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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
PARKINSON'S
FOUNDATION

There's power in numbers for support group members

BY DENISE GIBSON

Dystonia is a neurological movement disorder characterized by involuntary, sustained muscle contractions that can result in twisting, abnormal postures and arrhythmic tremors. It can affect one or more parts of the body and, as with Parkinson's disease, the same part of the brain—the basal ganglia—is affected.

In my journey with cervical dystonia, the Internet has been an invaluable resource. When I was first diagnosed with this rare movement disorder, I used the Internet to find out about it. When I wanted to learn from other patients about how to cope, the Internet gave me access to patient forums. Web seminars brought information to me in the comfort of my own home.

But the great information superhighway could not offer another kind of connection, equally important in my life—personal contact with others. The embarrassment of living with a movement



Photo by William Gibson

Denise Gibson pauses on a hike with her dogs, Aengus and Ffinian, on the Icicle River Trail near Leavenworth, WA.

disorder—because of my head tremors and my inability to speak clearly—as well as the resulting low self-esteem had left me isolated. Communicating with the patient forum via the web made me long to physically meet others with dystonia, people who would understand and accept my limitations. But I was living in Spokane, WA, where there was no support group and few others with dystonia.

During an appointment with my neurologist, Dr. Anthony Santiago, I overheard someone ask about starting a Parkinson's support group. A thunderbolt struck, and I asked if it would be possible to start a dystonia support group. Little did I know that would mean I would be the one to start it.

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National organization shares work of artists with Parkinson's disease

Do you find that creative activities—such as painting, drawing, dancing, singing, making jewelry, or playing a musical instrument—ease your Parkinson's symptoms? You're not alone. Many people with Parkinson's say creative endeavors temporarily relieve their symptoms.

Recognizing this, the Parkinson's Disease Foundation launched its "Creativity and Parkinson's Project" to explore, support, and encourage the therapeutic value of creativity in Parkinson's. The project hosts an online gallery of art by people with Parkinson's and invites anyone with the disease to show their work.

The project welcomes all forms of creativity—including painting, drawing, song, pottery, crafts, and more. Some of the works are featured in an annual calendar.

One artist whose work is displayed in the online gallery is Edwin Ferran. Here's what he says about himself and his work:

"I've been a good drawer/ sketcher since I was a kid, making my own Spiderman comics and such. ... It wasn't until five years ago or so that I dared put brush to canvas ... acrylics at first, in a very drawing-type manner. I have since 'graduated' to oils and, once I get over the mental speed bumps that steer me away from the studio, I find myself enjoying the process of seeing a painting unfold before me.

"I'm very much in a learning mode now, and I generally work from images clipped from magazines. I was diagnosed with Parkinson's in April 2005 and to date I am symptomatic primarily on my right side, which is fortunate artistically speaking since I am left-handed. I am curious how my art will develop as my disability progresses."

To see the online art gallery and learn more about the "Creativity and Parkinson's Project," visit pdf.org/en/creativity. And you can view Ferran's drawings and paintings on his own website, hap46st.com.

Excerpted with permission from the Parkinson's Disease Foundation website, pdf.org. The Northwest Parkinson's Foundation thanks the Parkinson's Disease Foundation for giving permission to reprint the article, "Dental Care Needs Extra Focus with Parkinson's," by Dr. James M. Noble, which appeared in the July/August Parkinson's Post.



The Stanwood, WA, Parkinson's support group poses for a photograph after a group trip to Trader Joe's this summer. Says group leader Tori Kelly (back row, second from left), "I guess you could say Parkinson's people wear many hats."

Fun is the focus for one vibrant support group

There are Parkinson's support groups all around the Pacific Northwest and across the nation. One such group meets monthly in Stanwood, WA. Its members are having a great time getting to know each other as they meet to hear speakers and go on group outings—including a recent trek to a local grocery store for cheese-tasting. Their main focus seems to be simply to have fun.

The group, led by Tori Kelly, has 14 members, several of them neighbors. "We are becoming friends and learning to live with a debilitating disease with grace, laughter, and love," she says.

They are a talented group, excelling at hobbies ranging from cooking to gardening to photography.

The Stanwood support group welcomes new members. They meet from 10 to 11:30 a.m. on the second Monday of every month at Lincoln School Senior Center (7336 276th St. NW / Stanwood, WA 98292). To learn more, call 425.422.1067.

To find support groups in your area, call the Northwest Parkinson's Foundation at 877.980.7500 or visit us online at nwpf.org/SupportGroups.aspx, where you'll find a national listing of support groups.

