

P A R K I N S O N ' S

A P U B L I C A T I O N O F

post

T H E N O R T H W E S T P A R K I N S O N ' S F O U N D A T I O N

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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!



**NORTHWEST
PARKINSON'S
FOUNDATION**

TAKING PART IN RESEARCH

Patients put their Parkinson's to use through studies

By Dav'ne Stahley

Maybe you've wondered why you should bother participating in a Parkinson's clinical trial or research study. After all, it can take years of research to achieve outcomes that benefit patients, and the results may not offer anything to help you on your own journey with Parkinson's.

Perhaps the simplest and most eloquent reason I've heard for taking part in research was something someone told me at a recent Parkinson's conference: "I have Parkinson's. I don't like it, but if I've got it I might as well use it!"

That sentiment seems to sum it up for a number of our readers who are participating in research or have done so in the past.

Rochelle Wright, a vivacious, high-energy redhead, was only recently diagnosed with Parkinson's and is involved in a study evaluating the impact of Parkinson's medications on movement, cognition and speech.

She describes herself as "highly competitive, proactive and very verbal" and believes that participating in research is one way to educate herself about Parkinson's disease.

"Anything I can do to help me understand myself and my (Parkinson's) process will be beneficial for me and the people around me," Wright said. "I'm



Photo by John Wright

Rochelle Wright spends quality time with her four-month-old granddaughter, Olivia Ryann Chamberlain, in Bellevue, WA.

interested in the (research) process and the results. And if I can help other people in any way, I'm all for it."

Besides participating in a Parkinson's study, Wright has become involved with a Parkinson's support group and is serving on the board of a local Parkinson's organization.

Wright said getting involved has made a significant difference in her attitude about and acceptance of Parkinson's.

Pete Beidler recently moved to Washington state from Bethlehem, PA, where he taught English literature at Lehigh University for four decades. He was diagnosed with Parkinson's a few years ago, about the time he and his wife, Anne, decided to move to Seattle to be closer to their children and grandchildren.

Continued on Page 4

Specialists' expertise a plus for patients

By John W. Roberts, M.D.

Patients and caregivers new to Parkinson's disease often ask me about the specialty of movement disorders and why it may be important to them.

The first thing to understand is the concept of a movement disorder.

Movement disorders are a diverse group of diseases that result in the inability to produce willed physical movements or that result in involuntary movements such as tremors. Many are caused by the dysfunction of part of the brain called the basal ganglia.

Essential tremor, tics, dystonia, Huntington's disease and Parkinson's disease are all movement disorders.

Parkinson's is one of the most common movement disorders and often accounts for more than half a movement disorders specialist's practice.

A movement disorders specialist is a type of a neurologist. Neurologists are physicians who treat disorders of the nervous system.

To become a physician, one must first complete medical school (or osteopathic school), which is usually

a four-year course of classroom and clinical study after college. The result is a medical (or osteopathic) degree.

To specialize in neurology, the physician then goes on to four more years of clinical training in a program called a residency. Most neurologists become board certified in neurology by passing an examination after their residency.

Finally, to become movement disorders specialists, neurologists will take one to three years of further clinical training, called a fellowship, before setting out on their own. Currently there is no board certification for movement disorders, but it is being considered.

There are many advantages to receiving care from a movement disorders specialist. First, these are physicians with a level of training in Parkinson's disease unmatched by any other group of health care provider.

Second, because movement disorders specialists typically see hundreds and sometimes thousands of Parkinson's patients every year, they have vast experience in the disease.

Third, these specialists have an incentive to keep up with the latest knowledge by reading the medical literature and attending scientific and educational meetings.

Finally and importantly, these are people who have an obvious passion for their chosen specialty. That devotion to the understanding of Parkinson's leads to better treatment for the patient.

There are of course many neurologists who are not movement disorders specialists per se but who are still competent in the care of Parkinson's patients. These are often individual neurologists who have a special interest in the condition and make an effort to keep up with the latest information. In a way,

they become self-trained movement disorders specialists.

