



Parkinson's Post

Awareness - Care - Education

NORTHWEST PARKINSON'S FOUNDATION

January/February
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.

Let's go for a Ride!*By Craig Howard*

It's winter. We drive to work with our headlights on, and we drive home with them on. Rain and crackling fires keep us inside, and many people can't think of a thing that would get them outside.

How about a bicycle ride?

The Cascade Bicycle Club's Seattle to Portland ride is July 12th and 13th this year. It seems like a lifetime away, but, believe it or not, this is the time to start training. And we would love to have you, or someone you know, join us in July.

Why do we do it?

The Northwest Parkinson's Foundation has participated in the "Pedal For a Purpose" program in the STP for the past three years. 2003 will be our fourth ride, and we anticipate having over 100 riders. When we ride we raise awareness about Parkinson's, and we also raise a significant amount of money for the cause. In 2002 we raised \$50,000; this year we anticipate raising \$100,000!

Who does it?

Team Parkinson's, as we're called, has been comprised of people ranging in age from 15 to 72. And a wide variety of people in between. Some have Parkinson's, some love others with Parkinson's, but all of us do it to achieve a higher quality of life for people with Parkinson's everywhere. Most do it because

they want to help, and they want a personal goal. And this goal is certainly a challenge, but attainable. And the rewards aren't limited to just yourself.

What does it take?

You have to have a bike. The last two years I've done it on an inexpensive mountain bike. But in the ocean of 7,000 riders you see everything out there – from \$6,000 road racing bikes to unicycles and rollerblades. (Honestly, we've seen both!)

It takes some time. Time to train, mainly. It takes some will. Team work helps a lot. Friends keep you training, and they keep you fired up to reach the goal.

Join us!

This is a call for riders. If you have thought about doing this ride, or you know someone else who might be interested, give us a call. We've got information on the ride, and have plans for lots of training rides and BBQ's and other fun stuff planned through the coming months. Let's go for a ride!

For more on the STP call (877)980-7500, or email nwpf@nwpf.org.

Craig Howard is co-founder of the NWPF, and he still can't believe he's finished the ride twice. His training started again January 2nd. choward@nwpf.org

Looking for Bicycles

We have a number of people who want to ride the Seattle to Portland ride, but they don't have a bicycle that's up to the task. If you have a bicycle in the garage that you think might be good enough to go the distance, and you're not using it, why not loan it or donate it? It will go to work right away raising money for the Northwest Parkinson's Foundation. Just call the number above and we'll discuss the options.

ProFiles:

Dr. Jeff Shaw of the Booth Gardner Parkinson's Care Center

by Carolyn Powell

Meet Dr. Jeff Shaw of the Booth Gardner Parkinson's Care Center's clinical team. Dr. Shaw earned his Bachelor of Science from the University of Georgia, and his Masters from Georgia State University, before earning his Doctor of Psychology (Psy.D.) in Clinical Psychology at the American School of Professional Psychology in Chicago. He went on to a Neuropsychology post-doctoral Fellowship and Assistant Professorship with the University of Missouri School of Medicine.

Dr. Shaw was drawn to study psychology because of an interest in how "people cope with adversity." His area of expertise, Neuropsychology, is where the brain and behavior meet. Neuropsychology is a blend of classical neurology's focus on the function of each location in the brain, and modern psychology's focus on behaviors.

During the week he provides neuropsychological assessment, individual and family counseling, and also supervises two clinical psychology doctoral students.

Dr. Shaw explains Cognitive Assessment as, "a thorough check up of thinking skills. A way to identify strengths and weaknesses. This in turn allows for targeted treatments and therapies to address those weaknesses."

At the Center, Cognitive Assessment is a key part of their patient driven, multidisciplinary model of care. A Cognitive Assessment makes a great beginning for the clinic evaluation process:

- ▶ It establishes a baseline of the patient's thinking abilities for future reference and comparison.
- ▶ It allows clinicians to see how people's cognitive abilities change as medications are adjusted, and then use that knowledge to adjust treatments.