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I was given the name of another person who had voiced a similar request. When Mary Jane Kellog and I first met and discussed forming a support group, her goal was to help others with blepharospasm, a dystonia affecting the eyes. I had been thinking of a support group addressing cervical dystonia, but within 30 minutes we knew that we wanted a support group to help people with any form of dystonia. It was obvious to us that, although the affected muscle groups were different, we all faced the same problems, had the same concerns, were dealing with brains that seemed wired in the same way, and could benefit from connecting with one another.

We had no idea how many people with dystonia might be out there, and whether anyone would want to join us. But we were wise enough to invite Dr. Santiago, who specializes in movement disorders, to speak at our first meeting.

The room was packed. More than 50 people showed up—patients, caregivers, and medical professionals—and from that one meeting, our support group of two grew to over 20.

As our numbers grew, so did our enthusiasm and the connections we forged. For our educational meetings, we invited a wide variety of medical professionals to speak. Anything that helped us cope became a good source of discussion. Any treatment that was effective became a topic worthy of being presented. And the perfect professional for presenting the information always seemed to cross our paths at the right moment in time.

The members of our group participated with suggestions and contacts. Often those with the most severe problems were the ones offering the best ideas, for they were the most experienced at coping with dystonia. Mary Jane worked tirelessly behind the scenes, contacting people with blepharospasm to give them information

and let them know they were not alone.

While education was important, we found that sitting and listening was not the key—the key was participation. So we started a conversation group to address individual needs and explore thoughts and concerns. We also encouraged members to participate in an ongoing meditation group. Meditation seemed to help immensely in learning to focus our minds, something that is difficult with movement disorders.

A Dance for Parkinson's group—based on the widely acclaimed method developed by the Mark Morris Dance Group—has formed, and since we helped in planning the local program, we think of ourselves as partners in the dance of reaching out to others who are creatively dealing with their physical challenges.

Plans call for a voice/signing group, similar to the popular Tremble Clefs singing program for Parkinson's patients. Members of our group also want to form a speakers panel to visit clinicians throughout the city and educate them about the various forms of dystonia. Another goal is to develop our website so that it can become an educational resource.

Being diagnosed with a movement disorder is like having the rug pulled out from under you. On one hand, it is a relief to find out what causes the pain, tremors, and twisting and it is a blessing to find medical help to treat it. On the other hand, the diagnosis feels like a heavy burden, because there is no going back to our existence before dystonia.

Connecting with others who experience the same problems is like having a weight lifted from our shoulders. Those connections enable us to share in our successes and support each other in our defeats, as reflected in these quotes from members:

“I have learned many ways in which to deal with the varying manifestations of the illness and its pain.”

“I am able to help others with

similar conditions.”

“I am not the only one dealing with dystonia, and there are people I can go to if my condition worsens.”

“[This group] has helped me understand what is going on in my body and is the main reason I am doing as well as I am today.”

“This support group has led me to doctors and therapies that have benefited me.”

“I have gained warmth and support from wonderful people.”

Our little group has now grown to more than 100 people with dystonia of all forms. Many members are not active participants, but they regularly mention how much they appreciate receiving the information that is sent out.

For others, just being connected and knowing the group exists is enough. Upon occasion I run into people who have not been active for a while, and I am delighted if I discover it is because they are doing so well. Much of that success is due to great medical care by movement disorder specialists, exceptional therapists, and experienced physicians. Equally important is the human spirit, with its determination to live life to its fullest.

As a support group leader, I can tell you that my participation in the group has helped me immensely in coping with dystonia. I was deeply saddened to lose my co-leader Mary Jane to a stroke. But it only inspired me to work harder in an ongoing effort to help educate others about this disorder.

In spite of the personal limitations of dystonia, I am always seeking ways to overcome them because—well, I prefer to explore beyond limitations.

The medical and therapeutic communities have been fabulous in sharing their time, knowledge, and facilities. And our dystonia support group has given all of us a glimpse into a different form of healing—one of the heart—in the midst of a movement disorder.

Day's sessions offer abundant information, inspiration

By Alecha Newbern

This year's HOPE Conference on Parkinson's brought together nearly 700 patients and family members from 10 states and featured a number of local and national experts on living well with Parkinson's disease.

Speakers at the Nov. 7 conference included J. William Langston, M.D., of the Parkinson's Institute in Sunnyvale, CA. Langston gave a keynote address that captured the excitement within the Parkinson's research community about the many potential new treatment paths being explored.

Other speakers included Laurie Mischley, N.D., a naturopathic doctor specializing in neurological conditions; Stephen Setter, PharmD, of the School of Pharmacology at Washington State University; Susie Ro, M.D., of the Swedish Neurosciences Institute, who addressed the complex topic of sleep problems; and Robert Wu, M.D., a retired anesthesiologist and pain special-



J. William Langston, M.D., founder and CEO of the Parkinson's Institute in Sunnyvale, CA, was the keynote speaker at the 2009 HOPE Conference on Parkinson's on Nov. 7 in Seattle.

