



NORTHWEST  
PARKINSON'S  
FOUNDATION

SEPTEMBER/OCTOBER 2003

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*Parkinson's Post is published by the Northwest Parkinson's Foundation, a 501(c)(3) charity. 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!*

The Northwest Parkinson's Foundation

# Parkinson's Post

*Awareness - Care - Education*

## Online caregiver training shows early impact

A free online course is proving to be a popular educational tool for the Parkinson's community. Since its launch just five months ago, the Parkinson's Curriculum of Care has attracted over 400 users who have logged in more than 3,600 sessions.

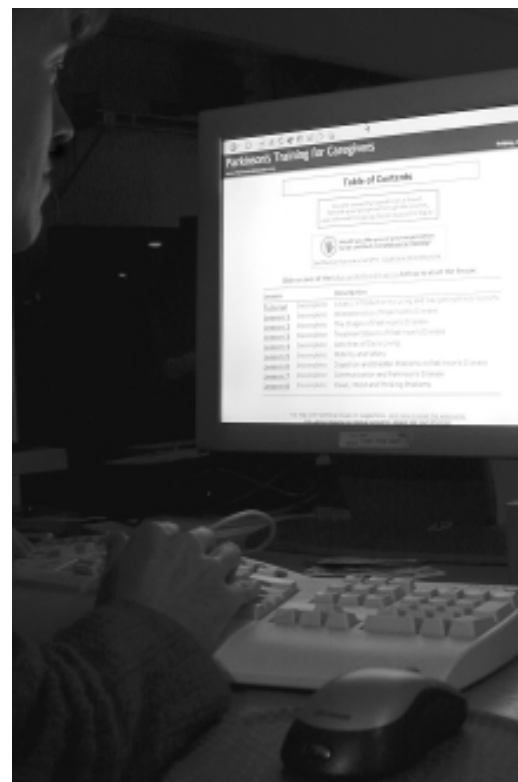
This specialty training course for in-home and professional caregivers comprises eight educational modules that outline "best practices" for caring for people with Parkinson's.

The course, conceived and funded by the Northwest Parkinson's Foundation through a grant from the Administration on Aging, was written and reviewed by a team of Parkinson's specialists.

Launched in April, the course helps caregivers understand the characteristics and stages of Parkinson's, its impact on physical and mental functioning, basic treatments, safety issues, communication techniques, and daily life with Parkinson's.

Bill Bell, Northwest Parkinson's Foundation executive director, said the online course was developed to address the lack of educational resources available for Parkinson's caregivers and the high turnover among caregiving staffs at care facilities nationwide.

"The turnover and lack of training made the need obvious to us," Bell said. "We saw it as a great opportunity to improve quality of life for those being cared for by paraprofessional health care workers."



The caregiver course can be viewed at [www.parkinsonseducator.org](http://www.parkinsonseducator.org).

"The curriculum is also appropriate for the in-home caregiver, especially those new to Parkinson's," Bell said.

Bell said the goal of the Northwest Parkinson's Foundation is to have caregivers nationwide complete the course. "Anyone with a loved one in a care facility should promote this training to that facility," he said.

There are plans to add modules to the course over time, and Bell welcomed suggestions from caregivers as to what additional information would be helpful.

To view or complete the course online, visit [www.parkinsonseducator.org](http://www.parkinsonseducator.org).

The Northwest Parkinson's Foundation values your comments on the course, which you can email to [feedback@nwpf.org](mailto:feedback@nwpf.org).

## Parkinson's: Trusted guru

By Marjo Miller

Parkinson's has become my most trusted teacher.

This was my first lesson as I embraced this condition and loved it as an inherent, inextricable part of me. I learned early on that denial and attempts to extricate myself from its symptoms only led to frustration and failure.

This brought me to my first great understanding of my former self, a self I valiantly attempted to reproduce. I was a disaster as I tried to carry on in my energetic pattern—at times my whole body would tremor under the strain. The business world of sales and promotions is anathema to this puzzling condition of out-of-control movement in various parts of my body. Embarrassed and confused by my symptoms, I found myself in an angry and resentful state, wondering what I

was to do for the rest of my life—for myself and for society.

