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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!



**NORTHWEST
PARKINSON'S
FOUNDATION**

Right care plus right attitude add up to quality of life for Seattle couple

By Joanna Glickler

When Bob and Ellen Bax heard the diagnosis seven years ago, they were devastated.

"We really didn't know what Parkinson's was," Ellen said. "But it felt pretty bleak."

The Baxes had suspected something was wrong. Bob had begun shuffling and in other subtle ways slowing down from what had been an active lifestyle that included walking four miles a day.

A visit to a neurologist confirmed their fears.

For nearly four years after his diagnosis, Bob visited his neurologist for annual checkups but was never prescribed Parkinson's medications to control his symptoms, which gradually grew more pronounced.

Then three years ago, his neurologist referred Bob to a Parkinson's specialist at the Booth Gardner Parkinson's Care Center in Kirkland, WA.

From that point on, Ellen said, "It was the difference between night and day. All of a sudden we had hope."

At the Center, Dr. Monique Giroux aggressively set to work in finding the right combination of medications for Bob, starting slowly with levodopa/carbidopa. "She was upset that he hadn't been prescribed the medications sooner, and she was tenacious about finding the right drugs for him," Ellen said.

These days, Bob takes several medications daily to address his various symptoms. "He has an iron stomach,



Bob and Ellen Bax at home in Seattle.

fortunately—he can handle the medications," Ellen said.

One positive outcome? "His face is expressive again," Ellen said. As if to illustrate, Bob flashed his generous smile.

At the Booth Gardner Parkinson's Care Center, Bob also has had regular sessions of speech therapy to help him project his diminished voice, as well as physical therapy to help him sit up straight. "That was amazing," Bob said of the latter. "I could look up and actually see people."

The self-care component

Bob Bax is a case in point of what the right medical attention can do for a Parkinson's person. While he moves slowly, he is steady on his feet. His speech requires his focus, but his quick wit always comes across. He remains active and engaged.

Continued on Page 2

Advocacy is a team effort

By Dennis O. Wright

Well, we've survived the onslaught of leaves clogging street drains, political ads filling TV screens, and election signs springing up in yards like mushrooms in a cow pasture. That must mean it's time to prepare for another year of congressional funding issues.

As you're no doubt aware, we need to be lobbying for more funds for Parkinson's research. In a functioning democracy, "If you don't make noise you won't get heard." Democracy requires your participation.

We're asking people to come forward again this year and help make government work for you and me. We need people from every congressional district to join us—to move beyond being individual faint voices so that our loud collective voice will be heard.

There is nothing new to the message we must continue to impress upon our leaders. We still want our fair share of the research funding. Our fair share is not an unreasonable request. We just need to say it louder and more often to be heard. Louder and more often can only be accomplished by more individual voices added to the whole.

I'm occasionally asked what the O stands for in my middle name. I assure you it is not "organized." So although I've been involved in the advocacy game for a number of years, I urge you to take advantage of a great new

resource. Judi Baker is the Washington state coordinator for the Parkinson's Action Network. Judi is not new to Parkinson's issues though she now has an official role—and a great organization backing her.

Whether you're in Washington or elsewhere in the Northwest or beyond, please help Judi get off to a strong start. Step forward and join us in reaching our goal, a cure for Parkinson's in our lifetime. You can contact Judi directly—she has all the materials, pre-written letters, and addresses for your representatives—at (425) 313-8886, judi@4itg.com, or 34727 SE Curtis Drive, Snoqualmie, WA 98065.

Let's enable researchers to find a cure for Parkinson's, and soon!

—Dennis O. Wright has been a longtime volunteer Parkinson's advocate and occasional writer for the Parkinson's Post.

Continued from Page 1

Keeping up with his Parkinson's hasn't been about medications alone. The added component of self-care is too important to overlook, he agreed.

Bob's self-care regimen involves a focus on healthful eating (though that doesn't rule out the occasional chocolate imported from the Baxes' native Holland) and regular exercise that includes weight-training for muscle tone. And while he can no longer walk four miles a day, he tries to get out as often as possible.

