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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.

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

Activist discovers gift of Parkinson's

It is tragic that something has to go wrong before we can realize the gift of the world and our lives.—John O'Donohue, Beauty

By Carey Christensen

Parkinson's disease is the best thing that ever happened to me. Sounds improbable, silly, downright ridiculous.

Imagine the conversation: "Did I tell you the news? You know that promotion I was up for? Well, hold on to your hat—I got Parkinson's instead! Can you believe it?! What a relief!"

But I mean it—my diagnosis has been a good thing. Parkinson's has sent me on an incredible journey of cascading events that stripped me of my identity, leaving me with infinite new possibilities, an authentic voice, a clear purpose, and the will to make a difference.

My diagnosis in 1999 led to divorce, job loss and displacement. There was a point where I lost all connection to community; it was the loneliest, scariest place I had ever been.

Until you don't have it, you take belonging for granted. The fundamental needs and rights of life are usually listed as food, water, shelter and health. I'll argue that community—the necessity to belong—be added to the list. Without community, I was discordant and quietly disintegrating.

I learned from searching the Internet that *belonging* is a familiar and important theme to writers, philosophers, theologians and poets. One person in particular, John



The author poses outside the U.S. Capitol during the 2003 Parkinson's Action Network Forum.

O'Donohue, encompasses all four disciplines. A former Catholic priest with a Ph.D. in philosophy, John resides in the Celtic embrace of west Ireland, where he writes poetry and pens bestsellers.

With the help of his words, I have been able to defeat the losses, turn them into triumphs, and navigate the world of Parkinson's advocacy. John confirmed my despair and validated my belief that belonging is as essential as breathing.

In his book, *Eternal Echoes: Celtic Reflections on Our Yearning to Belong*, he writes, "The hunger to belong is at the heart of our nature... When suffering comes into your life, it brings great

Continued on Page 3

Overcoming social anxiety with Parkinson's

By Karen Olson, M.A.
and Jeffrey Shaw, Psy.D.

Social situations can be anxiety-producing for anyone but especially so for people with Parkinson's. In fact, research suggests anxiety may occur in up to 40 percent of patients with Parkinson's.

Social anxiety—also referred to as *social phobia*—is characterized by fear of embarrassment, of being judged negatively, or of appearing incompetent to others.

Some develop anxiety because they believe they will lose control of their emotions in a social setting. They might sense wariness, fearfulness and timidity in these situations, and the result can be diminished self-esteem and feelings of inferiority.

Many of our patients at the Booth Gardner Parkinson's Care Center did not have these concerns prior to Parkinson's. But they now report feeling limited in their lives by what they understand are irrational fears.

Why is it common for Parkinson's patients to have feelings of discomfort in social situations? Fatigue makes it difficult to visit with family and friends for long periods of time, and involuntary body movements make it difficult to sit still. Rapid switches between "on" and "off" states can be difficult for others to understand.

In addition, some Parkinson's people are afraid of what others will read into their appearance. There are patients who avoid leaving the house for fear of embarrassing themselves in public or being judged incapable. Many of our patients have shared a concern that others will jump to negative conclusions—for example, mistaking symptoms as drunkenness.

Because of social discomfort and anxiety, individuals with Parkinson's may argue that they feel more comfortable spending time at home. In fact, avoidance is a common reaction to anxiety-provoking situations.

Unfortunately, avoidance just makes the worries and fears more pronounced.

Research supports the idea that individuals with Parkinson's who practice avoidance experience *increases* in fear and *decreases* in social interaction, which can lead to heightened depression and negative self-evaluation.

Indeed, a lack of social activity can lead to feelings of isolation, loneliness, hopelessness and dissatisfaction with life.

Research has shown that, in comparison with regular social interaction, social isolation is associated with more severe emotional distress and a reduced ability to think.

This is the second installment in a three-part series addressing how anxiety affects Parkinson's patients. Although anxiety is necessary for human survival, it is often destructive, causes unnecessary suffering, and can increase the severity of Parkinson's symptoms.

If you feel that social anxiety is limiting you, there are things you can do:

- ◆ Work to maintain your social contacts.
- ◆ Teach family and friends about

Parkinson's so they can better understand what you're going through.

- ◆ If you are having visible symptoms that confuse people or provoke their curiosity, it may be helpful to let them know what's going on. "My Parkinson's disease always seems to act up when I'm out in public" is one simple explanation you might offer.