- ▶ It serves as a catalyst for deciding which therapies (physical, occupational, and/or speech therapy, individual and family counseling, nutritional counseling, or pharmacological services) the patient should seek.

In addition to assessments, Dr. Shaw counsels patients individually or as a family. He finds that family sessions can help people discover available resources and how to use those effectively.

I met Dr. Shaw just after our family got the news that my father's cancer was terminal. Dad was my mother's primary Parkinson's caregiver, and loving husband of 44 years. He was an energetic, can-do kind of guy, and not destined to be an "easy" patient. We wanted help facing this with honesty, dignity, pragmatism and love. Our session with Dr. Shaw gave us strategies, tips and tools for working together while respecting each person's unique capabilities and limits. I left the Center that day feeling strengthened and encouraged for the days ahead.

"These sessions also allow family members to find a different framework for looking at their situation" says Shaw. He recommends that anybody experiencing stress related to changes in their medical, social, or family status consider counseling. Dr. Shaw says that by establishing a relationship with a counselor early, families then have that source of support "in the face of any future crisis." Some of his patients simply call to check in and maybe ask a question. For PD patients and their families, counseling can help simplify and clarify the choices facing them.

*The Booth Gardner Parkinson's Care Center is in Kirkland, Washington.
Telephone (425) 899-3123.*

January 20th - Telemedicine presentation

Dr. Monique Giroux of the Booth Gardner Parkinson's Care Center will make a telemedicine presentation on Parkinson's Monday, January 20th, at 2:00 p.m. If you're in the Seattle area, and would like to be there on the day of the presentation, or are interested in seeing it at a remote site in Pt. Townsend, Pt. Angeles, or Bremerton, contact David McIntire at (206)352-1459.

For locations in any of the following communities, contact Polly Patton at the PRC in Spokane: (509)473-6740: Chelan, Chewelah, Clarkston, Colfax, Colville, Davenport, Dayton, Deer Park, Ephrata, Grand Coulee, Ione, Moses Lake, Newport, Odessa, Omak, Othello, Pomeroy, Pullman, Republic, Sunnyside, Walla Walla.

Go Ask a Doctor! *By Guest Doctor Phil Ballard*

This issue's question: How do I make the most of most of my doctor appointment?

This is probably what you want from an appointment: Ample time for a thorough history and examination, discussion of your disorder and alternative diagnoses, causes, your prognosis, treatment options, medications, their side effects, etc. Sound good? You bet!

Now how long do you think such an encounter would take? It's probably a minimum of two hours! Unlike lawyers, physicians aren't paid by the hour. The squeeze between rising overhead and poor insurance reimbursements forces "efficiency." For most docs that translates to more patients in less time. You don't like it; and believe me, the doctors don't like it. But that's the reality of medicine in the early 21st century.

You can do a lot to make this time well spent. Here are some suggestions:

Do a reality check on your expectations. All your questions are not going to be answered in one appointment, so do some prioritizing. Select the two or three most important ones. Optimal treatment usually evolves over time, often with trial and error. Parkinson's and related disorders are just that way. See your physician as a consultant, and your treatment (which can indeed be very effective) as a collaboration.

Go prepared. Your medical history is the most important part of your evaluation. A good history gives critical information that will help separate Parkinson's from other disorders that can resemble Parkinson's, and it allows intelligent management of medications and other treatments. A rambling historical discussion argued between the patient and their spouse in front of the doctor is a nightmare. It's

important to provide a concise overview of what you know about your condition and the other factors in your life that may affect it.

Your checklist for an initial consultation:

- I have reviewed and am able to present a chronological 'story' of my disorder.
- I have sent ahead of time copies of my medical records and any MRIs, etc.
- I have a list of any other serious illness, operations or injuries I've had.
- I have a list of all the medications I take and when I take them.
- I am aware of any neurological disorders in my family.

Additionally, consider writing these things down as a synopsis, and for sure bring your spouse or important other. They often are aware of things that you aren't, and are another set of ears for what the doc tells you.

Checklist for a follow-up visit:

Usually the focus is on what has happened to your symptoms since you were last seen, or what the affect of treatment has been.

