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A B O U T U S

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!



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The author, flanked by sons Bennett (left) and Alex and their dog Sophie, has no trouble smiling at home after deep-brain stimulation surgery in February 2006. Photo courtesy of Jackie Hunt Christensen

Losing face

Getting out from behind the 'brick wall' of Parkinson's

By Jackie Hunt Christensen

We've all heard the expression, "Talking to you is like talking to a brick wall." Of course, what the speaker really means is, "You're not responding to me the way that I expect you to respond." It is usually uttered in frustration and ends with the accuser storming off.

People with Parkinson's disease often give the "brick wall" impression. In fact, nearly all Parkinson's patients will experience the symptoms. Our facial muscles become rigid and we lose many expressions—particularly the subtle ones that may have meaning to close family members.

On top of the loss of facial expression with Parkinson's, tightening of the

throat and vocal cords can make our voices sound flat and expressionless. Sometimes it's hard to enunciate, and we sound like we're talking with a mouthful of marbles. Often it's hard to project our voices, and we can't be heard. This can be very frustrating for family and friends, especially care partners.

One of the many tragedies of Parkinson's is that as the disease builds more and more of the brick wall, the more we, the patients, are crumbling behind it.

When I was first diagnosed with Parkinson's in 1998 at age 34, I was still coming to terms with the disease. I didn't have tremors, I didn't fall. I had not yet learned that Parkinson's affects more than just our limbs. Indeed, it affects the whole body and the mind as well. So I was blissfully unaware my face had become like a mask. My jaw was clenched all the time, regardless of my mood.

When I get angry, I tend to set my jaw and not say anything. (I realize this is

Continued on Page 4

Book geared to helping caregivers navigate Parkinson's



Parkinson's disease can have a major impact on quality of life, especially in its advanced state. Understanding what difficulties will be faced and being prepared to deal with them can make a world of difference.

The Comfort of Home™ for Parkinson Disease: A Guide for Caregivers, by award-winning author Maria M. Meyer and co-author Susan C. Imke, RN, MS, a Parkinson's authority, is the fourth title in the caregiving series *The Comfort of Home™*.

The book is designed to help caregivers, family members and people with Parkinson's better understand the day-to-day issues caregivers face and to guide readers through each caregiving stage.

Topics include preparing the home, purchasing equipment and assistive devices, traveling safely, helping with daily living activities, ensuring proper nutrition with special dietary guidelines for people with Parkinson's, exercising for increased flexibility, and strategizing to avoid caregiver burnout.

To order *The Comfort of Home™ for Parkinson Disease: A Guide for Caregivers* or other books on Parkinson's disease, visit www.nwfp.org/books.asp.

Practice breathing deeply for deeper health benefits

By Laurel Beck, MS, PT, NCS

What is it that we do thousands of times a day but rarely think about?

Breathe!

Breathing is essential for getting oxygen to our tissues, including the brain. However, an effective breathing pattern can positively impact our health in other ways.

In order to understand the importance of breathing, let's first consider some of the ways Parkinson's can limit the body. Rigidity can lead to thoracic kyphosis (forward-bent position of the spine), which causes weakness in the back muscles, soft tissue adaptation, restricted joint motion in the spine and rib cage, and hypoventilation (reduced breathing).

Pneumonia is more likely to develop and take hold in those with hypoventilation. The good news is there is a lot you can do to prevent it from happening to you—primarily by breathing well.

Deep-breathing techniques have been practiced through the centuries. Possibly the most familiar practices to us are yoga and meditation. Regardless of which approach you use, deep breathing can help by increasing oxygen levels, improving posture, strengthening muscles, stretching tight tissues, and allowing for rib expansion to “massage” the joints.

Deep breathing can also help with sleep, mood, stress management, energy level, ability to focus attention, and overall relaxation.

There are many approaches to deep breathing, and it is helpful to find the technique that suits you best. The following describes one type of breathing practice:

- Choose a quiet and calming environment.
- Lie or sit comfortably, with head and limbs supported.
- Close your eyes if it helps you relax and focus.
- Become aware of your breath; is it shallow or does it require effort?
- Slowly and effortlessly exhale fully. As you exhale, feel the stress and tension leave your body.
- Then allow the air to come back into the lungs. Inhale fully, again slowly and effortlessly.
- Repeat this process for as long as you wish.

If you take it slowly, you should not feel lightheaded or dizzy. You might

Deep breathing can help with sleep, mood, stress management, energy level, ability to focus, and relaxation.

start with three breathing cycles but work up to repeating the cycle for five to 10 minutes at a time.

