

PARKINSON'S

post

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THE NORTHWEST PARKINSON'S FOUNDATION

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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 the optimal quality of life for the Northwest Parkinson's community through awareness, education, care and advocacy.

We welcome comments and inquiries regarding this newsletter and all our activities. Our contact information can be found on the last page of this newsletter. We look forward to hearing from you!



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The author (center) stops for a photo in Lexington, WA, on July 15, the second day of the STP. He is flanked by friend John Dapper (left) and son Scott Heydrick.

Photo by Patrick Donohue

Rider applies own 'Pyramid' to long trek

By David Heydrick, M.D., M.S.

Twelve hours and 204 miles over two days on a bicycle was time well spent.

Participating as part of the Northwest Parkinson's Foundation's 100-plus-member Team Parkinson's in the Group Health Seattle-to-Portland Bicycle Classic (STP) on July 14 and 15 provided me a lot of time to observe, think and reflect—all while dealing with four flat tires!

In addition to the beautiful Pacific Northwest scenery, ideal cycling weather (overcast), friendly and highly organized Northwest Parkinson's Foundation staff and volunteers, inspiring diversity of Team Parkinson's supporters, and priceless experience of cycling with my oldest son Scott and faithful high school buddy John Dapper (and new friend Josh), what struck me were the features of the STP that support all the elements of my lifestyle-based Parkinson's Pyramid® (www.parkinsonspyramid.com).

The Parkinson's Pyramid is a science-based, integrated lifestyle "paradigm" I have been employing for the past three years in my own battle against Parkinson's. The paradigm advocates use of available, low-risk lifestyle therapies in four areas:

- symptom management with lowest-effective-dose medication and/or surgery
- stress management
- focused nutrition
- exercise

Applying these principles in my own life—including having deep brain stimulation surgery in 2005—has allowed me to work my way back from being totally disabled in 2004 to a point where my quality of life is dramatically improved and Parkinson's is mostly an annoyance. In fact, I use no prescription medication.

As I continue to present the principles of the Pyramid to U.S. and Canadian

Continued on Page 4

Maximize DBS with post-surgical services

By Sierra Farris, PA-C

In line with its comprehensive patient services, the Booth Gardner Parkinson's Care Center in Kirkland, WA, offers care for those who have had deep brain stimulation (DBS) surgery.

DBS is a treatment option for some patients with Parkinson's disease, tremor and dystonia. With focused therapy to maximize its impact, DBS can greatly improve a person's daily functioning.

At the Center, comprehensive care and teamwork distinguish the DBS program. Services are available under one roof and include care for patients with implanted neuron-stimulator systems for tremor, dystonia and Parkinson's.

The DBS program includes:

- Patient and family education about DBS
- Inpatient and outpatient rehabilitation tailored to the patient with DBS
- Evaluation to determine whether DBS will improve symptoms
- A counseling program for patients and families after DBS to include environmental and medical safety guidelines
- Comprehensive DBS programming and long-term maintenance care
- DBS programming troubleshooting, second opinions, lead placement and programming analysis
- Medication management
- Active communication with other treating physicians
- Community education
- Collaboration with regional area surgical centers

How can comprehensive care help after deep brain stimulation?

Rehabilitation. DBS can help many but not all symptoms of Parkinson's. Balance, motor initiation or freezing, speech, and swallowing problems may not improve or may become a

problem as Parkinson's continues to change.

At the Center, a team of physical, occupational and speech therapists who are experienced in both the disease and DBS tailor therapy to help patients set appropriate goals and optimize their overall functioning.

With focused therapy to maximize its impact, DBS can greatly improve daily functioning.

Rehabilitation is especially helpful in reducing injury risk for the patient with limited physical abilities before surgery that improve dramatically after surgery. Inpatient neurorehabilitation care is provided by trained specialists and is available for individuals requiring more intense rehabilitation.

Medical and programming teamwork. The Center's movement disorder specialists and DBS programmer are nationally recognized for their experience and education in DBS care.

They work as a team to optimize both DBS settings and medication management.

Neuropsychologists are included in this team to counsel patients about cognitive changes, surgery expectations, and life, relationship and work changes that may occur after DBS.