- I have thought about changes in my symptoms, and what my major concerns are.
- I am prepared to report new health problems that have arisen.
- I am able to report the exact times that I take my medications, when I start to experience an effect, and how long it lasts.
- I have done my homework, and know more about Parkinson's than I did earlier.

Do these things, and you've done your part to make your consultation productive and satisfying.

If you have questions for the doctor, address them to NWPF, P.O. Box 56, Mercer Island, WA 98040, or email them to nwpf@nwpf.org. Be sure to mention that you're writing with a question for this column. Questions will be chosen that raise important issues for the Parkinson's community at large.



Anti-oxidants in Parkinson's Disease *By Laurie K. Mischley, ND*

Understanding Anti-oxidants

Every cell throughout the body has a life of its own. Like humans, each cell that lives within us requires nutrients, breaths, and excretes waste. Free radicals are among the more dangerous of the waste products coming from cells.

Here's an analogy: Under normal conditions, each child on the playground has both pockets filled with money for lunch. Free radicals are like a child who only has one pocket full of money, and therefore not enough money for lunch. Of course the free radical does not want to starve, so it will steal money from another child's pocket, creating another free radical. Every time one child gets a pocket full of money stolen, he/she steals money from someone else. More and more free radicals are created, each one causing damage to the surrounding cells and tissues.

Simply put, the brains of individuals with PD have too many free radicals and not enough anti-oxidants

Under normal conditions, the body defends itself from free radical damage using anti-oxidants. Anti-oxidants are molecules with extra lunch money. The body makes some anti-oxidants (melatonin, CoQ-10, glutathione) and gets other anti-oxidants from the diet. Some anti-oxidants are more powerful than others, and some prefer one body part over another.

Oxidative stress occurs when there are too many free radicals or not enough anti-oxidants to quench them. Free radicals, in moderation, are normal! It is only when there are more free radicals than the body can cope with that oxidative stress results and causes disease.

Anti-oxidant Approach to Parkinson's Disease

As is the case with most diseases, several factors determine the initiation and progression of Parkinson's disease. To begin with, there may be a genetic predisposition or a toxic exposure (herbicide, pesticide, drugs) that initiates the disease process.

The second part of the disease is progression. It is estimated that the first signs of PD occur

only when 75% of the cells in the substantia nigra have died. The symptoms of PD are due to a loss of dopaminergic cells in the substantia nigra. As these cells die, the brain becomes short of dopamine and thus the body begins to experience the symptoms of PD. The conventional medicines for PD are targeted at increasing dopamine levels, which for a time helps the symptoms, but do nothing to slow progression.

What do we know about disease progression? While free radicals are not the sole cause for cell death, we now know that oxidative stress is largely responsible for disease progression. Simply put, the

brains of individuals with PD have too many free radicals and not enough anti-oxidants. Several dozen studies have shown this to be true and there is little disagreement among physicians and researchers in the field that this is the case.

It must be stressed that anti-oxidants are NOT the cure for Parkinson's disease, but supplementation may help slow disease progression. The anti-oxidant approach to PD is two-fold:

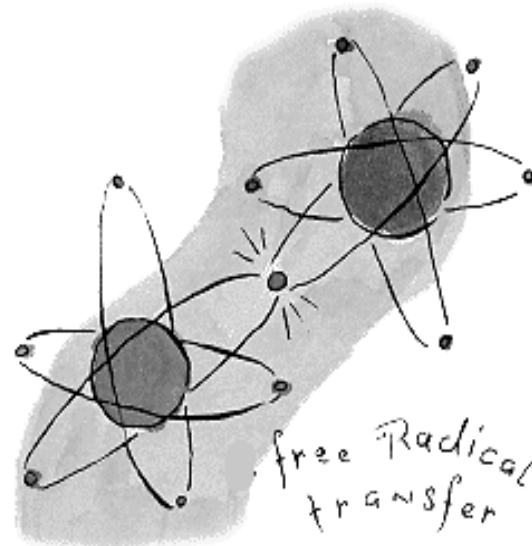
1. Reduce Free Radicals

In your diet

- Avoid alcohol, smoked and barbecued food, deep-fried foods, hydrogenated oils

Environmental exposures

-Toxins/ Herbicides/Pesticides: paraquat, rotenone, dieldrin



(all three have been associated with Parkinson's)
-Common air pollutants

Reduce sources of oxidation

- Iron: many individuals have higher-than-normal levels of iron, which can significantly increase oxidative stress in the brain, causing dopamine neurons to die much faster than they otherwise would. Your doctor can measure iron levels with a blood draw.