- ◆ When you're worried about what others think of you, ask yourself "So what?"

- ◆ Remember that most people are

compassionate and that many have a loved one who is also struggling with Parkinson's.

- ◆ Remember that other people are imperfect and are also concerned about having their imperfections noticed.

- ◆ Do not give too much weight to a few negative experiences. Account for the proportion of good and neutral things that happen when you are out and about. Do not let the impatience and rudeness of a few cloud your outlook.

- ◆ The "use it or lose it" rule really does apply. If you practice staying home and avoid going out, you will perfect the skill of staying home and not going out. You must practice social interactions—communicating, walking, shopping, and so on—to keep your proficiency.

- ◆ Look for a support group for Parkinson's people in your area. One source of support group listings is the Northwest Parkinson's Foundation website, www.hopeforparkinsons.org. Or for help finding a group near you, call the Foundation at **1.877.980.7500**.

- ◆ Consider counseling, which can provide coping strategies, support and educational services.

- ◆ If you experience significant social anxiety, talk to your doctor or counselor about these symptoms.

In conclusion, social anxiety can lead to patterns of avoidance and isolation, which are associated with declines in physical, cognitive and emotional functioning. Avoidance and isolation also feed back into feelings of depression and anxiety.

But by seeking the support of friends, family and professionals, most cases of social anxiety can be overcome. The results are more productive coping strategies and a more optimistic outlook on life.

Karen Olson is a doctoral student at Seattle Pacific University and a practicum student at the Booth Gardner Parkinson's Care Center in Kirkland, WA, where Jeff Shaw is a neuropsychologist.

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loneliness and isolation. Your life becomes haunted, your belonging breaks.”

Although at first impossible for me to comprehend, over time his words of possibility began to make sense. “It is through difficulty and opposition that we define ourselves,” he states, and in words imbued with the beauty of my home in the Pacific Northwest, “Through the fog of forsakenness, a new shoreline of belonging becomes clear.”

Slowly, I learned to be true to myself, to claim and define my own identity—not only for my own sanity but for the power it gives me. On the shore of my new identity I found the label “Parkinson’s patient” had become my greatest burden, my greatest power, and the source of my greatest comfort.

From burden to power

To many people the only thing I am is a person with Parkinson’s disease—and virtually all the important decisions about my life with Parkinson’s are made by those who view me this way. They establish the research agenda. They determine what information I receive.

Fortunately, being reduced to simply a disease also gives me power. Because it has taken everything, I have nothing to lose. *It is absolutely liberating.*

I was told recently by a national figure in the Parkinson’s world that “Patients make scientists uncomfortable.” Apparently a dead dopamine cell under a microscope is easier to deal with than a stooped patient standing before you.

I can, do, and in fact make it my business to ask the uncomfortable questions. The amazing thing is that people are beginning to listen. Maybe it’s because they know they have been wrong to exclude—but it was easy to exclude until someone, *many* someones, spoke up. Some examples:

◆ Patient pressure has caused research scientists to pay attention to our concerns about being excluded from the arenas of decision making,

The December 2005 issue of the medical journal, *The Lancet Neurology*, includes an editorial supporting patient efforts to create a Bill of Rights for clinical trial participants. *The Lancet* says, “(This) illustrates the urgent need for pharmaceutical companies, clinical researchers, and patients to join forces in modifying medical research... Parkinson’s disease advocacy groups in the USA are setting a remarkable example by working towards a Research Participant’s Bill of Rights that would entitle them to be better informed and make decisions according to their own appraisal.”

◆ Depression effects up to 80 percent of Parkinson’s patients but is rarely mentioned by doctors because they think telling us would depress us. Concerns expressed by patients and caregivers are one reason the non-motor symptoms of Parkinson’s are finally getting the attention they deserve.

◆ In a progressive and appreciated move, patients are included as part of the planning and program of the upcoming World Parkinson’s Congress, bringing their unique perspective and expertise to the table along with scientists, clinicians and other Parkinson’s professionals.

The greatest comfort

The third component of my identity as a “Parkinson’s patient” is that it is the source of my greatest comfort—it has given me a place to belong, a place of new and previously unknown creativity.

“The most intimate community is the community of understanding,” O’Donohue writes. “Where you are understood, you are at home.”

That is how I feel when I am with other Parkinson’s patients who are my



The author with her daughter, Elizabeth Abrahamson.

comrades in advocacy, my “Tribe”—utterly and completely and miraculously understood. It is a comfort wrought from shared experience.