Many feel best inhaling through the nose and exhaling through the mouth. The important thing is to be gentle with yourself, and to avoid forcing anything.

Do consult your health care professional if you run into difficulties with this exercise.

As your skills advance, you will be able to incorporate other techniques such as guided imagery or a hold-relax pattern to address specific areas of tightness or soreness.

Good luck, and breathe well.

Laurel Beck is a neurological clinical specialist in physical therapy with the Neuroscience Institute of Virginia Mason Medical Center in Seattle.



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.

Charting Your Course for Parkinson's Disease |

Valley River Inn, Eugene, OR | Dinner with Dr. David Heydrick on Saturday, April 14 (6:30 p.m.) | Educational conference on Sunday, April 15 (9 a.m. to 4:30 p.m.) | Details: Visit www.parkinsonsresources.org or call 1.800.426.6806.

Let's Bowl Over Parkinson's | Sunday, April 15 | 9:00 a.m. start | A bowling event to benefit the Northwest Parkinson's Foundation and the Everett (WA) Parkinson's Support Group | Brunswick Majestic Lanes, 1300 164th St. SW, Lynnwood, WA | Deadline for T-shirt orders is April 8 | Details: Call D. J. or Shirley Bennett at 425.259.5979.

Soaring to New Heights: Understanding the Impact of Parkinson's Disease on our Community Wednesday, April 18 | 4 to 8 p.m. | Center for Health & Healing, Oregon Health and Science University, Portland, OR | Details: Call 503.494.0276.

Annual Dinner & Auction | American Parkinson Disease Association, Washington Chapter | April 21 | St. Demetrios Church Hall, Seattle, WA | Cost: tables of eight, \$475; single tickets, \$65 | Details: Email developmentdirectorapda@gmail.com or call 425.443.8269.

Parkinson's Communication Group | 1 to 2:30 p.m. the first Wednesday of each month | Booth Gardner Parkinson's Care Center, Kirkland, WA | Monthly program for Parkinson's patients to practice speech volume in a relaxed, welcoming environment with other movement-disorder patients | Facilitated by speech pathologist Shirley Glazer, MS, CCC | \$5 per session; coffee and cookies provided | To register or learn more, call 425.899.3000.

Neurological Exercise Group | Booth Gardner Parkinson's Care Center, Kirkland, WA | Gentle stretch

and strength exercises for patients with Parkinson's and other neurological disorders such as multiple sclerosis and stroke | \$20 per four-week session | Call 425.899.3000 for time and date information.

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

Women with Parkinson's Disease | 1 p.m. the first Thursday of each month | Spokane, WA (location varies) | A support group to discuss the particular issues of women with Parkinson's; group members share information, support and laughter | Call Julie Willis at 509.467.2240 or the Parkinson's Resource Center at 509.473.2490 to learn more.

Team Parkinson's 2007 | We're seeking volunteers to support the team during the Group Health Seattle-to-Portland Bicycle Classic in Spanaway and Centralia, WA, and Lexington and Portland, OR | July 14 and 15 | Details: Call Dav'ne Stahley at 877.980.7500 or davne@nwpf.org.

2007 HOPE for Parkinson's Conference | Presented by the Northwest Parkinson's Foundation and American Parkinson Disease Association, Washington Chapter | Nov. 10 | 9 a.m. to 4 p.m. | Hilton Seattle Airport & Conference Center, Seattle, WA | Details: Call 1.877.980.7500 or email info@nwpf.org.

Got an announcement to share? 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 or email it to davne@nwpf.org.



Jackie, Paul and Bennett Christensen, July 2006. Photo courtesy of Jackie Hunt Christensen

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immature and not constructive. I'm working on it.) So my husband was accustomed to the clenched jaw meaning I was mad or upset with him. It took him *months* after my diagnosis to finally ask me one day, "Are you mad at me for some reason?" Shocked, I said, "No! Why do you ask?" Then he told me that for a long time, my face had been like a mask and I looked mad all the time.

I began to cry, wondering what would have happened to our relationship if he had not summoned the courage to ask if I was angry. I promised to work harder at telling him when I actually *am* angry, and begged him to please always ask me if he was unsure about whether I was pouting or just being a person with Parkinson's.

Sometime around 2001, when I was at a neurology appointment, my doctor asked, "Have people been asking you to repeat things?"

"Yes," I replied indignantly. "What's with that?"

Dr. Tuite explained that my voice was very hard to hear at times, because of muscle rigidity from Parkinson's. My voice seemed plenty loud to me. In

fact, when it felt to me that I was yelling, he said my speech was at a normal volume for conversation. He referred me to a speech therapist.

