



NORTHWEST
PARKINSON'S
FOUNDATION

May - June
2003

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The Parkinson's Post is published by the Northwest Parkinson's Foundation, a 501(c)3 charity. Our mission is to establish the optimal quality of life for the Northwest Parkinson's Community.

We welcome comments and inquiries regarding this newsletter and all our other activities. We can be contacted at the address and numbers 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

So Much to be Hopeful For

As we walk through our lives, facing the variety of challenges that we all do, it is simple human nature to anticipate what comes next. The pessimist spends this time dreading. The optimist spends it hoping. But all of us must continue living. We had the opportunity to meet someone last week who has plans to drive a tractor from San Francisco to Seattle. Mike wants to raise awareness for the Parkinson's community. We suggested, gently, that he was crazy. He smiled. "Of course I am. But you know what? I've got to do something."

At the Foundation we've had that feeling a lot – that there's something to be done. Often, none of us know what it is. But we know there's something. So we figure out what might be best, and we just start doing it.

What we know is that great advances are being made in Parkinson's research. Every week we hear of new treatments, new medications, and new avenues of research pointing toward a cure. Our job is to help people be as healthy and active as possible so that they can take advantage of these advances as they become available.

The underlying message in Mike's actions is that he has hope, and wants others to have it too. By raising awareness he'll be an "agent of change" in the community. People might seek out better care. Others may contribute to the cause. But Mike wouldn't do it if he didn't think there was positive change possible. He is possessed of a hope that the answers to Parkinson's lie before us. And his actions will help all of us reach for them.

Another person I met a few weeks ago wants to start a walk-a-thon in her community. Candi has no idea where to start, how it's done, how hard it might be, how much it will cost. She just knows that others had done it elsewhere, so why not her?

Candi's energy is infectious. I know that whether she gets an event launched in her community or not, she will get deeply involved in efforts to change things. And it will spread hope to many, many others. After I spoke to a group in Billings, Montana, in September a couple took me aside and said they were interested in starting a campaign with retailers across Montana. One of those "buy a paper tulip and fight Parkinson's!" sort of things you see in stores and banks. I encouraged them to follow the idea. And that was the last I thought of it ... until February. Turns out they got Albertson's grocery stores and Wells Fargo bank to participate across Montana. They've now enlisted a large group of people who are caught up in the positive possibilities. And it's all happening this summer.

We're not suggesting that everyone needs to go start a state-wide effort to change the face of Parkinson's care and research. But there is just so much to be hopeful about. And all of us can do something. Join the walk-a-thon in your area. Write a letter to congress. Make paper tulips. Or simply get up and get yourself enrolled at the local gym. Start with yourself and the rest will follow.

Planned Giving Equals Legacy for Parkinson's Community

There are many ways to provide for a cause you believe in. You've probably written a check. Perhaps you've given an in-kind gift of personal property. You may even have transferred ownership of stock to a charity. Some gifts are quick decisions. Others, namely those termed planned gifts, necessitate—as the name suggests—a little planning.

The most common form of planned gift is the bequest. For many donors, a bequest is a way to give more significantly than would be possible during their lives. For others, a bequest rounds out a lifetime of philanthropy. Including a charitable gift in your will or living trust is the simplest way to leave a lasting legacy for what matters to you the most.

Charitable gifts made by bequest are deducted from a donor's federal estate tax, meaning that assets from your estate that would otherwise go to the government instead benefit the charity of your choice. In the case of the Northwest Parkinson's Foundation, charitable support advances our mission: to optimize quality of life for our Parkinson's community through awareness, education, advocacy and care.

Bequests can take several forms, but typical bequests are specific or residual. The former

might be the donation of a specific sum of money or a specific item, such as a house. The latter describes a bequest for which the remainder of a donor's assets becomes a charitable gift after all expenses and specific bequests have been paid out.

The bequest is just one type of planned gift. There are also gifts of retirement assets like pension plans or IRAs, gifts of life insurance policies or proceeds you no longer need, and "life income" gifts that provide you or others you designate with regular payments for life.

All these planned giving options have tax benefits. As with any significant financial decision you make, it is best to consult with your attorney, accountant or financial advisor to help guide your planning.