I have been a yoga student for more than 30 years, and as I meditated I gradually integrated my condition and learned to “listen” to its message.

Meditation was frustrating for months as my arms and legs and, at times, my whole body vibrated under the strain I imposed on it to stay still.

But it was when I practiced breathing techniques and let go to the condition that minutes later I would find myself in a totally responsive state that opened my consciousness to the truth that Parkinson's was to be my trusted teacher. For me, it is a barometer for my subconscious. It warns of fatigue when I am prone to “push on,” it cautions in certain circumstances and, most importantly, it responds positively to truth and to healthy relationships. It is just below my skin, monitoring every vibration 24 hours a day. It is my best friend, and I have come to love its diligence and integrity.

I can only speak for myself, but many times when I am engaged in what I call good works in speech or deed, my soul becomes

so consumed with the process that the formerly uncontrollable condition just floats away.

As I discern the conditions, projects and relationships that are healthy for me, Parkinson's syndrome is an invaluable tool for measuring good. I use the term “syndrome” because it fits this positive premise of growth from the condition, rather than the word disease, which has negative connotations. *Syndrome* allows for the billions of interpretations that take place each day within each Parkinson's person's life.

What has Parkinson's taught you? Would you be comfortable sharing with us? It could be important for someone else to hear. My greatest lesson thus far is that we are here to love and serve. May our insights enlighten one another. Namaste!

*Marjo Miller is co-founder and executive director of the Seattle Jiva Yoga Program, which serves hundreds of people with physical challenges at the Miller Center in Seattle.*

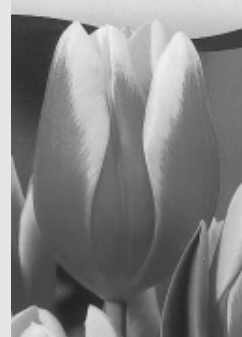
*Namaste is a universal yogic greeting that means “The light in me salutes the light in you.”*

## Montana creates community for support, cure

A grassroots effort called “Hands Around Montana” has raised over \$20,000 for Parkinson's support and a cure since its kickoff in April. The group has undertaken a variety of creative fund-raising projects, including sales of tulip pins, tulip bulbs, notecards and a CD, and a grocery store chain collaboration.

Corrine Fredrickson of Lewistown, whose Parkinson's diagnosis came in 1999 just days after her retirement from a banking career, spearheaded the effort with her husband, Jim. But they quickly recognized a need for more. “Being in such a rural state, we have come to realize there is such a tremendous need for support and awareness concerning Parkinson's here,” Jim said.

To learn more: 877.426.3727 or [handsaroundmt@attbi.com](mailto:handsaroundmt@attbi.com)



**The tulip has become a symbol of hope for Parkinson's people and their loved ones.**

## Gates Foundation funds effort to reach deeper

Believe it or not, our greatest challenge at the Northwest Parkinson's Foundation is finding the people in the Northwest who are living with Parkinson's, so they can benefit from our work. That effort just got a boost thanks to the Bill & Melinda Gates Foundation, which has provided a grant of \$50,000 for the purpose of building awareness in the Parkinson's community.

An estimated 70,000 people in the Northwest live with Parkinson's. When one accounts for the family members and care providers of this population, the Parkinson's community grows dramatically. It is our goal to connect as much of the Parkinson's community as possible to the beneficial resources available. The Gates funding will help provide for awareness materials and their distribution throughout the Northwest.

Care to give this effort a boost of your own? Tell others about this free newsletter and encourage them to subscribe. The *Parkinson's Post* isn't just for people with Parkinson's but for family, friends, and in-home and professional care providers as well.