My speech therapist seemed to be more like a drama coach. She told me to exaggerate my facial expressions, which would make them appear normal to the rest of the world. She encouraged me to read aloud—to my sons, my husband, anyone at all—so that I could practice speaking loud enough and with expression. And she gave me permission to sing along with the radio, a habit of mine that my husband hates.

She explained that Parkinson's affects more than voice volume. It also affects vocal expression or tone. Although comedian Stephen Wright has managed to make a career out of his deadpan monologues, I prefer to be able to convey sarcasm, silliness or sincerity by the tone of my voice.

These losses of expression can have effects we don't even realize. Because of our flat reactions, others may misconstrue our responses as apathetic, angry or aloof. Unless they know us well and are assertive enough to ask, they may decide not to interact with us anymore.

This can have devastating results. Here is one possible scenario: Your adult children travel across the country for a holiday visit. They don't know much about Parkinson's and only see you once or twice a year. You are thrilled to have them home, but you don't want them to worry about you, so you don't talk about anything related to Parkinson's. When it's time for them to leave, you are very sad. But your kids can't see that. You look and sound as if you couldn't care less. Your kids are disappointed and confused. "Gee, Mom didn't seem to care one way or another

that we came home. Why should we bother?" The children stop visiting just when you need them most.

At a leadership retreat I attended in 2001, we were all asked to give impromptu speeches on one of our passions or goals. I chose to talk about Parkinson's and my passion not only to find a cure but to prevent further cases. I happened to mention in my speech the symptoms of facial masking and voice changes in Parkinson's. It's a good thing I did, because the facilitator told me if he hadn't known this, he'd have thought I didn't give a hoot about my topic. And I'd been trying to exaggerate my emotions!

Some relationships may not even have a chance to happen. A couple of years ago, a fellow Parkie said, in essence, that she knew some people who didn't approach me at a conference because I looked aloof, stuck-up. All I could think was, "I don't *mean* to look that way!" She understood, because it had happened to her, too.

I began to wonder how many

'We may not be able to break down the brick wall just yet, but we can definitely make sure people know there's someone on the other side.'

people I had not met because of Parkinson's, and it made me angry. It *still* makes me angry, but I'm trying to channel that anger into educating others about these symptoms of Parkinson's. We may not be able to break down the brick wall just yet, but we can definitely make sure people know there's someone on the other side.

Jackie Hunt Christensen is author of the book, "The First Year—Parkinson's Disease: An Essential Guide for the Newly Diagnosed" (2005, Marlowe). She lives with her husband and two sons in Minneapolis.

Coping with loss of expression, voice

Here are some tips for coping with the loss of facial expression or vocal projection in Parkinson's—for both patient and caregiver.

If you have Parkinson's

- “Think LOUD,” the tagline of Lee Silverman Voice Therapy. It means remembering that if it feels like you're yelling, others should be able to hear you.
- Exaggerate your expressions and speech.
- Sing along with the radio! Join a church choir.
- Read aloud. Children's books, especially Dr. Seuss, often provide tongue-twisters and opportunities to make silly faces.
- Use a speech-enhancing device.

If a loved one has Parkinson's

- If you're unable to hear what is being said, gently remind the person with Parkinson's to “think LOUD.”
- Ask your loved one to describe his or her mood. Does the mood match how he or she looks and sounds?
- Encourage your loved one to sing aloud—despite the quality of singing!
- Ask your loved one to read aloud to you or the kids or grandkids, and to act out the characters and events.

To learn more about Lee

Silverman Voice Treatment, visit www.lsvt.org/main_site.htm. The website has a national list of LSVT-trained speech therapists.



Photo by Bob Stahley

Volunteers and sisters Joy Headland and Laurie Mann (at far right) explain Team Parkinson's to people who stopped to learn more about the Northwest Parkinson's Foundation effort during the Group Health Bike Expo in Seattle in March. Over the course of the two-day event, volunteers talked to hundreds of interested people, and more than 200 signed up to learn more about Team Parkinson's.

Team puts power behind pedaling for Parkinson's

By Dav'ne Stahley

Team Parkinson's members will join thousands of cyclists at the Group Health Seattle-to-Portland Bicycle Classic (STP) and other athletic events in 2007, pedaling, running, swimming, walking and climbing their way to quality of life for Parkinson's families.

Since 2001 more than 400 Team Parkinson's members have raised nearly \$370,000 in support of the programs and services of the Northwest Parkinson's Foundation.