The Northwest Parkinson's Foundation depends upon your generosity to carry out its mission. Our ability to positively impact the Parkinson's community relies on your support—now and in years to come.

If you have questions about giving to the Northwest Parkinson's Foundation, please contact us at (877)980-7500 or nwpcf@nwpcf.org.

H.O.P.E. Goes Into Second Printing

Board member Hal Newsom's book H.O.P.E. was published early in 2002. It recently sold out, so we have done a second printing. If you haven't gotten your copy of H.O.P.E. you can order now - they're back in stock. This is what others are saying:

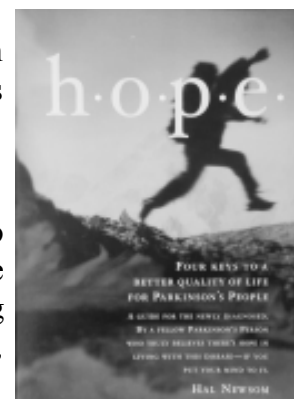
"This book not only lived up to the title, but it gave me some clear direction on what I might do next - in many different situations. It's been a guide as well as an inspiration."

-Derrick R., Klammath Falls, OR

"I bought it like I have half a dozen other Parkinson's books. But I was so surprised when I read it! The message is different than any other book I've seen. It's so strongly pro-patient and pro-active. Not only did I start exercising again, but I ordered seven more copies: one for each of my kids." *-Anne T., Spokane, WA*

Buy it directly from the Northwest Parkinson's Foundation for \$14, which includes shipping. Send your check to NWPF - HOPE, P.O. Box 56, Mercer Island, WA 98040.

As Hal has directed since the first book sold, all proceeds go directly to the Northwest Parkinson's Foundation.



What is Essential Tremor?

Essential Tremor (ET) was so named, ironically, because it's essence was unknown. But since the discovery of ET, a great deal has been learned. Because of it's similarity to Parkinsonian tremor, misdiagnosis between the two conditions happens occasionally. Essential tremor is typically somewhat more benign than Parkinson's, and treatment is considerably different.



ET affects upwards of three million Americans. It is the most prevalent movement disorder, the incidence of which increases with age. Other synonyms for ET include: familial tremor, benign essential tremor, senile tremor, or senescent tremor. Fifty percent of the people with ET have a family history of the condition. Because ET and Parkinson's disease can both present with a tremor, ET is commonly mistaken for Parkinson's disease.

The most common symptoms of essential tremor are shaky voice, nodding head, arm tremor, and hand tremor. Hands are the most common body part affected by ET, although the head and voice are frequently affected (Parkinson's rarely affects the head). The trembling is usually equal on both

sides of the body, however ten percent of people with ET have tremor beginning in one hand or on one side of the body. ET rarely affects the legs.

Fortunately the tremor rarely becomes disabling, but it may cause difficulty when performing daily activities. Eating, drinking, and holding or using objects and tools can all be impaired. As the person with ET ages, the tremors may begin to lessen in frequency but increase in amplitude. Additionally with ET when the affected body part is moved the tremor may appear to worsen. This is different than the typical Parkinson's tremor. But another contrast to Parkinson's is that ET does not tend to commonly cause bradykinesia (slow movement) or muscle rigidity.

People with ET rarely exhibit resting tremor, unlike people with Parkinson's. Another difference between the two is that the hand tremor usually begins in the thumbs in PD, whereas ET's hand tremor usually begins in fingers 2-5. If the tremors begin in the leg or arm on one side of the body, then it is more likely Parkinson's.

The treatments for essential tremor include medications, therapy, and surgery. Deep brain stimulation (DBS) surgery is very effective in treating essential tremor.

Kristin Johnson is a PharmD candidate at Washington State University. Stephen M. Setter, PharmD, is An Assistant Professor of Pharmacotherapy at Washington State University's College of Pharmacy.

Other Essential Tremor Information

The International Essential Tremor Foundation is on the web at www.essentialtremor.org, or you can call or write:

IETF
P.O. Box 14005
Lenexa, Kansas 66285
Toll free: (888) 387-3667

The IETF is a paid membership organization, however, so you will not get newsletters and other info unless you join - starting at \$25 per year.