Parkinson’s has been and continues to be an experience of great loss, turbulence and disability. This disease wreaks havoc with my body and my

finances, while I keep depression at bay with medication and counseling. But it also has become an experience of new friends, opportunity, purpose, inner strength and spirituality.

If you are in the depths of despair, the very thought of ever again being in a place of light seems absurd. Inspiration is elusive and singular.

You might find it in the tenets of religion, the verse of a song, a conversation with a stranger, your relationship with a friend, the embrace of your family, or the beauty of nature.

I was inspired and protected by the words of one author, the power of advocacy, the comfort of community, and unfaltering love for my daughter.

It was not easy, but eventually I came to understand that the burden of Parkinson’s is the best thing that ever happened to me.

Be patient with yourself, treat yourself kindly, and you might be surprised.

Carey Christensen was diagnosed with Parkinson’s in 1999 at age 41. She is Washington State Coordinator for the Parkinson’s Action Network and created the website www.cognition.org that focuses on mental health aspects of Parkinson’s disease. She lives in Stanwood, WA, with her teenage daughter, Elizabeth, Harvey the cat, and the wonder dog, Truly.

Benefits of regular exercise not just physical

By Karen Olson, M.A. and Martha Glisky, Ph.D.

Most people know that keeping physically fit is important for general health. We know there are many *physical* benefits of exercise, including increased strength and stamina and reduced risk of heart disease and other health problems, such as obesity, diabetes and some cancers.

But did you know there are also mental benefits from regular physical exercise? Research has brought to light both the cognitive and emotional benefits of exercise.

As individuals age, they tend to decrease their level of physical activity. In addition, a Parkinson's diagnosis can result in a further decrease in activity for a variety of understandable reasons. These include the basic challenges of keeping physically active when experiencing difficulties with motor function and balance, general lifestyle changes such as retirement, concern that sporting activities might worsen your condition, or simply decreased motivation or desire to engage in physical activities.

Tips for boosting your activity

- ◆ Always check with your doctor or physical therapist before beginning an exercise program.
 - ◆ Choose a time of day when your symptoms are well controlled by your medications, and when you have adequate energy.
 - ◆ Begin exercise regimens gradually and try to work up to the recommended level (usually at least 20 minutes three times a week).
 - ◆ Begin and end a workout with stretching and breathing exercises. This helps warm up your muscles, prevent stiffness, and improve flexibility and balance.
 - ◆ Build on your walking skills, even if you need to hold on to someone or something.
 - ◆ Try water exercise, which is easy on the joints.
 - ◆ Work at your own pace, even if it seems slow.
- Do not be discouraged if the exercises seem hard at first. Your body should adapt.
- ◆ Good nutrition and good eating habits are essential for providing and maintaining energy.
 - ◆ Do something you enjoy and that you have easy access to. If it's not easy and fun, you are much less likely to adhere to the program.
 - ◆ Try to exercise at least a little, even when you do not feel like it. Often even a small amount of exercise will make you feel better.

Indeed, research confirms there is often an across-the-board decrease in activity following Parkinson's diagnosis.

Research documenting the physical benefits of exercise has been well established for the general population, as well as more recently for older individuals and those with various medical conditions.

In Parkinson's specifically, a good exercise plan has been shown to help the body cope better with the disease by increasing walking ability, maintaining flexibility and good posture, keeping muscles strong and joints supple, and improving circulation.

In addition, exercise has been shown to help individuals with Parkinson's deal with day-to-day stress and give them a sense of accomplishment and control over their condition.

These benefits can be seen for individuals in all stages of Parkinson's, and Parkinson's patients who exercise regularly have lower rates of mortality than those who do not.

Research examining the mental benefits of exercise is much more recent and less well understood. However, there is a strong suggestion of numerous cognitive and emotional benefits of physical exercise, both in the general population as well as in older adults and those with neurological illnesses such as Parkinson's.

Normal aging and Parkinson's have been shown to decrease overall thinking speed. This slowing can affect a variety of cognitive functions such as memory, attention and problem solving. Regular aerobic exercise has been shown to help speed up these processes and improve performance on related tasks.

In addition, numerous studies have demonstrated increases to overall mood, sense of well being and quality of life, as well as decreased depression in individuals who engage in regular exercise.

Research shows that, although there may be cognitive and emotional benefits from all types of exercise, engaging in aerobic exercise seems to provide the most notable benefit. Aerobic exercise is any type of activity that increases your heart rate and gets your blood pumping.