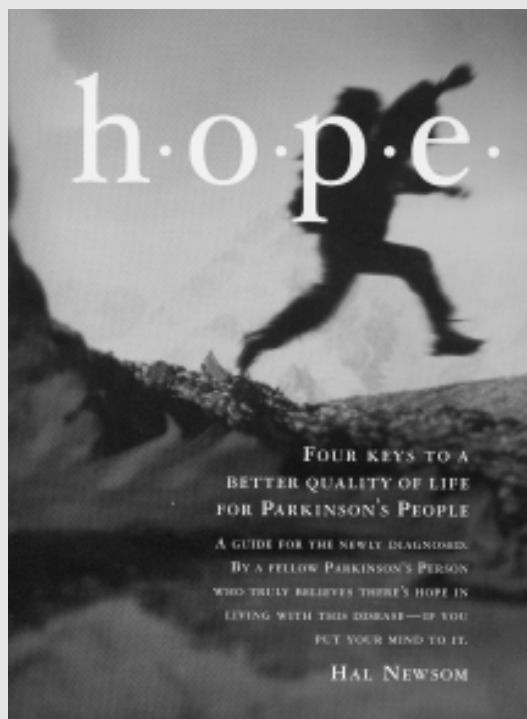
## Seattle Foundation helps outfit new office—and you can help, too!

A \$10,000 grant from the Seattle Foundation is helping outfit new office space of the Northwest Parkinson's Foundation with computer and office equipment that will contribute to our efficiency.

This funding complements the generosity of another donor (who wishes to remain anonymous), who has enabled us to rent a wonderful office space in downtown Seattle.

Redoing your own office? Moving? Looking to donate furnishings and equipment? If you live in the Seattle area, look no further—we are still in need! Our wish list includes the following good-quality items: lateral filing cabinets, shelving, a computer server, a digital camera, a photocopier, a high-quality laser printer—and network expertise!

Contact Development Director Joanna Glickler about making a donation: 877.980.7500 or [joanna@nwpf.org](mailto:joanna@nwpf.org).



## Book a source of H.O.P.E. for people with Parkinson's

Hal Newsom's book H.O.P.E., now in its second printing, provides a positive look at life with Parkinson's.

If you and your loved ones haven't read this intimate and inspiring personal account, there's no time like the present.

Newsom, who has lived well with Parkinson's for 10 years, serves on the board of the Northwest Parkinson's Foundation and is a dedicated Parkinson's educator and advocate. Always open to new ideas and suggestions on how he can help, Newsom is willing to talk to anyone at any time about Parkinson's. Email him at [hope@nwpf.org](mailto:hope@nwpf.org).

As Hal has directed since the first book sold, all proceeds benefit programs of the Northwest Parkinson's Foundation.

You can buy H.O.P.E. directly from the Foundation for \$14, which includes shipping. Send your check to NWPF / P.O. Box 56 / Mercer Island, WA 98040.

# Surgical therapies promising for some with Parkinson's

By Anthony Mosley, M.D.

Though medical therapy treats the symptoms of Parkinson's effectively during the initial stages of the disease, it may not adequately manage symptoms in later stages. Over time, people commonly develop motor complications—including involuntary movements (dyskinesia) and fluctuation between bradykinesia (slowed movement) and dyskinesia, often with little optimal movement throughout the day. And there are unpredictable freezing episodes that become resistant to even the most skillful attempts at medical management.

For a small subset of people with Parkinson's for whom optimized drug therapy cannot control disabling motor symptoms, surgery is an alternative.

Parkinson's patients for whom drugs are no longer providing satisfactory control over symptoms may be candidates for surgery. To be a candidate for surgery, patients must also be in otherwise good physical and mental condition.

James Parkinson observed in 1817 that acquired structural lesions of the brain's motor pathways can relieve the symptoms of Parkinson's. Surgical treatment of the disease at the level of the basal ganglia (clusters of neurons deep in the brain that exhibit abnormal activity in Parkinson's) dates back to 1939, when pioneering procedures achieved significant success but high mortality.

A variety of surgical procedures were developed throughout the 1940s and 1950s, but with the introduction of levodopa in the 1960s, surgical treatment of Parkinson's fell out of favor.

However, subsequent recognition of the limits and complications of medical therapy in advanced Parkinson's, along with an improved understanding of basal ganglia physiology and refinements in modern neurosurgical techniques, has led to renewed attention to surgical treatments over the last decade.