In many communities that are far from "official" movement disorders specialists, these neurologists provide excellent care.

Finding a movement disorders

Movement disorders specialists have an obvious passion for their chosen specialty. That devotion to the understanding of Parkinson's leads to better treatment.

specialist is not always easy. Word of mouth between patients can be a good source, but sometimes patient referrals come with bias.

Referral from a primary care physician or from another neurologist is usually meritorious, but referring physicians may not always be aware of all the specialists in a community.

The Internet is a powerful tool for finding a specialist, but sometimes details about an individual physician's education and background are not available on websites.

Advice from a patient-advocacy organization like the Northwest Parkinson's Foundation is reliable. These organizations are usually familiar with the movement disorders specialists in the community and are committed to supporting quality health care.

It is reasonable for the patient to use more than one source of information when searching for a specialist.

The Pacific Northwest now has several movement disorders specialists based in the major metropolitan areas—including Seattle, Tacoma and Spokane, WA, and Portland, OR.

John Roberts is a movement disorders specialist with Virginia Mason Medical Center's Neurosciences Institute in Seattle.

ON THE BOARD

Welcome, Dr. Giroux!

The Northwest Parkinson's Foundation welcomes to its board Monique L. Giroux, M.D., medical director of the Booth Gardner Parkinson's Care Center in Kirkland, WA.

Giroux directed the center from 2000 to 2003 and returned to the position in July.

She spent the prior four years as medical director for Outpatient Movement Disorders at the Cleveland Clinic in Ohio.

This marks the first of a new feature in the Parkinson's Post. "Ask the Expert" will appear as a monthly column, with questions from readers addressed by Parkinson's specialists. Got a question? Email it to questions@nwpf.org or mail it to 400 Mercer Street, Suite 401, Seattle, WA 98109-4641—or call us toll-free at 1.877.980.7500.

My husband is having hallucinations in the evenings. What causes hallucinations and what can be done about them?

Martha Glisky, Ph.D., a neuropsychologist at the Booth Gardner Parkinson's Care Center in Kirkland, WA, describes hallucinations as sensory perceptions that happen while awake that are mistakenly thought to be real.

In Parkinson's, hallucinations are most commonly visual and described as objects, people or animals. For many, they are benign visions that the individual experiencing them knows are not real. In more severe cases, a person may not know the visions are not real or may be distressed by and try to interact with them. Illusions can also occur in which a real object is perceived but misinterpreted—for example, trees are mistaken for people.

Not all people with Parkinson's experience hallucinations. The risk of hallucinations is greater in older people, those with cognitive problems, and those taking higher doses of Parkinson's medicines.

It is important to inform your doctor about even the mildest hallucinations because they may alter how you "see" and interact with your environment. An example is the person who trips or falls while trying to step over a dog that is not really there. Another good reason to tell your doctor is that treatment is available.

In some cases, hallucinations may be a sign of another medical problem or condition that requires treatment such as an infection, dehydration or a side effect of a new medication.

Although all Parkinson's medications can cause hallucinations, some are more likely than others to do so. Your clinician can work with you to review your medicines and make changes to treat the hallucinations while still optimizing physical and mental function.

Finally, cognition- and memory-enhancing medications such as rivastigmine (Exelon) or antipsychotic medicines such as quetiapine (Seroquel) or Clozaril may help curb hallucinations.

Among specialists who can help with the management of hallucinations is the occupational therapist. Kay Ballen, OTR/L, an occupational therapist at the Booth Gardner Parkinson's Care Center, has clear advice for patients and their families.

"Improving household lighting, using night lights and addressing vision problems like cataracts can be helpful," Ballen said. Occupational therapists can also work with families to identify and reduce potential safety hazards, she said.

Neuropsychologists, counselors, occupational therapists and other specialists can all help by offering strategies for redirecting behavior and alleviating distress.

Pension Protection Act creates tax-free opportunity for some donors this year

The new IRA charitable rollover is something to get excited about ... and it's a great way to make a tax-deductible year-end gift that will make a difference.