The key to increasing your level of exercise is finding an exercise program you enjoy and will do on a regular basis, so that you maintain a consistent regimen. Before starting or changing an exercise regimen, it is important to consult your doctor or physical therapist to ensure you engage in a program that will suit you and accommodate any limitations you may have.

Exercise can include activities you may already engage in regularly such as walking, gardening and housekeep-

Continued next page

Yoga boosts mental health, complements fitness program

By **Lori Newell, M.A., C.P.T., R.Y.T.**

Living with Parkinson's presents a multitude of symptoms and can turn everyday tasks into real challenges. A priority for most is the ability to remain independent at home and to be able to perform the activities of daily living.

Some symptoms of Parkinson's—namely tremor, stiffness, slow movement and balance problems—can make it more difficult to do such things as get dressed, get in and out of the car, stand up from a chair, and walk.

Combining a traditional exercise program with yoga is a comprehensive approach to addressing the various needs of people with Parkinson's.

Yoga teaches participants "mindful movement" to help increase awareness of changes and sensations in the body. Taking this knowledge and applying it while moving can help participants perform their exercises and daily activities with more consciousness. This mindfulness can reduce the risk of falls or injuries as participants begin to think about their movements with a calmer mind and make safer choices.

For example, to address difficulty getting in and out of a chair, a traditional exercise program might include several repetitions of squats—standing in front of a chair and slowly bending at the knees and reaching the hips back until lightly coming into contact with the chair, and then coming back to standing. This will help build strength in the upper leg muscles—the ones required to lift and lower with control.

However, if inactivity has weakened these muscles, people often crash down into the chair with little control.

So while it is important to strengthen the muscles with exercises such as squats, performing a static yoga posture such as the chair pose can help. The chair pose is the same as a squat except that you hold the downward position for several breaths, versus coming up and down repeatedly. Holding this posture combined with calm breathing will help to build control.

Yoga also emphasizes deep diaphragmatic breathing. Different from the fast, shallow breathing of aerobic exercise, this breathing strengthens the lungs and diaphragm and helps with voice projection.

Lastly a complete yoga practice includes instruction in basic relaxation techniques that help people manage stress—and managing stress is an important component in managing symptoms of many conditions, including Parkinson's.

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: Using Movement and Meditation to Manage Symptoms. The book is available through the Sacred Space Health Center Inc. / P.O. Box 99 / Harwichport, MA 02646 / 508.367.6311 / www.sacredspacehealthcenter.com. Mention the Northwest Parkinson's Foundation when placing your order and a portion of your purchase will be donated to this organization.

Continued from previous page

ing. In addition, specific exercise classes or programs including swimming, stationary cycling or tai chi can provide additional opportunities for cardiovascular fitness.

The most important thing is to find a type of exercise you will continue to do regularly. Some people find exercise classes helpful, including dance or movement therapy, and exercising with a group can provide an ideal opportunity to socialize.

It's never too late to begin an exercise program. Even people who have been sedentary most of their lives show improvements as soon as four months after starting to exercise regularly.

The physical benefits of aerobic exercise are clear. However, the equally important cognitive and emotional benefits are still being explored. The most common theories suggest that exercise increases blood supply to the brain and boosts the levels of several important neurochemicals. These increases can in turn increase survival of brain cells (neurons), contribute to the development of new neurons, and increase the number and

plasticity of brain synapses, resulting in a more efficient, adaptive brain.

Dopamine, a vital chemical diminished with Parkinson's and associated with movement problems as well as symptoms of depression, may be boosted with exercise. Regular exercise may also increase the brain's ability to develop new ways of communication to compensate for neuronal changes. It may additionally protect the brain from damage by increasing its resistance to injury and environmental stressors.

So find a physical activity you enjoy then check with your doctor or physical therapist about beginning your program. Then start reaping the physical, intellectual and emotional benefits regular exercise can bring!

Karen Olson is a doctoral student at Seattle Pacific University and a practicum student at the Booth Gardner Parkinson's Care Center in Kirkland, WA. Martha Glisley is a neuropsychologist at the Center.

Dear Friends,

The Northwest Parkinson's Foundation would not exist without the support of a great many generous people whose donations sustain our work.

If you haven't already done so, I hope *you'll* include the Northwest Parkinson's Foundation in your year-end giving. Over the past two years, we've watched our constituency **double**. We're now providing services to 15,000 Parkinson's families a year.