Community support group. People with Parkinson's seem to benefit from the opportunity to share their experiences about DBS with others.

The Booth Gardner Parkinson's Care Center will host a quarterly DBS support group beginning this fall (see next column for support group details).

Sierra Farris, PA-C, returned to the Booth Gardner Parkinson's Care Center this summer after gaining national recognition as a DBS programmer and educator. She is an integral member of the Center's DBS team.

Center starts support group for DBS patients

Join others who have had deep brain stimulation surgery, who are considering surgery or who are just curious about DBS at a quarterly support group offered by the Booth Gardner Parkinson's Care Center.

Guest speakers will explore the latest on DBS, and group discussions will cover how to live well with DBS, the latest safety information and patient stories.

The support group is open to anyone with Parkinson's disease, tremors or dystonia. Caregivers, family and friends are welcome to attend. Refreshments will be provided.

The group, hosted and moderated by DBS programming specialist Sierra Farris, PA-C, will meet from 10 a.m. to noon beginning Sept. 28. In 2008, the group will meet on April 25, July 25 and Oct. 24. Group size is limited and pre-registration is required. Call 425.899.3000 to register or learn more.

Center experts available for groups, seminars

Booth Gardner Parkinson's Care Center Medical Director Monique Giroux, M.D., and other Center specialists are available to the Western Washington Parkinson's and movement disorders community to speak at support groups, conferences and educational seminars.

Topics such as "New and Upcoming Medications for Parkinson's Disease," "To Drive or Not to Drive: That is the Question," "The Comprehensive Team Approach to Parkinson's Disease" and programs tailored to group interest are available.

For details, contact Robert Brazell (rfbrazell@evergreenhealthcare.org or 425.899.3123). The Center team will do its best to accommodate requests.

ON THE CALENDAR



Don't forget there's strength in numbers!
A great way to kick the blues is to seek the support of others. Consider educational opportunities, support groups, and events in your area as ways to build your network and get to know others.

Young-Onset Parkinson's Eastside Network | 7 to 8:30 p.m., first Wednesday of the month | North Bellevue Senior Center, 4063 148th NE in Bellevue | Facilitated by Carin Mack, MSW (206.230.0166 or socialwkr@earthlink.net) | Details: 425.443.8269

Private consultation with social worker Carin Mack, MSW | Greenwood Senior Activity Center, 525 N 85th St., Seattle, WA (206.297.0875) | 8 a.m. to noon, first Monday of the month, and other times by appointment | Service provided by Washington Chapter American Parkinson Disease Association | Free of charge Details: 206.230.0166 or socialwkr@earthlink.net

Parkinson's Caregiver Support Group | 12:30 to 2 p.m., fourth Monday of each month | Booth Gardner Parkinson's Care Center, Kirkland, WA, Room Tan 134 | Confidential support group provides a comfortable environment for bringing up issues and emotions faced while providing care for a loved one with Parkinson's | Facilitated by Jeff Shaw, PsyD. | Details: 425.899.3000

Well-Spouse Group | 4 to 5:30 p.m., first Monday of each month | Greenwood Senior Activity Center, 525 N 85th St., Seattle, WA (206.297.0875) | Group addresses needs of the well spouse of a chronically ill partner; members care for loved ones with a variety of disabilities, including Parkinson's. | Facilitated by Carin Mack, MSW (socialwkr@earthlink.net or 206.230.0166)

Women with Parkinson's Disease | 1 p.m., first Thursday of each month | Spokane, WA (location varies) | Support group to discuss issues of women with Parkinson's | Members share information, support and laughter | Details: 509.467.2240 or 509.473.2490

Neurological Exercise Group | 12:45 to 1:45 p.m. Booth Gardner Parkinson's Care Center, Kirkland, WA | Gentle stretch and strength exercises for people with Parkinson's and other neurological disorders | \$20 per four-week session; requires pre-registration | Call 425.899.3000 for dates.

NWPF gears up for second-annual HOPE Conference

The Northwest Parkinson's Foundation and Washington Chapter American Parkinson Disease Association will present the second-annual HOPE Conference on Parkinson's from 8:30 a.m. to 3:45 p.m. November 10 at the Hilton Seattle Airport and Conference Center.