He and Ellen both read, write, watch television and talk. "If you don't use it, you lose it," Ellen said of keeping the mind engaged. "My own theory is that the brain can relearn certain things, even with Parkinson's. Okay, so your brain doesn't make dopamine anymore—well, find other ways to make it work."

As Bob's primary caregiver, Ellen has found the Internet to be a rich source of information about Parkinson's. She said that especially for those in remote areas, without easy access to the specialist care the Baxes have benefited from, the Internet is a great tool. "I would say to others, read. There's so much material out there. After reading, we learned it's not so bleak. Accept the diagnosis and educate yourself."

She encouraged others to tap into the available resources, including the support groups that meet regularly in many parts of the region. "Knowing you're not alone—that's a tremendous help."

Attitude, attitude, attitude

More than anything, the Baxes have learned to be positive about all things, even Parkinson's.

"Dealing with Parkinson's—as a patient or a caregiver—is 99 percent attitude," Ellen said. "We feel very blessed in life, despite the Parkinson's."

Bob and Ellen, who met in Fresno, CA, and have been married 39 years, use humor to defuse the stress of living with Parkinson's. For example, when Ellen explained that the drug Seroquel, used to curb hallucinations, made Bob doxy and indecipherable, he fired back, "It's her hearing."

"We laugh a lot about things," Ellen said, smiling. "Though once in a while I get angry, not at Bob but with the Parkinson's. He did all the right things—good health, ate well, exercised. It doesn't seem fair."

It doesn't always seem fair to Bob, either. A retired Boeing flight test engineer, Bob has made a series of unwelcome adjustments to accommodate Parkinson's. The biggest concession? His decision to give up driving. "That was the hardest thing," he said, "having to depend on someone else. I'm still trying to cope with that."

But the Baxes count their blessings, stay active, and laugh. And others always notice. Ellen quoted Dr. Jeff Shaw, neuropsychologist at the Booth Gardner Parkinson's Care Center, as saying: "There go the Baxes—attitude, attitude, attitude. I wish I could bottle it and give it to all my patients."

—Joanna Glickler is NWPF development director.

Holidays a popular time for ‘recreational worrying’

By Jeffrey Shaw, Psy.D.

It doesn't take a psychologist to determine that the holidays are anxiety provoking. Much of your stress is optional. Are you a recreational worrier?

Anxiety is necessary to keep us alive. If we didn't worry about having enough food or shelter, we would die. In other words, anxiety is a Wonderful Motivator.

Unfortunately, humans are prone to worrying just as much about the minor details—e.g., “What if Uncle Joe doesn't like the gift?” or “What if I spill the gravy during the holiday meal and embarrass myself?”

These three questions will help you choose how much of your energy to expend on your favorite worries:

1) What can I do about it? Note that most of our worry pertains to things that we can't control (such as the weather, other people's feelings, non-preventable illness or accidents). For most situations we will have to see if and when we cross that bridge.

Sometimes we irrationally believe that if we worry enough, we can prevent the terrible thing from happening altogether.

2) So what? So what if the bad thing *does* happen? You will cope with it as you always have. And I bet that one or two bad things have probably happened in your past. You've made it this far, haven't you?

Recreational worriers tend to have a couple of special skills. First, we “catastrophize” the consequences of even minor events. For example: “I just know that the turkey will probably not turn out right, and I will probably spill gravy and I will be so embarrassed that I will die, and then ... we will be poor and homeless with no friends.” You get the idea.

Second, we underestimate our ability to cope and to obtain assistance. When catastrophizing, each bad outcome falsely leads directly to the next problem, as if we are helpless to alter the process or enlist the help of other people.

We also forget about our capabilities—our ability to explain to others what happened, use humor to acknowledge our human limitations, and appreciate the compassion of others regarding the struggles inherent to life.

3) Am I being a perfectionist? Watch out for statements such as I should or I must, as these are signs you may be holding yourself to unrealistic expectations. Share in the planning of events and commitments, and set limits for your involvement.

Guilt is also a strong motivator and is a cousin to anxiety and stress. Try to hold yourself to the same standards you have for others. It's amazing how much less tolerant we are of our personal limitations compared to our expectations of others.