Langston detailed his career in research, from his groundbreaking work with "frozen addicts" in the early '80s to the exciting work he and others are involved with today toward strategies to slow or halt the progression of Parkinson's.

for his positive contributions to the Parkinson's community.

Chief among these are his inspiring book, *H.O.P.E.: Four Keys to a Better Quality of Life for Parkinson's People*, which he published with the foundation in 2002, and his idea for a skyrocket event to unite the Parkinson's community, which grew into the first HOPE Conference on Parkinson's in 2006.

Now in its fourth year, the conference has grown into the largest gathering of its kind in the Northwest, illustrating the profound and positive impact that Newsom has made in the

ist, who shared an inspiring story of his own journey with Parkinson's.

During the event, Hal Newsom, a Parkinson's patient, author and founding board member of the Northwest Parkinson's Foundation, was honored

lives of patients and families.

In addition, the Northwest Parkinson's Foundation announced the launch of its new online Wellness Center, a virtual community focused on hope, healing, and wellness for all who



Monique Giroux, M.D., right, medical director of both the Northwest Parkinson's Foundation and Booth Gardner Parkinson's Care Center, chats with patient and advocate Carey Christensen at the 2009 HOPE Conference on Parkinson's.

are touched by Parkinson's.

Patients, families and caregivers can register through the foundation's website (nwpf.org) to become active members and gain access to information, therapies, and professionals.

Members can also set and track their personal development, exercise, or nutrition goals as part of an individual wellness prescription.

The center is being developed by Monique Giroux, M.D., medical director of the Northwest Parkinson's Foundation and the Booth Gardner Parkinson's Care Center. Information, tips, and ideas will be posted to the online Wellness Center soon.

Missed the HOPE Conference? Check out the talks online at nwpf.org/Events/Presentations.aspx.

Tackle FoG by tweaking drugs, trying therapies

By Susie Ro, M.D.

Freezing of gait—FoG for short—is one of the most common gait-related problems experienced by people with Parkinson's, possibly affecting more than 70 percent of patients.

FoG is a sudden break in voluntary motor activity that interrupts a movement or a switch from one movement to another. It may manifest in a variety of ways, but most often people complain their feet are “glued to the floor.” The feet may shuffle in place so much that a person comes to a complete halt, is unable to turn, or falls.

Some people experience trouble taking a first step (gait-ignition hesitation) or getting out of a chair as forms of this “motor block,” though FoG is generally considered distinct from other Parkinson's symptoms, such as bradykinesia (slowness) or rigidity (stiffness).

FoG can result in loss of independence, anxiety, and social isolation since people can begin to fear situations that commonly trigger freezing—tight or crowded spaces, doorways, elevators, or stressful or rushed encounters.

Sometimes FoG can be treated with medications. Often minor changes—a slight increase in drug dose, taking pills first thing in the morning before getting up, or dosing more frequently and on time—can prevent medication from wearing off unpre-



dictably. Wearing off can be minimized with injections of apomorphine, a quick and short-acting dopamine drug that can serve as “rescue” therapy. Deep brain stimulation (DBS) surgery may also be an option for some people with severe motor fluctuations.

Unfortunately, many people continue to experience frequent or unpredictable episodes of freezing even while their medications are controlling other symptoms like stiffness, slowness, and tremor. This phenomenon is known as ON-time freezing. When freezing occurs in the *on* state, drugs and surgery cannot prevent it. What else can be done?

Just as certain stimuli can trigger freezing, others can help people overcome it. In the film “Awakenings,” based on the book by neurologist Oliver Sacks, Robert DeNiro plays a man who is severely immobile due to post-encephalitic parkinsonism (a Parkinson's-like syndrome occurring after a viral brain infection). The film shows another patient who is initially unable to cross from an area with plain tile flooring onto another with checkered tile. Yet if someone throws a ball at this patient, he reacts quickly by reaching up to catch it.

This scene illustrates the idea that reacting to cues involves a different brain pathway from generating spontaneous, automatic movements internally, which is more difficult for patients with Parkinson's disease.

Many patients discover on their own that using external or internal cues can help them overcome freezing. One ingenious example is a man who engineered an extension to his cane so that every time he placed it on the ground, a fold-out stick would land on the ground in front of him, cueing him

to step over it. Another is the U-step laser cane, which projects a red laser beam on the ground when the cane is pressed down.