The effort began when Northwest Parkinson's Foundation co-founders Bill Bell and Craig Howard and a group of board members, patients, and family members decided to ride the 2001 STP. Their efforts raised almost \$40,000 that year, and Team Parkinson's was born. The team has since increased its “pedal power,” raising \$100,000 in 2006.

For Team Parkinson's cyclists in the STP, a volunteer support team is on hand at stops along the way. Team members enjoy a phenomenal lunch provided by Cameron Catering, which donates its services. Other team perks include a 10-

minute spot massage by Mariann Wilson and simple bike repairs by Kyle Fisher of Alpine Hut. Both donate their time.

Lawn chairs to relax in, blankets to flop on and camaraderie with other riders make these stops fun and friendly.

Chris Jewell has been involved with Team Parkinson's for four years. “Being part of Team Parkinson's is a great experience,” he said. “It's a lot of fun. It's also really gratifying to see the effort grow each year.” Jewell's sons, Sam, 17, and Pat, 15, are also on the team.

In addition to receiving a limited-edition Team Parkinson's 2007 jersey for raising just \$150, team members have the chance to win great prizes, all donated. These include a custom-fit bike valued at \$2,500 (funded by Hos Bros. Construction and built by Alpine Hut), two round-trip tickets anywhere Alaska Airlines flies, and a mini-vacation at any of 60 Worldmark Resorts. For every \$300 raised and collected by Aug. 31, 2007, team members receive one ticket in the prize drawing. Those who raise \$500 or more also qualify for a refund of up to \$75 of their event registration fee. All this makes pedaling for Parkinson's a great value!

Visit Team Parkinson's online at www.nwpf.org to learn more or sign up, or call 1.877.980.7500.

Dav'ne Stahley is development director at the Northwest Parkinson's Foundation.

Fall-proof body and home for safer living

By Liz Taylor

Although many of us want to live at home as long as we can as we grow older, home is where most injuries occur because of falls, forcing us to move. Numbers tell part of the story.

- Falls are the leading cause of fatal and nonfatal injuries for people older than 65 in the United States.
- Ninety percent of the 300,000 hip fractures treated annually occur because of falls, most at home.
- One in three people over 65 fall each year.

But numbers don't begin to describe the devastating pain, trauma, cost, embarrassment, inconvenience and permanent disabilities that a fall can bring. First you're on your feet, then you're on your face. In less time than it takes to read this sentence, your days of living independently may be over.

Greta Wolfe of Lake Stevens, age 81, recently emailed me her experience: "I am SO very careful, never rush and watch my step. Still, things happen. I stepped out onto the balcony to bring in a plant, and I must have got one foot wet, because stepping back into the kitchen, I slipped and fell but GOOD! I sat for a time and decided I had not broken anything, then slowly pulled myself up, holding onto cabinet handles and the door handle. I hurt, but stood still to make sure I was OK. Otherwise I wondered, how would I reach the phone and close the door if I HAD broken anything???" It was scary."

Most of us assume that age leads to frailty, and frailty leads to falls — that it's normal, inevitable, and there's nothing we can do to stop it. Incorrect, say the experts. While our bodies certainly change as we get older, most falls can be prevented. And when they can't, there are ways to handle them, to get help and prevent further injury. Now there are two books—each a companion to the other—to tell us how.

They were written by two physical therapists with well over 40 years' combined experience. Gail Davies and Fran Scully of New Jersey worked in a long-term care facility and saw firsthand "the devastating effects that a fall can bring, a fall that might have been prevented," wrote Davies in an email. "That's what prompted us to write the books."

Geared to older people and their families, rather than professionals in the health-care field, both books are highly readable with large print and no medical jargon, amply illustrated and easy to understand.

At first they put all the material into one book, then were concerned it would be too heavy, so they divided it into two.

"Fall Prevention: Don't Let Your House Kick you Out!" (\$13.95, Infinity Publishing, 133 pages) helps readers identify and eliminate fall hazards by inspecting the entire house—from the front door to the back, with side trips through the garage, basement and garden then pointing out simple things you can do to keep from splatting on your nose.

Fifty percent of falls occur on stairs, the book says. What makes stairs challenging is that they require our muscular, visual, cardiac, sensory and balance systems to work together, which is why, "stairs need to be as safe as possible." The book offers dozens of safety tips and solutions. Some will seem obvious—"install a secure hand rail"—and others less so, such as avoiding plush or patterned carpets, extending the hand rail beyond the stairs' length, and planting your foot fully on shallow treads.