The IRA rollover, part of the Pension Protection Act of 2006, created a charitable giving opportunity for donors who will be at least 70½ before December 31, 2007.

If you meet the criteria you may roll over up to \$100,000 tax-free from your IRA account to a qualified public charity this calendar year, after which the opportunity expires. A married couple may give as much as \$200,000 tax-free if each has an IRA.

IRA rollover gifts can come from traditional or Roth IRAs and sometimes from a simple IRA under certain tax conditions; 401(k) and 403(b) plans do not qualify.

Now you have a chance to make a major gift in your lifetime, avoid a big tax bite, and delight in the realization of your vision for a cause you are passionate about: quality of life for people with Parkinson's.

Contact your bank, broker or mutual fund company for an IRA distribution form. Contact Development Director Dav'ne Stahley with questions about this opportunity.

Got an announcement?

If you'd like to announce a Parkinson's-focused support group, educational opportunity, or special event relevant to the Northwest Parkinson's community, drop us a line. We will include in "On the Calendar" announcements of 60 words or fewer promoting events in the Northwest.

The submission deadline is the first week of each even-numbered month for publication the following month. Items will be placed in the calendar based on space available. Mail your announcement to the Northwest Parkinson's Foundation (400 Mercer St., Ste. 401, Seattle, WA 98109-4641) or email it to davne@nwpf.org.

Within a few months of arriving in the Puget Sound area, Beidler joined a Parkinson's yoga class and signed up for a Parkinson's study at the University of Washington.

"It was fun being involved in a research study, and Anne was part of the control group. I don't suppose that the results of the study will help me," Beidler said, "but they might help somebody else. Besides, it was a chance to meet new people."

According to Jim Leverenz, M.D., an associate professor in the departments of neurology and

psychiatry at the UW and a staff neurologist at the Seattle Veterans Administration Hospital, one of the primary reasons for the creation of the Washington Parkinson Disease Registry was to improve communication between researchers and patients with Parkinson's.

Leverenz said the registry will assist researchers with recruitment of patients for clinical trials and other studies, as well as ensure patients are informed regarding the research opportunities available to them.

Research participation can include clinical trials, which usually involve an intervention of some sort. For example, one group of participants receives a new drug while a control group receives a placebo. The researchers are then able to identify differences in reaction to the drug.

Other, nonclinical research studies generate new knowledge that can later be used to develop treatments for Parkinson's patients.

In one example, researchers are testing the hypothesis that some kind of environmental exposure is linked to Parkinson's disease.

Studies of this sort often need hundreds of subjects who are willing to be interviewed about their backgrounds.

It is the hope of Leverenz and registry co-director Cyrus Zabetian, M.D., that the registry will speed up their goals of finding better Parkinson's treatments and ultimately a cure.

Participation in the registry, Leverenz and Zabetian pointed out, is only an agreement to be contacted about research studies; registrants are under no obligation to participate in any studies for which they are contacted.

Kristie A. Spencer, Ph.D., is an assistant professor and researcher in the department of speech and hearing sciences at the UW. Spencer is evaluating the effect of anti-Parkinsonian medications on movement preparation, cognition and speech.

'I don't suppose that the results of the study will help me, but they might help somebody else.'

She theorizes that people with Parkinson's may have difficulty switching between movements and thoughts, or in maintaining a prepared movement or thought over time.

"I am particularly interested in what happens in the brain when people are preparing to move or speak," she said.

Spencer is seeking people with Parkinson's, with and without speech impairment, who are native English speakers, to participate in her NIH-funded study.

"To better understand response preparation, I use button-press and speech reaction-time tasks to help pinpoint the source of any deficits," Spencer said.

In addition to the reaction-time tasks, study participants complete tests of memory, speech and language. Control participants (often the Parkinson's patient's care partner) are needed as well and complete the same tests and tasks.