This growth makes your support more important than ever.

By giving, you'll help us reach out to those in need, and you'll be supplying each new family with:

◆ Educational resources that empower patients to help themselves—including our book *H.O.P.E.* and this bimonthly newsletter.

◆ Tools developed with caregivers in mind—such as our online Parkinson's Educator curriculum and our new publication, *Who Cares for the Caregiver?*

◆ Our toll-free resource line that connects callers to personalized guidance and support.

If Parkinson's has touched you or someone you care for, please consider supporting our work through a gift today. Thank you so much!

All my best to you and yours,



Bill Bell, Executive Director

P.S. You'll find an envelope inside this issue for convenience in making your tax-deductible donation. Gifts must be received or postmarked by Dec. 31 to qualify for a 2005 tax deduction—so please don't delay!

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Booklet advises, comforts caregivers

A new booklet offers sound advice and gentle support for those who care for a loved one with Parkinson's. Beneficial reading for patients and caregivers alike, *Who Cares for the Caregiver?* is available free to Parkinson's families.

The booklet, written by Hal Newsom, author of *H.O.P.E.—Four Keys to a Better Quality of Life for Parkinson's People*, stems from Newsom's life with Parkinson's and from his many conversations with caregivers, including his own primary caregiver—his wife, Peggy.

Call 1.877.980.7500 or email info@nwpf.org to receive a copy of the caregiver booklet or of *H.O.P.E.*

Changes to Medicare drug benefit focus of next telehealth session

Linda Garrelts-MacLean, R.Ph., C.D.E., will give an overview of changes and opportunities surrounding the new Medicare rules for prescription drugs at 2 p.m. P.S.T. on January 16, 2006. Her talk will be broadcast in several Northwest communities over the Parkinson's Telehealth Network. To find out if your community has a connected telehealth site, visit our website at www.nwpf.org/telemedicine.asp or call us at 1.877.980.7500.

Online curriculum instructs in care for Parkinson's people

New to Parkinson's? Or simply looking to learn more? An online curriculum, the Parkinson's Educator, can help.

Developed for paraprofessional caregivers, the



Photo by Craig Howard

Len Gratteri, far left, draws the winner in the raffle of a Harley Davidson motorcycle he donated to the Northwest Parkinson's Foundation. The drawing took place November 23, and Kory Bair of Bothell, WA, won with the purchase of a single ticket, #487. Pictured with Len, from left, are Foundation staff members Joanna Glickler and Elizabeth Pelham; Len's wife, RuthAnn Gratteri; Brock Radloff, owner of Classic Ironworks in Redmond, WA, where the raffle was promoted; and Kerry Hovenkotter and her husband Marty, Foundation volunteer and ticket seller extraordinaire. We extend our sincere gratitude to the Gratteris, Hovenkotters and Radloffs, as well as to all who participated in this raffle, which raised \$20,000 in support of our programs and services.

Parkinson's Educator is also beneficial for family caregivers or anyone looking to better understand Parkinson's disease.

The curriculum, which highlights "best practices" in caring for Parkinson's people, was written and reviewed by a team of Parkinson's specialists. The curriculum can be explored at www.parkinsonseducator.org.

There is no charge to complete the modules.

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Boost mileage of old car with donation

Thinking of selling or trading your old car, boat, motorcycle, trailer or RV?

Why not donate it to the Northwest Parkinson's Foundation instead? It's easy, it's tax-deductible, and your donation will help us achieve our mission—quality of life for the Parkinson's community.

We can accept donations of vehicles located in Western Washington. Get the process rolling by calling us toll-free at 1.877.980.7500. If your vehicle can be accepted for donation, a qualified company will pick it up and complete all the necessary paperwork. You'll receive a receipt certifying that you donated the vehicle. This letter shows the IRS that you are authorized for a charitable deduction.

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**BOOTH GARDNER PARKINSON'S
CARE CENTER** | 12039 NE 128th St.
Kirkland, WA 98034 | **425.899.3123**

The Booth Gardner Parkinson's Care Center is a regional center of excellence in the treatment of Parkinson's patients.

Board welcomes new member, Lyman Hull

The Northwest Parkinson's Foundation welcomes Lyman Hull to its board of directors. A retired attorney, Hull was a founding member of the Seattle firm Porter, Kohli & LeMaster. He and his wife, Gretchen, live in Seattle.