Remember that the embarrassing moments and “catastrophes” in our life usually make for the best stories. So now, when I am in the middle of one these stressful events, I start taking mental notes on how to best tell the story later. Ask me about the time I spilled gravy on the dog...

—Dr. Shaw is the Booth Gardner Parkinson's Care Center neuropsychologist.



Caregivers invited to share stories

Take the 70,000 people with Parkinson's in the Northwest and double that number. Maybe triple it. That might begin to account for the many “others” who live each day with Parkinson's—the caregivers.

Caring from day to day for a person with a chronic illness is a labor of love. It can also take its toll on a caregiver's physical and emotional well being.

Recognizing the critical role of the in-home caregiver, November has been named National Family Caregivers Month.

Coinciding with this nationwide recognition month, caregivers are invited to tell their stories through a National Family Caregivers Association online program.

The NFCA points out that caregivers lack a public voice, and there is currently no easy way to make caregiver needs known to legislators, the media and health professionals. Its “Family Caregiver Story Project” seeks to create this voice for caregivers.

Parkinson's caregivers can contribute a story by way of a link at www.nwpcf.org.

The NFCA notes that family caregivers rarely have a chance to talk about their feelings. “Family caregivers can find great solace in reading other caregivers' stories, and sometimes by writing out a story and sharing it with family or friends, a family caregiver may actually get some of the help they need,” according to the website.

Center's director shares vision for future

By Anthony D. Mosley, M.D.

I'd like to take this opportunity to share plans for the Booth Gardner Parkinson's Care Center.

As many of you are aware, Dr. Monique Giroux and Sierra Daniel, P.A., left the center earlier this year, and I came in to assume the medical directorship. We've assembled a new clinical team that includes Alida Griffith, M.D., and Berta Leis, R.N., Ph.D.



Dr. Mosley

In terms of a brief introduction, I'm a Bay Area native with a background in engineering, including a graduate degree, prior to completing my medical education at University of California-San Francisco, medical internship at Yale-New Haven Hospital, neurology residency at University of California-Los Angeles, and movement disorders fellowship at UCSF/San Francisco V.A. Medical Center. I have particular clinical experience in the selection of people with Parkinson's for deep brain stimulation (DBS) surgery and their post-operative programming and management.

Dr. Griffith attended Harvard as an undergraduate. She graduated from the University of Massachusetts School of Medicine, Dartmouth-Hitchcock neurology residency, and a movement disorders fellowship at Harvard-affiliated Beth Israel Deaconess Hospital in Boston. She has expertise in botulinum toxin injections for dystonia, as well as has extensive DBS experience. A second clinician was clearly needed to meet patient demand at the Center, and we are fortunate to have a physician of

Dr. Griffith's caliber to support the Center's growth.

Dr. Leis has expertise in Parkinson's from the perspective of a clinical nurse as well as a researcher focusing on Parkinson's during her doctoral studies at the University of Arizona and as a post-doctoral fellow in kinesiology. She has assumed leadership of our patient-education efforts, and she plays a key role in day-to-day clinic operations and in coordinating our research and outcomes efforts. She also has the expertise to answer questions and assist in medical visits, which increases our flexibility and enables us to address patient needs more expeditiously.

We also welcome our new speech therapist, Andrea Miles, M.A., CCC-SLP, who has five years' experience as a speech pathologist and is certified in Lee Silverman Voice Treatment for people with Parkinson's.

And we have a new administrative manager, Joe Foecking, P.T., M.H.S., a physical therapist with experience supervising therapy services at Cleveland Clinic, as well as expertise in neurological rehabilitation and in evaluating clinical outcomes.

My plans include further improving the clinical care provided by the multi-disciplinary team at the Center; making enhancements to our educational offerings for physicians and other health workers, patients and families; and adding clinical outcomes tracking and clinical research to enhance the medical care of people with Parkinson's at the Center and possibly around the world.

Our education efforts are key to good quality of life for patients and their caregivers. We've participated in regional patient education conferences and begun our own series of quarterly educational seminars for patients.