- Heavy metals: aluminum, manganese, mercury, lead, zinc, copper (a hair test is a screening tool – about \$50)

- Homocysteine – Higher in patients taking L-DOPA, homocysteine contributes to PD, heart disease, and dementia. It can be easily measured by your physician and easily reduced with vitamin supplementation.

Drugs/supplements

-Vitamin C – normally an anti-oxidant, vitamin C can actually cause free radical damage in the brains of individuals with PD. If you are taking vitamin C, make sure you have adequate amounts of glutathione!

-L-DOPA- in vitro studies suggest L-DOPA may cause oxidative damage. Try medications without side effects before increasing your L-DOPA dose.

2. Increase Anti-oxidants

In your diet

- Increase fruits and vegetables- blueberries, soy, cranberries

- Lycopene - shown to be low in PD patients; tomatoes are a great source

Exercise

-Naturally induces the body to produce anti-oxidants

Supplement with anti-oxidants

Glutathione, Co-enzyme Q10, vitamins A & E, flavanoids, cysteine, Lycopene... the list of possibilities is long. Consult with your GP, your neurologist, and/or a Naturopathic Doctor to discuss what might be right for you.

(Note of caution: Do not supplement without the advice of a knowledgeable physician! Each

individual is different and for some the anti-oxidants listed above may be inappropriate or even harmful. Make sure your doctor knows exactly what you are taking!)

Can a blood test determine anti-oxidant status?

It is not yet possible to directly measure free radicals, but some labs across the country have come up with good ways to indirectly assess how well your body deals with oxidative stress.

Tests are now available to determine anti-oxidant status, glutathione, and Co-Q10 levels, all of which have been shown to be low in individuals with PD. An entire oxidative stress panel can be done for \$250...but it's not likely to be covered by insurance.

Iron levels have been shown to be elevated in PD patients and can be a significant contributor to oxidative stress. A comprehensive iron test is likely to be covered by insurance and costs approximately \$65.

What next?

The links between oxidative stress and Parkinson's have been shown in many studies, but a clear understanding of the relationships is elusive. For now! As you probably know, each person's Parkinson's is different. Anti-oxidant treatments make for an even more complex puzzle, but the benefits can be great.

Consider a consultation with a Naturo-pathic Doctor (N.D.), and discuss your interest with your neurologist. Working as a team is the best way to make progress in your life with Parkinson's.

Laurie K. Mischley is a naturopathic physician in Seattle. She studied Pre-Medicine and Nutrition Science at Penn State University, and received her Doctorate in Naturopathic Medicine from Bastyr University. Her practice and research are focused on neurodegenerative conditions and clinical conundrums. She can be reached at the University Health Clinic: (206)525-8012, or lauriemischley@attbi.com.



The Giving Pages

We want to thank everyone who finished 2002 with such a generous outpouring of support. The Northwest Parkinson's Foundation exists to help the Parkinson's community, and we couldn't do it without your support. Thank you - we look forward to a great year!

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Upcoming Events

January 20th, 2 p.m.

Dr. Monique Giroux of the Booth Gardner Parkinson's Care Center will conduct a presentation via telemedicine. This means that support groups in select communities around the Northwest will be able to see the presentation on television at a central location - and ask questions live! See the box on page two of this newsletter for locations and contact information.

July 12th and 13th

Seattle to Portland Ride. Two days, 200 miles, with a goal of \$100,000 raised for Parkinson's. See article this issue - join us!

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January/February 2003

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