The best source of information is a doctor trained in movement disorders. When looking for a neurologist, ask about their training in this field - it can make a significant difference in your quality of life.

Mr. Wasson Goes to Washington

An Account of a PWP's (Person With Parkinson's) testimony before the U.S. Senate Judiciary Committee

Last year, one of the hottest debates in Congress was over embryonic stem cell research (ESCR), particularly the technique known as somatic cell nuclear transfer (SCNT). The House passed a bill outlawing ESCR, making it a crime punishable by a fine and ten years in jail. The corresponding Senate bill, sponsored by Sen. Brownback (R-KS), also criminalized such research. The Senate killed that bill but did not have the votes to pass a pro-ESCR bill. The debate is hot again this year, with the sides only slightly more drawn.

On March 19, 2003, I testified before the US Judiciary Committee, in favor of ESCR and SCNT (also referred to, when used for medical research, as "therapeutic cloning"). The purpose of this research is to regenerate cells and tissue in sick or injured human beings, not to reproduce another human being. But the opponents of ESCR and SCNT define all research using cloning of human cells or tissue as "reproductive cloning," the making of a human being. The hearing at which I testified was appropriately entitled, "Drawing the Line Between Ethical Regenerative Medicine and Immoral Human Cloning."

*"Compassion and common sense must prevail. Ignoring the potential of therapeutic cloning would be a national tragedy and a huge mistake. But as with so many potential scientific advances, a vocal and well-organized minority is trying to stop this research."
-Greg Wasson, before the U.S. Judiciary Committee*

Somatic Cell Nuclear Transfer is the process of extracting the nucleus of a donor egg and replacing it with the nucleus of one of the patient's cells—a hair follicle or skin cell. The newly formed cell is then encouraged to begin cell division through means of chemistry or electricity, which quickly produces embryonic stem cells. After a few days the stem cells are transplanted into the brain, or wherever needed, and hopefully continue to multiply. In the case of Parkinson's disease, the stem cells

transplanted in the brain would become dopamine-producing cells.

Just about everyone, aside from the "Raëlian" cult, opposes human reproductive cloning. The issue is whether a five-day-old unfertilized cell mass amounts to the reproduction of human life. For the great majority of Americans the answer is no, and they support SCNT for medical research.

I argued that SCNT is an attempt to restore human life, not destroy it, and that:

Compassion and common sense must prevail. Ignoring the potential of therapeutic cloning would be a national tragedy and a huge mistake. But as with so many potential scientific advances, a vocal and well-organized minority is trying to stop this research. Galileo, Columbus, and a South African doctor named Christian Barnard, all held scientific beliefs that frightened their contemporaries. But the earth does revolve around the sun, the earth is round, and heart transplants are everyday miracles. Today the target is therapeutic cloning.

My testimony seemed to go over well. At least Senator Orrin Hatch, the committee chair and a great proponent of ESCR and SCNT - despite being a pro-life conservative - said, "I agree with Mr. Wasson," something I never imagined I would hear from that source. He also said something as an aside that fuelled my hope: "I don't think the Brownback bill will pass."

With the US Senate stalemate, it is up to state legislation, such as the bill that was passed last year in California, to legalize and protect ESCR and SCNT. This is our charge, to let people know first what it is like to have Parkinson's, and then what regenerative medicine can do for us People With Parkinson's and for the 128 million other people in America with incurable chronic diseases.

Greg Wasson is National Field Representative for the Parkinson's Action Network. In 2002 he received the first Millicent Kondracke Award for Outstanding Advocacy presented by Michael J. Fox. He has had PD for eight years and lives in Cotati, CA with his fiancée, fellow PWP and PD activist Ann Campbell. He can be reached at (707)795-7017.

Dry Mouth Issues - More Than a Nuisance

Dry mouth may seem like more of a nuisance than a medical condition, but long-term dry mouth can be painful and may eventually develop into a serious health concern. Not only is dry mouth just “part of” having PD, there are also literally hundreds of medications that can cause dry mouth. But there are also easy solutions.