Parkinson's patients in Spencer's study receive \$200 (plus reimbursement for such expenses as parking and bus fare) and control participants receive \$75 for completion of the study.

For details, contact Spencer at kas@u.washington.edu or 206.543.7980.

AT THE CENTER

Participants sought for study into effect of medication

The Booth Gardner Parkinson's Care Center seeks volunteers to participate in a research study for recently diagnosed Parkinson's patients.

Those accepted into the study will participate in 10 clinical visits and five telephone interviews over 15 months.

You may qualify for this study if you are between 30 and 79 years old, have been diagnosed with Parkinson's within the past two years (stages I-II) and are currently not taking any Parkinson's medications.

Study procedures will include EKGs, lab work, and an evaluation of your physical and mental health.

The purpose of this study is to assess the effect of early vs. later treatment in Parkinson's with Pramipexole (Mirapex®).

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.

Issaquah Parkinson's support group | 1:30 to 3 p.m., second Monday of the month | Our Savior Lutheran Church, 745 Front St. S, Issaquah, WA 98027 | Facilitated by Carin Mack, MSW (206.230.0166 or socialwkr@earthlink.net)

Whidbey Island Parkinson's support group | 1 p.m., first Friday of the month beginning in January | Oak Harbor Senior Center, 51 SE Jerome, Oak Harbor, WA 98277 | Facilitated by Carolyn Hansen (360.279.1785)

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

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

Parkinson's caregiver support group | 12:30 to 2 p.m., fourth Monday of the month | Room Tan 134, Booth Gardner Parkinson's Care Center, Kirkland, WA | Confidential support group provides a comfortable environment for talking about the 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 support group | 4 to 5:30 p.m., first Monday of the 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)

PuSH pushes to housing goal

PuSH for PD held its annual fund-raising event on September 23 at the Lake Union Crew House. A silent auction provided an opportunity to bid on a variety of items and experiences. Wine and food—including delicious desserts—contributed to a festive gathering.

PuSH for PD is advocating for special housing for people with Parkinson's disease. The group is moving closer to securing property for the Northwest's first supportive living residence for those with Parkinson's.

To stay informed about the group's progress, visit its website at www.pushforpd.org.

For details, contact Wendy Holman at pushforpd@seanet.com or 206.365.7872.

PDF puts symposium online

The Parkinson's Disease Foundation's 50th anniversary educational symposium, *Frontiers of Science and Clinical Advances in Quality of Life*, is available online through October 2008.

The symposium featured Parkinson's experts presenting the latest in Parkinson's science and quality-of-life initiatives, reviewing the progress over the last 10 years, and sharing their expectations of future advances.

Visit www.pdf.org/50th/webcast.cfm to watch the symposium.

Share your experiences

The Parkinson's Resource Center in Spokane, WA, is launching a volunteer mentor program to link people who are experienced in their journey with Parkinson's with those not as experienced. Volunteers may work anonymously by telephone.

For details, call E'lise Balogh at 509.473.2490.

HOPE recap in next issue

Look for a recap of the second-annual *HOPE Conference on Parkinson's* in the January/February 2008 issue of the *Parkinson's Post*. The annual educational event is co-hosted by the Northwest Parkinson's Foundation and Washington Chapter American Parkinson Disease Association.

Caregiver well-being essential to care giving

By Lori Newell, MA, CPT, RYT

Caregiving for a loved one can be a rewarding but stressful job. There are not only medical appointments and medications to manage, there may also be financial concerns, the need to relocate to more a suitable living environment, and a complete change in daily habits.

While the top priority may seem to be meeting the needs of the person who is ill, it is as essential for caregivers to take care of themselves.

For many, the job of caring for another can become all consuming. But if you continually neglect your own needs, you may find yourself burned out and exhausted.

Think of taking care of yourself not as a luxury but as a necessity.

Caregivers I have worked with often start my classes by saying they feel guilty about taking time for themselves when their loved one is so ill. But after taking some time to replenish themselves, they often find they have more energy to give to their loved one.