In addition, I have presented to local physicians, Dr. Jeff Shaw, our lead neuropsychologist, has presented to local psychologists, and Anne Zylstra, P.T., our lead physical therapist, has made presentations to therapists throughout the Northwest.

I'm expanding our efforts to educate healthcare professionals to share our expertise so that people with Parkinson's who don't know about the Booth Gardner Parkinson's Care Center, or who can't visit on a regular basis, still can receive great care.

Such efforts are necessary to extend the Center's impact to people with Parkinson's throughout the Northwest. We are working closely with our partner, the Northwest Parkinson's Foundation, on these initiatives.

Another component to improving the quality of healthcare for people with Parkinson's is our new effort in health outcomes measurement and clinical research.

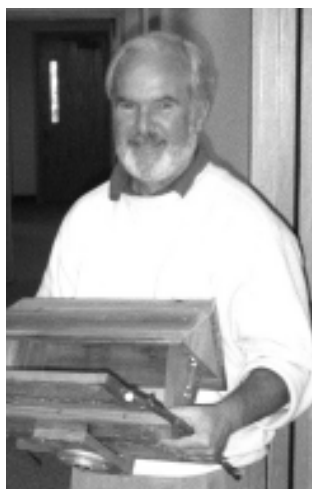
This effort will aid in determining if a Parkinson's intervention is beneficial. For many common Parkinson's interventions, the medical literature shows conflicting results on effectiveness. At the Center, our mix of many disciplines under one roof puts us in a unique position to answer questions about how to effectively treat non-motor problems in Parkinson's and to provide insight into what works.

Along these lines, we've begun to collect outcomes data from medical visits and therapy interventions. Those of you who are patients at the Center may be asked to participate in this.

We're also involved in the study of new drugs. Currently, we are recruiting patients on levodopa (Sinemet) for a study to determine if a new formula-

Continued on Page 5

Booth Gardner, former Washington state governor, carries a birdhouse he made especially for the July 2000 opening of his namesake Booth Gardner Parkinson's Care Center in Kirkland, WA. Gardner, who serves on the board of directors of the Northwest Parkinson's Foundation, was diagnosed with Parkinson's eight years ago.



What makes a Center better

By Craig Howard

Many of our readers have been with us for three or four years, and have heard a lot about what the Booth Gardner Parkinson's Care Center does. Newer readers, however, have heard us mention it, without getting all the details.

The original idea was created by Bill Bell. Bill's mom had been dealing with Parkinson's for 13 years, and he had been with her from the day of diagnosis. They had been to doctors far and wide, but could not find a center of knowledge and treatment.

As the symptoms progressed, Bill's frustration grew. He had other family and friends with Parkinson's at that point, and one day he came up with an idea.

What if you could get a neurologist who specialized in movement disorders and team that doctor up with the other professionals who could have an impact on a Parkinson's patient? What if you could put them all together, creating a team? House them all in one easily accessible building? Then assure them financial stability until the treatments stood on their own and the patient base supported their work?

Continued from Page 4

tion of ropinerole (Requip) helps delay the onset of dyskinesias (involuntary abnormal fidgety movements).

And we're collaborating with the University of Washington on a study of how genes might affect whether one gets Parkinson's and on how different genes might affect one's response or side effects from Parkinson's treatment.

We welcome you to call the Center at 425.899.3123 for an information package, or visit our website at www.evergreenhealthcare.org.

Anthony D. Mosley, M.D., is medical director at the Booth Gardner Parkinson's Care Center in Kirkland, WA.

With this idea, the Northwest Parkinson's Foundation was born. One of our founding board members was former governor of Washington state Booth Gardner. Gardner, who found much better care for his Parkinson's through his affiliation with the Northwest Parkinson's Foundation, became involved in our efforts to aggressively build a winning center.

We found a natural partner for these ambitious plans in Evergreen Healthcare, a hospital and care facility in Kirkland, WA. Evergreen possessed the healthcare expertise we needed, including a deep understanding of the increasingly complex insurance and Medicare systems.