These examples demonstrate that a patient with freezing may not be able to take a large step spontaneously but will be able to move forward if he sees a line on the ground and tells himself to “step over the line.” The idea is that visual cues shift patients' attention to an alternative, more conscious motor-control pathway to regulate their gait.

Auditory, tactile, and even cognitive cues can also be helpful strategies in overcoming FoG. Rhythmic cues such as listening to music or a metronome can help. One patient was able to maneuver in her tight kitchen by listening to rhythmic music and synchronizing her movements to the music if she got stuck.

Another patient kept a small ball in his pocket. When he needed to get out of a chair or interrupt frozen walking,

Got an idea for overcoming FoG? Pop it in our Tip Jar at nwpf.org/Submissions/default.aspx.

he would bounce the ball a couple of times to get unstuck.

These sorts of tricks, often discovered by patients themselves, are potentially endless.

Some 40 percent of patients report that paying attention to every step helps. This is thought to be one reason people generally do better climbing stairs than walking on a flat surface. When patients tell themselves to take longer steps, alter how they shift weight, stamp their feet, or count silently, they are able to overcome FoG.

Sometimes rehearsing a sequence of movements sub-vocally by chanting

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Gifts to the Northwest
Parkinson's Foundation support educational resources including our website, email updates, caregiver booklet, newsletter, patient-education programs, and conference. Gifts also fuel outreach and advocacy 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.

We list tribute contributors in each *Parkinson's Post*. All donors are recognized in our annual *Report to Contributors*. 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@nwpf.org to learn more. Listed here are those who made tribute gifts from **August 16 to October 14, 2009.**

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Foundation welcomes its first medical director

The Northwest Parkinson's Foundation is proud to announce its first medical director.



Monique Giroux, M.D., will work alongside staff to create and implement programs, educational materials, and self-care strategies for patients, caregivers, and the professional community.

Giroux is medical director of the Booth Gardner Parkinson's Care Center in Kirkland, WA, and a national thought

leader in improving wellness and multidisciplinary care.

"Having watched Dr. Giroux do her highly specialized work over the past decade, we are thrilled to have her expertise added to our mission," said Bill Bell, Northwest Parkinson's Foundation executive director.

Giroux received her medical degree from the Ohio State University and completed residency in internal medicine and neurology at Yale. She received fellowship training in movement disorders at Emory University and is board certified in internal medicine and neurology.

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Dear friends of the Parkinson's community,

Throughout the year, the Northwest Parkinson's Foundation strives to keep you abreast of all the many ways to live well with Parkinson's disease. While much of the information we provide focuses on the patient, we also recognize the vital role caregivers play in the health and well being of people with Parkinson's.

Being a caregiver is a challenging and rewarding journey. It is a careful balancing act between the needs of the caregiver and the needs of that person's loved one and requires its own special network of support and inspiration.

In 2003 we created ParkinsonsEducator.org, a free online training program for professional and in-home caregivers. Over the last six years, changes in technology and advances in treatment and care have made the program obsolete. Our goal is to upgrade the program and re-launch it in 2010 so that we can continue to educate and inform caregivers, especially those who are new to the world of Parkinson's, about ways they can help people with Parkinson's while taking care of themselves.

We hope you will consider making a gift of \$10, \$25, \$50, or your most generous contribution to support this important program. It can make all the difference to those who are just starting their journey as caregivers and help thousands of patients get the care and treatment they need to live well.

It is also a unique opportunity to honor the caregiver who has supported you and your loved ones throughout the year. Your gift will be a meaningful tribute to the Parkinson's partner in your life and an inspiration to all the unsung heroes in our community.

With your help, we can continue to support all who are touched by Parkinson's, including the caregivers and families who offer so much help and hope. Thank you for considering a year-end gift to the Northwest Parkinson's Foundation, and happy holidays to you and yours.

Warm regards,

Bill Bell
Executive Director





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mnemonic phrases, such as “move to the edge of the chair, put hands on chair arms, place feet flat on floor underneath you, nose over toes, head up, stand tall,” can help.

Physical therapy is integral in helping patients deal with FoG. In addition to analyzing freezing triggers, therapists can work with patients to find cognitive or sensory cues to help them overcome freezing. This practice involves both formulating strategies to help transform movements from automatic to voluntary control and exercises to “seal in” the “retraining” of the brain.

Lastly, cognitive-behavioral therapy can be helpful for patients whose freezing is triggered by emotional stimuli, such as panic attacks or agoraphobia (fear of being trapped in a public space), even if these anxiety symptoms were initially triggered by the freezing itself.

FoG is a common symptom of Parkinson's. Ask your doctor to explore some of the treatment options with you.