Patients may undergo ablative surgery, a precise process of destroying specific brain tissue to alleviate symptoms, or deep brain stimulation (DBS), which involves implanting an electrode in the brain through which electrical stimulation is delivered.

Some ablative procedures can be accomplished with radiosurgery, which uses targeted radiation from a source outside the head to destroy cells in a specific brain location. Most commonly, however, both the ablative procedure and DBS are performed surgically. They involve drilling a small hole in the skull through which the surgeon passes a recording electrode and then either an ablative probe or a DBS lead to the intended target.

Precise targeting of these small areas deep in the brain is achieved using imaging and intraoperative recordings of brain activity to accurately map the target. Typically, local analgesia is used so the patient can remain awake to answer questions during the process and to allow for neurological examination, important in confirming correct surgical targeting during the course of the procedure.

In today's techniques for Parkinson's, three areas of the brain are targeted:

- ◆ Part of the thalamus involved in motor function called the ventral intermediate nucleus (Vim)
- ◆ The internal segment of the globus pallidus (GPi)
- ◆ The subthalamic nucleus (STN)

Procedures targeting either the GPi or STN can improve all cardinal features of Parkinson's. A pallidotomy is an ablative procedure targeting the GPi. An experimental procedure, called subthalamic nucleotomy, targets the STN.

Pallidotomy is a valid choice for a patient who has mostly unilateral symptoms, or for whom device maintenance and programming would be difficult. The chief disadvantage of pallidotomy is that it carries a very high risk of serious side effects when done on both sides of the brain.

In contrast, DBS procedures can be performed safely on both sides of the brain to effectively treat axial (midline) and bilateral symptoms. DBS also leaves the brain relatively intact so that the patient might more readily benefit from future therapeutic advances.

*(Continued on next page)*

## National Institutes of Health seeks genetic study volunteers

People with Parkinson's can help contribute to an understanding about the causes of the disease by participating in a National Institutes of Health study.

Scientists recently released news of a hereditary link to Parkinson's in a small population. This finding will help scientists understand the biological chain of events that leads to Parkinson's.

Genes are the body's blueprints or building plans for constructing healthy proteins, cells and other materials. As with blueprints for a building, if the blueprints (genes) for the human body contain mistakes (mutations), there is a good chance for structural problems down the road. Understanding gene mutations and predicting the consequences of these structural problems gives scientists and doctors the ability to intervene with drug therapies.

The NIH is seeking participants in the study, which will run through 2005. Participants will be asked to submit a blood sample and answer questions by phone or mail questionnaire. People may also participate in the study in person, by making a trip to the NIH in Bethesda, MD. There, they will receive an evaluation by a Parkinson's specialist.

There is no cost for study subjects, whether they participate by mail, telephone or in person. The NIH will reimburse all transportation and lodging for each participant and a travel companion.

Those interested in participating are asked to contact Anthony Crawley at 301.402.9277 or [crawleya@ninds.nih.gov](mailto:crawleya@ninds.nih.gov). When leaving a message, indicate your name, phone number and the best time to reach you.



## Drug combo addresses 'wearing off' effect

**By Sara McIntyre and Steve Setter**

In June the FDA approved Stalevo®, a triple drug combination for treating Parkinson's.

Stalevo is a combination of levodopa, carbidopa and entacapone. Levodopa and carbidopa are the ingredients found in Sinemet®, the most widely used medication for the treatment of Parkinson's.

Entacapone is the active ingredient in Comtan®. Adding Comtan to Sinemet can help Sinemet work longer, proving beneficial for people who experience a "wearing off" of their Sinemet.

This wearing-off phenomenon is common for those on Sinemet. When an individual first begins Sinemet, the effects may last up to eight hours. Over the months and years a patient takes it, however, Sinemet gradually works for fewer hours of the day, requiring a change in both the potency and frequency of dosage. Fifty percent of Parkinson's people will experience wearing off within the first few years of Sinemet therapy.