Together, in less than a year and a half, Evergreen and the Northwest Parkinson's Foundation opened the Booth Gardner Parkinson's Care Center on July 3, 2000.

Why is it different?

Believe it or not, very few cities have anything even remotely as complete as the Booth Gardner Parkinson's Care Center. Profit is not the actual driving force at many hospitals; more accurately, not losing money is the driving force—the insurance system makes this very challenging.

The Booth Gardner Parkinson's Care Center has proved that comprehensive Parkinson's care does not have to be a liability to a hospital's business.

The difference a comprehensive center can make is this: A person can go to a movement disorders specialist at the Center (there are currently two full-time neurologists on staff), and discuss the particular issues adversely affecting the patient's life. The doctor can then refer the patient to a speech therapist, a physical therapist, an occupational therapist, as well as a neuropsychologist—all of whom work in the same place. The advantages to this kind of attention are dramatic.

This team can talk together, evaluating patient issues and needs, thus making recommendations that will very often improve quality of life—for people with Parkinson's as well as for their family members. (After all, we're *all* living with Parkinson's.)

The Booth Gardner Parkinson's Care Center was created by people living with Parkinson's, from the patient's perspective. It has been largely supported through gifts by individuals who saw the vision with us—the public has been generous indeed. And it has paid off in creating worldclass care for Parkinson's and raising the bar for other care providers.

This model is being carried to other parts of the country. We hope to see care continue to improve.

The healthier people with Parkinson's are, the more ready they will be to take advantage of the cure. And that's something all of us can look forward to.

—Craig Howard is co-founder of the Northwest Parkinson's Foundation. He can be reached at choward@mwpf.org.

T H E *Giving* P A G E

The Northwest Parkinson's Foundation exists solely through the support of the community. This support comes in the form of gifts from individuals, families and companies, as well as through foundation grants for special projects.

If the work we do has helped you or someone you know live a better life with Parkinson's, we ask that you consider making a contribution. Our work helps thousands, and it's achieved only because of your generosity.

Those listed here made gifts between Oct. 1 and Nov. 12, 2003.

To each and every one of you, we extend our heartfelt thanks.

Mr. and Mrs. Marty Ackerman
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THE GOVERNORS CIRCLE

While every single donation to NWPF makes a difference in our work for the Northwest Parkinson's community, a group of very special donors truly sustain our work through leadership gifts.

In an effort to recognize these most generous supporters, we've created the Governors Circle in honor of the two former governors of Washington state who have served on the NWPF board since the beginning—Daniel J. Evans and Booth Gardner.

The Governors Circle recognizes donors whose cumulative giving during the year totals \$5,000 or greater. Governors Circle donors in 2003 will be invited to a reception with the governors in the early part of 2004.

For more information about the Governors Circle, please contact Development Director Joanna Glickler at 1.877.980.7500 or joanna@nwpf.org.

We look forward to thanking this special group of donors!

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In memory of George Moore
Mrs. W. Lee Moore

In memory of John Pulsipher
Mr. Ronald Pulsipher

Rasagiline shows promise as early Parkinson's therapy

By Sara McIntyre and Steve Setter, PharmD

Rasagiline is being studied as a new drug for the treatment of early-stage Parkinson's. It is also being looked at in combination with levodopa/carbidopa for its potential benefit to maintenance therapy.

Studies have shown promising results that indicate rasagiline may offer the advantage of a well-tolerated, once-a-day therapy for people with Parkinson's.

Rasagiline is a selective inhibitor of monoamine oxidase type B (MAO-B), similar to selegiline (Eldepryl®). Selegiline was the first drug to gain attention as a possible neuroprotective agent, which means it could stop or delay the loss of dopamine-producing cells in the brain.

It has not yet been proven selegiline is neuroprotective, but it has been shown in animal studies to protect dopamine neurons. Rasagiline also shows promise as a neuroprotective agent, but further studies are needed before this is definitively known.

Rasagiline is now in the last stage of the Food and Drug Administration's approval process and a decision is expected later this year.

Studies show it is effective as monotherapy treatment in early Parkinson's, but it may be more helpful as add-on therapy to levodopa/carbidopa (Sinemet®) or along with a dopamine agonist (i.e. Mirapex® and Requip®).