Because living with the issues brought on by a chronic illness can be stressful, finding ways to manage stress is often a very important component of the caregiver's daily routine.

Managing stress is important because constant stress causes the nervous system to become overactive and can lead to health problems such as high blood pressure, heart disease, chronic pain, digestive problems and obesity.

So while you may not want to take time for yourself, it is better to do so to prevent health problems.

It is also important to help prevent the burnout that can occur when caregivers try to do more than they are able without taking breaks. Symptoms of burnout can

include fatigue, stress, anxiety and depression.

It is well documented that regular exercise, especially aerobic exercise, is a great stress reliever.

It is recommended that everyone aim for 20 to 30 minutes of aerobic exercise three to five days a week at a minimum.

Taking a brisk walk is a great form of aerobic exercise and can be easy for caregivers to accommodate because it can be done just about anywhere and anytime. It does not require any investment in equipment (except a good pair of walking shoes) and you do not have to take time to travel to a gym.

Yoga and tai chi are other movement techniques that can help manage stress. Both techniques combine deep diaphragmatic breathing with gentle movement to help calm the mind and relax tight muscles in the body.

For both of these forms of exercise it is usually best to start by taking a class from an instructor to

One of the best ways to take care of your loved one is to make sure you are taking care of yourself. In doing so, you will have the energy to give to another.

make sure you learn to make the movements correctly and to help prevent injury.

As you become more familiar with the routines you can practice at home using videos.

A regular meditation practice is another great way to manage stress. There are many meditation techniques but all aim to free the mind of stressful thoughts, giving the mind and body a rest from constant worry and tension.

ASK LORI

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 84, Mastic Beach, NY 11951.

So try a few stress-reducing techniques and see which work best for you and your situation.

For many caregivers a major issue is who will look after their loved one while they are away at a class. One way I have worked around this is to offer classes at the same time a Parkinson's support group is being offered.

Try contacting local teachers to see if you can arrange a for a class to be offered at a good time for you and other caregivers you know.

So remember, one of the best ways to take care of your loved one is to make sure you are taking care of yourself. In doing so, you will have the energy to put into caregiving.

Lori Newell is a certified personal trainer and yoga teacher, as well as author of "The Book of Exercise and Yoga for Those with Parkinson's Disease." The book is available through Living Well Yoga and Fitness (www.livingwellyogaandfitness.com) and costs \$23.95 (price includes shipping and handling).

It can be ordered online or by sending a check or money order to P.O. Box 84, Mastic Beach, NY 11951. Group discounts are available.

Newell will donate 30 percent of the cost of each book to the Northwest Parkinson's Foundation when you order directly from her website and mention that you read about it in the Parkinson's Post.

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 giving generously throughout the year in honor or memory of special friends and loved ones. Listed here are tribute gifts made between August 20 and October 14, 2007.

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Kristy Fleming of Portland, OR, was a top Team Parkinson's fund raiser who won a team drawing for a custom-fit bicycle from Alpine Hut. The bike was donated by Hos Bros. Construction. Fleming rode in the Group Health Seattle-to-Portland Bicycle Classic in July. To learn more about the team's effort this year, visit us online at nwpf.org/teamparkinsons.asp.

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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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New specialist joins Seattle institute

Susie Ro, M.D., has joined the staff of the Neuroscience Institute at Swedish Medical Center in Seattle, WA. Board certified in neurology and clinical

neurophysiology, Ro serves as medical director of the movement disorders program.

In addition to diagnosing and treating Parkinson's and other movement disorders, Ro specializes in electromyography and neuromuscular disease.

One of her areas of expertise is Botox injection therapy for movement disorders—specifically dystonia, hemifacial spasm, spasticity and sialorrhea.

She also screens patients for appropriateness for deep brain stimulation to control symptoms of movement disorders.

Prior to coming to Swedish, Ro was a clinical instructor in neurology at Evanston Northwestern Healthcare in Illinois, where she also worked in the Muscular Dystrophy Association clinic.