U.S. Sen. Patty Murray will welcome conference guests, and the keynote speaker will be Davis Phinney, former professional road bicycle racer who in

1986 became the first American to win a stage at the Tour de

HOPE.
Parkinson's Disease

France. Phinney was diagnosed with Parkinson's at age 40 and in 2003 established the Davis Phinney Foundation to fund research into Parkinson's disease.

The day-long conference will feature speakers from the Booth Gardner Parkinson's Care Center in Kirkland, WA, and the Virginia Mason Neuroscience Institute and University of Washington Department of Neurology, both in Seattle, WA.

Sessions will cover new and emerging therapies, cognitive changes with Parkinson's, physical therapy, exercise, self-care strategies, depression, caregiver concerns and young-onset Parkinson's.

Registration forms are available at www.nwpcf.org and www.waparkinsons.org. For more information, call 877.980.7500 or email info@nwpcf.org.

HOPE Conference seeks Parkinson's artists for exhibit

Once again the HOPE for Parkinson's Conference will feature works of art by people with Parkinson's disease.

If you are an artist and wish to participate, you must be able to attend the conference.

For more information, call Pam Dibbs at 425.442.9301 or Kim Mills at 847.707.6031.

audiences—including at the Governors' Conference on Parkinson's last November in Seattle, which some readers of this publication may have attended—I am always encouraged by the typical response: "Now I have hope."

What was intriguing to me about the STP was that it encompassed the whole Parkinson's Pyramid.

Symptom management

Scott and I took up cycling last year to join the Pedaling for Parkinson's team in RAGBRAI (Register's Annual Great Bike Ride Across Iowa), a 500-mile effort over seven days.

Cycling has become my refuge and, like many riders with Parkinson's, I find myself "free from PD" while riding.

Interestingly, via cycling and a variety of other exercise, and by living by the principles of the Pyramid, I have been able not only to remain off medication but to turn down my DBS settings about 10 percent (probably because regular aerobic exercise increases the available striatal dopamine).

Several people with Parkinson's rode with Team Parkinson's this year (for a list of riders with Parkinson's, see the box on this page). We were able to do so because low-dose medication and/or surgery allowed us to improve our symptoms enough to train via cycling, running, swimming, weightlifting, and other activities.

Yes, fatigue and aches were incurred on the ride, but these quickly dissipated as we rode through the cheering crowd and floating bubbles at the finish in Portland.

Stress management

Okay, getting four flat tires on the first day was a bit stressful (if not statistically off the charts!), even bringing out my usually well-controlled tremor.

Fortunately, my "caregivers" (i.e., support crew), Scott and John, patiently came to my rescue each time.

Subsequently, waiting for the unpredictable *hiss*s of air from a tire reminded me of the stress of unpredictable symptomology that people with Parkinson's and their caregivers face hour after hour, day after day.

But I adapted and adjusted my attitude, reminding myself of a principle of the Parkinson's Pyramid that I teach others: The brain is the key to determining what is stressful.

Of course, what better way to reduce stress than a 100-mile bike ride, and for further stress relief, why not do it again the next day?!

Actually, there is significant science to show that (even much less) aerobic exercise decreases serum markers of oxidative stress and inflammation that increase with psychological stress.

Focused nutrition

The interesting thing about the well-stocked STP rest stops was that, like life, they presented choices about nutrition.

Of course, there was plenty of water to stave off the ill effects of dehydration. Also abundantly available was neuron-demise-fighting, antioxidant-rich, anti-inflammatory fresh fruit.

Of note here is that the Team Parkinson's rest stop food was incredibly healthful. The stops included homemade power bars of granola with natural honey.

There were (ordinarily) less-than-ideal choices too, including high-fructose-containing "energy bars" and "energy drinks."

But as I teach in the Parkinson's Pyramid, exercise is the wild card, and science suggests that aerobic exercise can make up for some non-ideal food choices.

Finally, when you burn 10,000 calories and take in only 6,000 during the STP, you're operating in a calorie-restricted state that is thought to be neuroprotective (at least until you dive into that huge pasta dinner to celebrate your accomplishment!).