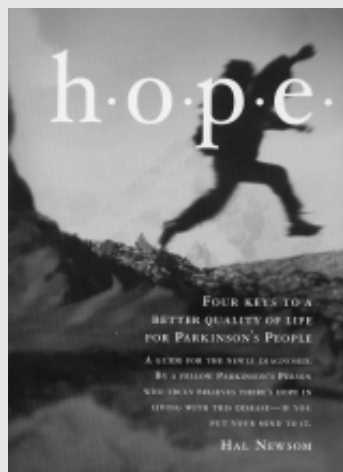
Doses of 1 to 2 mg of rasagiline once a day have been shown effective in early Parkinson's as both a monotherapy and combination therapy. Rasagiline showed a significant decrease in Parkinson's symptoms and improved motor function and quality of life.

The longest study of rasagiline has been one year. Further studies are needed to determine the long-term effects of rasagiline. To date, rasagiline has been shown to be safe and well tolerated.

Rasagiline may not have the same side effects as selegiline—such as rapid heartbeat, severe headache and insomnia. The most common side effects reported by patients while under treatment with rasagiline include drowsiness, headache, stomach pain, lightheadedness, dry eyes and dry mouth.

Rasagiline will be marketed by Teva Pharmaceuticals.

Sara McIntyre is a PharmD candidate at Washington State University's College of Pharmacy, where Steve Setter is a member of the faculty.



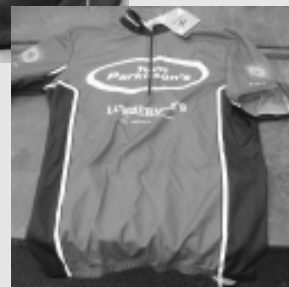
Put your holiday dollars to work for Parkinson's

Looking for a special gift for your loved one with Parkinson's this holiday season? Hal Newsom's book H.O.P.E. could be just the thing. H.O.P.E. offers a positive, practical look at life with Parkinson's. And proceeds from book sales benefit the Northwest Parkinson's Foundation.

You can buy H.O.P.E. directly from NWPf for \$14 (includes shipping).

Also available for that special Parkinson's person in your life—two items of clothing to inspire that fitness regimen. We're offering a sleeveless Cutter & Buck golf fleece, embroidered with "Drive One Classic, Northwest Parkinson's Foundation." This roomy fleece is black with olive lining and stitching. Sizes M, L, XL. Priced at \$60 (includes shipping).

We're also offering a "Team Parkinson's" Sugoi biking jersey (imprinted with Seattle-to-Portland bike ride sponsor Lumbermen's logo). The jersey is available in royal blue with black and white trim. Sizes M, L, XL, XXL. Priced at \$40 (includes shipping).



Call 1.877.980.7500 to place your order today, or send a check, made out to NWPf, to P.O. Box 56, Mercer Island, WA 98040.



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Seattle-area volunteers can help two causes at once

Northwest Parkinson's Foundation volunteers have a chance to help raise funds for another worthy cause while promoting this one!

Seattle public television station KCTS is gearing up for its on-air winter fund drive, and NWPF has committed to help out this year. We're seeking volunteers to help answer phones at the KCTS calling banks from 6:30 p.m. to 11 p.m. Dec. 1. If we're able to round up 10 or more volunteers, we'll be interviewed about NWPF on-air.

NWPF is always looking for innovative ways to reach the Parkinson's community, and the KCTS fund drive presents just one more way for us to get the word out about our programs.

KCTS promises an evening of fun for volunteers, as well as dinner.

Call NWPF's Elizabeth Pelham at 1.877.980.7500 to sign up.

NWPF welcomes Bob Story

The NWPF Board of Directors extends a warm welcome to Bob Story, the newest member of the board.

Bob brings a wide range of expertise to the table. As chairman of the Seattle Financial Group, he has been active throughout his career in industry, having served as president of both the Seattle Mortgage Bankers Association and the Washington Mortgage Bankers Association. He is a 1953 graduate of the University of Washington School of Business.

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