Other topics include floor dangers, including throw rugs (my, ahem, downfall), glare, the pros and cons of floor materials; bathrooms ("the most dangerous room in the house"); kitch-

ens; bedrooms; and outdoor spaces. It offers solutions in lighting, telephones, how to stop procrastinating on repairs ("FYI: The cost of one to two months in a nursing home or assisted-living facility equals the cost of updating your bathroom") and how to prepare for home emergencies.

While the first book talks about structural and instrumental ways to prevent falls, the second book, "Fall Prevention: Stay on Your Own Two Feet," (\$12.95, Infinity Publishing, 108 pages) addresses the human element: us!

The build-up to falling begins early, the book says: At age 40, a person's muscle mass, strength and balance begin to decline. However, strength and balance exercises can increase muscle mass and improve balance, even among 90-year-olds.

"Inactivity is not the answer to preventing falls," says one heading, "Inactivity can actually cause a fall!"

The trauma of falling—and the vicious circle of fear it begins—becomes a continuing spiral of inactivity and fear that can easily result in more falls. The book talks about how to address this fear, as well as how to get up from the floor and dust yourself off. My reader, Greta Wolfe, did it right.

Other important topics include your posture, your balance (my favorite question: Can you stand securely on one leg?), your muscle strength, simple exercises to do in your kitchen, painful feet, vision and how to select a doctor you can trust to help you.

The authors' website is www.fallpreventionadvisors.com.

Liz Taylor's column runs Mondays in the Northwest Life section of the Seattle Times. This article first appeared in the Times' Jan. 15, 2007, issue and is reprinted here with permission. A specialist in aging and long-term care for 30 years, Taylor writes and gives workshops. You can see all her columns at www.seattletimes.com/growingolder/.

The right thing to do

Dav'ne Stahley, development director of the Northwest Parkinson's Foundation, visited with David Dittmer, president of **Lumbermens**, and Kerry Severtson, executive secretary, about Lumbermens' ongoing sponsorship of Team Parkinson's.

Stahley: You've been a generous sponsor of the team since 2000. How did your relationship with the Northwest Parkinson's Foundation and Team Parkinson's begin?

Dittmer: In the late '70s (former Washington Gov.) Booth Gardner was on our board and was very involved in our business. When he told us he had Parkinson's disease and asked Lumbermens to sponsor an effort to raise money for Northwest Parkinson's Foundation, we said yes right away.

Stahley: Is philanthropy an important part of Lumbermens' corporate culture?

Severtson: Our charitable giving philosophy is based on our pride in the communities in which Lumbermens has a presence. We want to support those communities and one of the best ways to do that is through charitable donations.

Dittmer: We've always been a contributor at the store and corporate level. We were prompted to ratchet up our giving in the late '80s and early '90s, when lumber mill closures meant a lot of workforce reductions. We wanted to find a way to help those communities which were hardest hit, so we began to donate to every food bank in the towns in which we did business on an annual basis. We continue to do that to this day. That spring-boarded us to being more conscious about community involvement.

Stahley: I understand you support other

Continued on next page

You may have noticed a change to recent issues of the *Parkinson's Post*. Rather than list all current donors in every issue, we've decided to publish a *Report to the Community* each year that summarizes the full year of giving. This change will give us more room to bring you educational and informational articles. We'll continue to print in each issue the names of those in whose honor or memory donations have been received, along with their donors.

Listed on this page are those who made honor or memorial donations between Jan. 11 and March 11, 2007. *Thank you!* Your gifts support our educational programs, including our website, weekly email update, caregiver booklet, newsletter, and annual Parkinson's conference. Donations also help fuel our outreach and advocacy efforts on behalf of patients and their families.

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MARCH / APRIL 2007

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organizations besides the Northwest Parkinson's Foundation.

Severtson: We got started with the food banks and our charitable giving just went on from there. We support children's hospitals because we want to give children the opportunity to become adults and help them have better lives. We support the Red Cross because we can support a broader range of people with immediate needs who need help in their very lowest moments. We had already been supporting them on 9/11 and our employees did an amazing job personally after 9/11. We also are very supportive of Habit for Humanity.

Stahley: In a nutshell then, why do you do all of this? Why are you so philanthropically minded?

Dittmer: From a company standpoint, we give because it's the right thing to do. We

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don't do it for mercenary reasons. If a company is giving to get publicity they are giving for the wrong reasons. If it's never given back to our (cash) registers it's just fine because we know we've given back to others. We are not giving to get, we are giving to give. As I said before, we give because it's the right thing to do.

Severtson: I feel that charitable giving is the heart of Lumbermens. It's not our business, it's not the brain. It's the heart. The best part of my job is being able to represent the heart of Lumbermens.

Lumbermens has 76 branches in five states.

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