THANKS!

In addition to dozens of Team Parkinson's 2007 members who are friends and family to people with Parkinson's, the team includes six people with Parkinson's.

For their commitment to raising money and building awareness for the Parkinson's community, our special thanks goes to Janet Dowell (Lacey, WA), Willy Fuller (Opelika, AL), David Heydrick (Frederick, MD), Chris Jewell (Seattle, WA), Mike Mikkelsen (Bellingham, WA), and Craig Waterbury (Federal Way, WA).

A variety of exercise

Training for and doing the STP required the five S's of regular exercise advocated by the Parkinson's Pyramid: strength, stretch, step, slow and smarts.

Weight training and stretching are of obvious benefit and nicely augment the aerobic interval training ("step") and high cadences of cycling, all concepts taught in the Pyramid to stimulate a variety of neural pathways.

Even "slow," highly controlled fine movements (those used in changing a tire, for example) were necessary during the STP.

Finally, "smarts," or brain challenges, were abundant as fast decision-making and problem-solving were needed intermittently, including to manage the logistics of traveling cross-country by plane with two bike boxes.

So there it is. Team Parkinson's, the STP and the Parkinson's Pyramid—made for each other like a hand in a glove, or better yet, like a rider on a bike.

David Heydrick is a Maryland-based neurologist. He has a part-time private clinical practice, is an inspirational speaker (he takes requests for speaking engagements on his website, www.parkinsonspyramid.com), and is writing a book titled "Back in the Game: The Parkinson's Pyramid®."



Team members tackle fund raising (and hope raising) with creativity

Team Parkinson's member and artist Mike Mikkelsen (pictured above with his sister, Karin Utzinger of Bozeman, MT) has created a stylized seagull garden sculpture with a twofold purpose: to inspire hope in the Parkinson's community for a better, more joy-filled and productive life, and to raise money for the Northwest Parkinson's Foundation.

The Bellingham, WA, artist, who has Parkinson's disease, makes an orange bird representing the Parkinson's patient and a yellow

bird representing the Parkinson's caregiver. The birds are 14 inches long by 4.5 inches wide and made of 18-gauge powder-coated steel. The 6-foot rod they stand on, and other hardware, is stainless steel.

For a limited time, the artist and his wife, Anne, are offering a premium of one bird for every \$100 gift, or 12 birds (an entire flock) for every \$1,000 gift made to their Team Parkinson's site (www.nwpcf.org/participant.asp?id=87).

This offer will continue until December 31, 2007, or while supplies last. Fifty percent of each purchase qualifies as a tax-deductible donation.

As Team Parkinson's members, the Mikkelsens are excited to be able to make this premium available to help the Northwest Parkinson's Foundation continue its work to support Parkinson's patients and their families.

For more information, contact the Mikkelsens at 360.756.5209 or parkinsonsgardenart@hotmail.com.



Front row from left, Becky, Patsy, Penny and Angie, and back row from left, Christina and Zenith, all employees of the Char-Burger Round-up In & Out in Pendleton, OR, supported Team Parkinson's member Sue Petersen in this year's Group Health Seattle-to-Portland Bicycle Classic.



Team Parkinson's members pose at the rim of Crater Lake at Crater Lake National Park in Oregon as they prepare for the 100-mile Volcanoes to Valleys cycling event. From left to right are Matt Rogers, Randy Rogers, Walter Suttle, Hal Applebaum, Dan Gruber, Robert Ogle and Anna Martinson.

Evaluate your fitness program for best results

By Lori Newell, MA, CPT, RYT

Most people are well aware of the varied benefits of exercise—from building a strong heart to maintaining muscle tone to reducing stress and helping you get a better night of sleep.

Still, sticking to an exercise program can be a challenge.

The first rule: Find exercise you enjoy. Remember, the best exercise program is the one you actually do.

A well-rounded exercise program should contain three components: 1) aerobic/cardiovascular exercise, 2) strength/resistance/weight training, and 3) stretching/flexibility/range-of-motion exercises.