Stalevo has its own set of possible side effects, so talk to your doctor to discover if it's right for you.

*Sara McIntyre is a PharmD candidate at Washington State University. Steve Setter, PharmD, is assistant professor of pharmacotherapy at WSU.*

*(From previous page)*

Relative disadvantages of DBS include device cost, hardware maintenance and need for multiple programming visits. Randomized clinical trials are underway to better clarify the relative merits of DBS of the GPi versus STN.

Thalamotomy and Vim DBS are effective for tremor only; therefore, they are not of much practical use for the majority of Parkinson's patients who are troubled by other motor

symptoms. Bilateral thalamotomy, like bilateral pallidotomy, has a high rate of unacceptable side effects. Fetal cell transplantation, dopaminergic neurotrophic factor therapy, and other experimental procedures will be reviewed in a future article, but they all lack evidence to support their general clinical use at present.

*Dr. Mosley is a movement disorders specialist at the Booth Gardner Parkinson's Care Center in Kirkland, WA.*

# T H E *Giving* P A G E S

The Northwest Parkinson's Foundation exists solely through the support of the community. This support comes in the form of donations from individuals, families and companies, as well as through grants from charitable foundations 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 contributions between August and September 2003. **Thank you, all!**

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 Ms. Kathryn Wright

**In memory of Mary Carlson Martinell**  
 Mr. Bill Martinell

**In memory of Mr. Goatcher (father)**  
 The Goatcher Family

**In memory of Petronella Waidelivh**  
 Mr. Richard Peppin

The Northwest Parkinson's Foundation is making plans for incorporating volunteers into our work. We're identifying projects that can be accomplished by groups or individuals, all at one time or over an extended period, and from our offices or a volunteer's home. We welcome your project suggestions and—of course—your time as a volunteer!

Here's a sampling of prospective volunteer projects:

For Northwest-wide volunteers:

- ◆ Spreading the word—Identify and contact pharmacies, primary care physicians, neurologists, nursing homes, and caregiving services in your area with packets of materials we've prepared to benefit Parkinson's patients.
- ◆ Research online in support of various projects. Great for the computer-savvy volunteer with a home computer, or someone willing and able to join us at our Seattle offices.

For Seattle-area volunteers:

- ◆ Office support—including assembling large mailings and doing database projects.
- ◆ Events—including the annual summer Seattle-to-Portland bike ride, for which volunteers are needed to help with event promotion.

Interested in volunteering? We'd love to have your support! Please call Elizabeth Pelham toll-free at 877.980.7500 or email her at [elizabethp@nwpf.org](mailto:elizabethp@nwpf.org).



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SEPTEMBER/OCTOBER 2003

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**E V E N T S**

- ◆ **Advances in Medical Treatment for Parkinson's** / Movement disorders experts present the latest on managing motor complications in Parkinson's and on dystonia and botulinum toxin (botox) / 3:30 to 6 p.m. Oct. 30 / Evergreen Hospital & Medical Center, Tan 100 (Kirkland, WA) / Free of charge / 425.899.3000
- ◆ **American Parkinson's Disease Association Symposium—Mind, Motion & Hope** / Hear the latest from Parkinson's experts; for Parkinson's people, family, friends and caregivers / 8:30 a.m. to 3 p.m. Nov. 1 / Shoreline Community Center (Seattle, WA) / \$24 / 206.543.5369, 888.400.2732 (toll free) or [apda@u.washington.edu](mailto:apda@u.washington.edu)

- ◆ **Everett (WA) Support Group** / Benefit from the support of others on the fourth Saturday of each month, 2 p.m. / Call Hazel Forbes: 425.776.1535

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**Parkinson's advocate  
Benton dies at 80**

Harry A. Benton of Tacoma, WA, died Sept. 12 in Tacoma. He was 80.

Benton served as president of the Northwest Chapter of the American Parkinson Disease Association from 1985 to 1997 and remained as a board member until his death. Described as a positive thinker and consensus builder, as well as a loyal, modest and kind professional, Benton was instrumental in his APDA chapter's national prominence.

Harry will truly be missed.