our website, email updates, caregiver booklet, newsletter, patient-education programs, and conference. Gifts also fuel our 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. We list tribute contributors in each issue of the *Parkinson's Post*. (All donors are recognized in our annual *Report to Contributors*.) Listed here are those who made tribute gifts from **February 10 to April 15, 2009**.

**Something new: family funds**

With a minimum donation of \$2,500, family members and friends can create a family fund in honor of a loved one. Gifts we receive through the creation of family funds will support general operations and be listed permanently in our newsletter and on our website. Contact Keri Kellerman at 877.980.7500 or [keri@nwpcf.org](mailto:keri@nwpcf.org) to learn more.

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Remembering Mom with a family fund

By Don Mitchell

My dad and siblings have all been active with the Northwest Parkinson's Foundation since our mom, Mary A. Mitchell, was diagnosed with the disease. The organization helped us to understand some of the things Mom was going through and to realize we weren't alone.

When our mother passed away in February, we began the tough task of making the arrangements for her memorial. We decided we would ask friends and family to donate to the Northwest Parkinson's Foundation, rather than send flowers in remembrance. We were looking for a way to help others while honoring the memory of a devoted mother and wife.

I called the organization and learned we could set up a special lifetime fund in Mom's honor. Not only would the donations received at the memorial service go into this fund, but all future donations in her name—including those I raise in my annual Team Parkinson's bike ride—would also go into the fund. We now have a lifetime memorial we know will help others who are impacted by Parkinson's disease.

*Don Mitchell lives in Kenmore, WA, and is the owner of Trane Commercial Systems. He has been a member of Team Parkinson's since 2007.*



# Parkinson's community loses friend, champion

IN APRIL THE NORTHWEST PARKINSON'S FOUNDATION bid a loving farewell to Tina Bell Torrance, who passed away peacefully in the company of her family and companions.

Tina, who lived with Parkinson's disease for 27 years, was one of eight founding board members of the

organization. She was Executive Director Bill Bell's mother.

Bill conceived the idea for the Northwest Parkinson's Foundation after he and his mother struggled to find a focal point for resources on living well with Parkinson's disease.

Tina's grace and generosity of spirit helped shape the character of the organization, which continues to reflect how she and Bill chose to navigate Parkinson's—with a positive, able attitude and a determination to enjoy life terrifically through it all.

One of our greatest achievements—one in which Tina played an instrumental role—was to co-found

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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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the Booth Gardner Parkinson's Care Center, which opened in 2000 and has since become a national model for comprehensive treatment and care.

We continue to be inspired by the positive steps Tina took to live meaningfully with Parkinson's disease.

To honor her legacy, we encourage each of you to take a moment every day to focus on one simple thing you can do to live well. That is the greatest gift you can make in remembrance of this amazing lady.

We have also created the Tina Bell Torrance Family Fund to honor her contributions and to carry her legacy forward.

Funds donated in her name will be used to support the ongoing operations of the Northwest Parkinson's Foundation and ensure that our programs continue to bring hope and wellness to thousands of patients and families.

In this way her spirit will remain with us, inspiring and bettering lives throughout the Northwest and beyond.