Xerostomia is the clinical term for dry mouth. It is a result of the salivary glands not producing adequate amounts of saliva to wet the mouth. Some symptoms of xerostomia include: dry, tough and sticky oral cavities, cracked lips, difficulty with chewing and swallowing, open sores, and oral infection. Often, medication induced xerostomia may subside after continued therapy, but many people with PD have some degree of dry mouth persist.

So why is xerostomia such a big concern? Saliva is part of the initial process of digestion. Prolonged periods of xerostomia can contribute to malnourishment. Secondly, xerostomia can lead to painful chewing, speaking, and swallowing. Patients with painful xerostomia may not chew their food properly, and when you combine this in a person with PD who may

already have difficulty swallowing, there is an amplified risk for choking. Improper chewing can also add to malnutrition problems. Finally, saliva helps protect against tooth decay and periodontal (gum) disease. Saliva does this both by neutralizing the destructive acids produced by plaque, and by washing away the sugars on your teeth that can feed the plaque bacteria. Some people with PD who have long standing dry mouth require extensive dental work due to tooth decay caused by xerostomia.

If changing a few habits isn't enough to alleviate your dry mouth, your physician may make suggestions of prescription or non-prescription products to help.

Some people with PD report excellent relief of dry mouth with Myntz or Sqyntz, sorbitol based products available in the candy section of grocery stores. Always remember that the best defenses against xerostomia and tooth decay are good oral hygiene and regular check-ups with your dentist.

Kristin Johnson is a PharmD Student at Washington State University College of Pharmacy.

Seattle to Portland Ride - Training Continues...

Now it's May. The 200 mile Seattle to Portland ride is coming up - 7,000 people will make this ride July 12th and 13th. The 100 members of "Team Parkinson's" will be amongst them, having dusted off their bikes and started putting in the mileage this spring to get in shape.

The STP ride has turned into a wonderful fundraising event for the Northwest Parkinson's Foundation. One of the great beauties of it is that, unlike traditional fundraisers, this one costs almost nothing. We have one sponsor for Team Parkinson's - Lumbermens Building Centers - who contributed \$10,000 again this year. That money will cover all incidental costs, like team riding jerseys, rental of a support vehicle, and supplies to keep the team humming. That means that all donations our riders get for this event go directly to serving the Parkinson's Community.

We would love your support on this ride. If you *didn't* dust your bike off, but want to make a difference, why not challenge us to complete the ride? Send your donation with a note that it's to support Team Parkinson's, and help make this event that much more of a success.



If your bike still sits in the garage like this one...

The Giving Pages

The Northwest Parkinson's Foundation exists solely through the support of the community. This comes in the form of grants for special projects, but primarily through donations made by individuals and families. If the work we do has helped you or someone you know to live a better life with Parkinson's, we ask that you consider making a contribution. The work we do helps thousands, and it's done only with your support.

The people listed here made contributions in March and April of 2003. Thanks to everyone who helps us make a difference!

Mr. & Mrs. Bob Amburgh-Whitney
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In Memory of Donald Anable

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In Memory of Clarence Yoder
Betty Yoder

**Porridge for Parkinson's -
an event thrown by
Marty and Colleen Taucher**

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Rhoda Altom
Mr. & Mrs. Charles Atterbury
Cynthia Baker
Alta Barer
Colleen Barrett
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**NORTHWEST
PARKINSON'S
FOUNDATION**

New Contact Info:

P.O. Box 56
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98040

Telephone: (877) 980-7500

E-mail: nwpf@nwpf.org

www.nwpf.org

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May/June 2003

Upcoming Events

Young Onset Support Group - Kirkland, WA

New group meets third Wednesday of each month at Evergreen Hospital from 7:00 to 9:00 p.m. Contacts - Mitch Levy:

res06h12@gte.net

or call Ann Guthrie: (206)543-5369.

Group Health Seattle to Portland Bike Classic

July 12th and 13th

200 miles in two days. Team Parkinson's will be there!

More info: (877)980-7500

or www.nwpf.org

Washington APDA Walkathon - Redmond, WA

September 13th, 2003

Call (206)543-5369, or toll free: (888)400-2732

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