All are important, but for different reasons. Aerobic exercise strengthens the heart and lungs and reduces your risk of cardiovascular disease. Common aerobic activities are walking, biking, swimming and dancing.

Weight training strengthens the muscles, and strong muscles can help you prevent falls and make activities such as rising from a chair easier. Strength training involves moving your body against some kind of resistance—machines, free weights, tubing or even your own body weight.

Stretching exercises are designed to increase the range of motion in muscles and joints. Increased flexibility helps with everyday tasks such as turning your head to back up the car, grooming, and reaching items in high and low places.

Before you get started, there are some important things to keep in mind.

Know your instructors' background and experience level. Currently there are no licensing requirements for personal trainers and fitness, yoga, Pilates and Tai Chi instructors. You must be an educated consumer.

Check to see if your instructor has a degree or certification in an

exercise-related field. There are three major national certifications to look for: ACSM (the American College of Sports Medicine), ACE (the American Council of Exercise) and AFAA (the Aerobics and Fitness Association of America). But consumer beware: There are many programs in which instructors with no previous fitness knowledge or experience can be certified in a weekend course or even over the Internet!

(Note: Instructors should always face the students throughout the class and they should check for correct alignment and good exercise form.)

Know contraindications for any medical conditions you have. Always check with your doctor or a licensed physical or occupational therapist before starting an exercise program. Joint

The first rule: Find exercise you enjoy. The best exercise program is the one you actually do.

replacements, osteoporosis, heart disease, diabetes and other conditions have specific considerations when it comes to exercise.

Use common sense and listen to your body. Exercise shouldn't hurt. While feeling achy or stiff after exercise is normal, pain is a signal that something is wrong. Never exercise to the point of pain, and discontinue any exercise that makes your symptoms worse. You should never "feel" the exercise in your joints, neck or back.

Every exercise you do should have a clear purpose. When deciding if an exercise is good to do, ask yourself the following questions: Why am I doing this particular exercise? Am I really targeting the area I'm trying to work on? Do I feel it where I'm supposed to? Is this a safe way to do the exercise, or is there another version that would be better for my posture, balance, body mechanics or joint health?

ASK THE EXPERT

Got a question about exercise, yoga or meditation? Lori Newell will try to answer one or two questions in each column.

Email your questions to info@livingwellyogaandfitness.com or mail them to Living Well Yoga and Fitness, P.O. Box 34, Killawog, NY 13794.

Lori Newell is a certified personal trainer and certified yoga teacher, as well as author of "The Book of Exercise and Yoga for Those with Parkinson's Disease." It is available through Living Well Yoga and Fitness, P.O. Box 34, Killawog, NY 13794 or www.livingwellyogaandfitness.com. The book costs \$23.95 (price includes shipping and handling). It can be ordered online or by sending a check or money order to the above address. No phone orders are accepted. Mention this publication when placing your order and a portion of your purchase will be donated to the Northwest Parkinson's Foundation.

Reaching the Washington Parkinson Disease Registry

The telephone contact information to participate in the Washington Parkinson Disease Registry (WPDR) was incomplete in our last issue.

To sign up for the Registry, a statewide database of individuals with Parkinson's disease interested in participating in research studies, call 800.329.8387 ext. 66080.

The WPDR is a collaborative effort of the Northwest Parkinson's Foundation, Washington Chapter American Parkinson Disease Association and University of Washington Department of Neurology.

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

We are privileged so many in the Northwest Parkinson's Foundation family support our mission by making gifts throughout the year in honor or memory of special friends and loved ones. A tribute gift is a special way to honor or remember a loved one.

Listed here are those who made tribute gifts between July 1 and August 20, 2007.

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The Northwest Parkinson's Foundation is a cofounder and partner of the **Booth Gardner Parkinson's Care Center** (13030 121st 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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Seattle-area volunteers sought

Volunteers are at the heart of so many organizations, and the Northwest Parkinson's Foundation is no different. We're seeking a few good volunteers to help with office and special projects. Volunteer opportunities include data entry, receptionist and telephone duties, and assistance with Team Parkinson's and the HOPE for Parkinson's conference.

Call Development Director Dav'ne Stahley at 877.980.7500 to learn how you can help.

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