

I N S I D E

Researching 'forced' exercise | 2

Day focuses on wellness | 3

HOPE conference highlights | 3

Team Parkinson's 2011 | 4-5

The giving pages | 6-7

Remembering a board member | 8

A B O U T U S

The **Parkinson's Post** is published by the Northwest Parkinson's Foundation, a 501(c)(3) charitable organization.

Our mission is to establish an optimal quality of life for the Northwest Parkinson's community through awareness, education, advocacy and care.

We welcome your comments on this newsletter and all our activities.

Visit us at nwpf.org



NORTHWEST
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Pushing the limits with Parkinson's

BY SUE SWANSON

I hate to diagnose people with Parkinson's disease because they often become couch potatoes. I was puzzled by these words from a neurologist. When I was diagnosed at 52, I was still quite active and was compulsive about remaining so.

That first year after diagnosis was full of exercises and supplements as well as a resistance to medications.

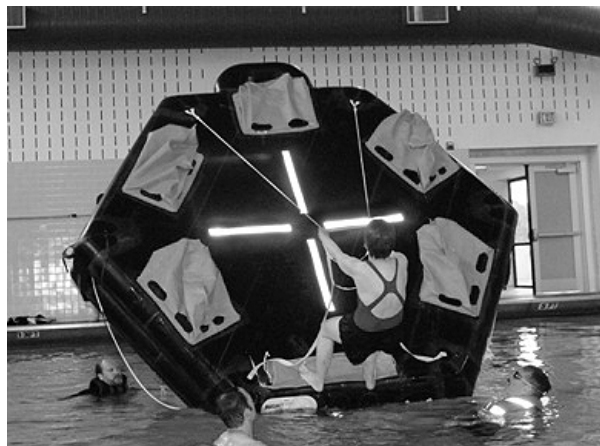
But while I kept going, I didn't feel good. I had yet to meet the movement disorders specialist who would inform me I had met my "controlling match" and we'd be doing things his way.

Eventually I was doing many common "Parky" things—walking the dog, going to exercise classes, gardening, napping ... and taking the medications.

While I felt life was good, I now realize I had been settling into viewing myself as old and infirm. I was seeing lots of limitations in the present and future.

But that was going to change.

In January 2010 my husband Nils and I read about organizations that provide surgeries in developing nations for women suffering from obstetric fistulas due to obstructed labor.



Courtesy photo

The author flips a life raft during training with the organization Mercy Ships.

Without access to C-section, some women who are too small to deliver a baby experience a fistula—a perforation of the bowel or bladder—during delivery. This damage leads to chronic incontinence and infection.

In addition to physical suffering, many women with fistulas suffer psychologically when they are shunned by their families and communities.

Nils and I learned that the organization Mercy Ships operates the Africa Mercy, the largest non-governmental hospital ship in the world, and performs surgeries to repair fistulas.

A few days after reading about the organizations that help women with fistulas, Nils surprised me by asking, "What would you think of serving on the Africa Mercy for two years?"

I nearly caused him a stroke when I replied, "Sure!"

We feared we'd either be rejected or that something would come about in

> CONTINUED ON PAGE 7

Research tests power of ‘forced’ exercise in symptom control

By Jay Alberts, Ph.D.

In 1892 Harry Darce composed “Daisy Bell.” The most recognizable part of this song is:

*It won't be a stylish marriage—
I can't afford a carriage,
But you'd look sweet upon the seat
Of a bicycle built for two.*

It seems Mr. Darce was ahead of his time in lauding tandem bicycling. In 2003 I rode a tandem bicycle in the Register's Annual Great Bike Ride Across Iowa—otherwise known as RAGBRAI. My “stoker” that week was 48-year-old friend Cathy Frazier.

Cathy had been diagnosed with Parkinson's disease five years earlier. During that week in 2003, Cathy observed that it didn't feel like she had Parkinson's disease.

It was evident in a birthday card she wrote that week to another rider on the inaugural “Pedaling for Parkinson's” team. The result of this simple act astounded Cathy and me. Like many other people with Parkinson's, Cathy had been experiencing micrographia—small and illegible handwriting. But it wasn't evident in her handwriting on that birthday card.

I attributed Cathy's improved handwriting and sense of good health to the clean Iowa air and our steady diet of apple, blueberry and gooseberry pie and homemade ice cream.

But over the next few years, as I continued to ride tandem with Parkinson's patients, I kept hearing them say they felt better after tandem cycling. I could no longer attribute these improvements to air or diet.

In 2007 I begged, borrowed and robbed (from my own bikes) enough equipment to develop a tandem cycle that could be used in an exercise study.



Courtesy photo

On the road: The author riding tandem with his son Grant.

Before my colleagues and I started the study, I briefly considered the possibility that the research would be a waste of time. But that thought was quickly dismissed by a lingering question: Why are patients showing improvements in tremor and handwriting when they are only exercising their legs? The changes in upper-extremity function must mean exercise is changing brain function.

When I reviewed the literature related to the effects of exercise on Parkinson's, I realized that the promising studies used “forced exercise” to train their parkinsonian rodents. In a typical forced-exercise paradigm, the animal is placed on a motorized treadmill and “encouraged” to keep pace to avoid coming into contact with an electric grid at the rear of the treadmill. Hence, they must maintain a relatively high rate of exercise.

I reasoned that maybe when Parkinson's patients rode tandem with me it was a form of forced exercise—without the electricity. That is, the patients typically pedaled 50 to 60 rpm when they rode alone, but on a tandem with me, I controlled the pedaling rate

at 80 to 90 rpm.

We have since completed our initial studies of the effects of forced and voluntary exercise on motor function in Parkinson's patients. The results are promising as patients in the forced-exercise group exhibited a 35 percent improvement in clinical ratings of motor function after eight weeks of forced exercise. These results are preliminary, and many questions remain. But I look forward to further research and answers.

Meanwhile, I am pleased to know that folks in the Northwest are jumping on the bikes! A group has formed a Pedaling for Parkinson's exercise program at UW Medicine's Northwest Hospital in Seattle.

To me, a great benefit of these types of exercise programs is that they have the potential to alter the patient's role. Rather than being a passive recipient of medication or surgical intervention, patients can take a more active role in the treatment of this disease. So keep on pedaling!

Dr. Jay Alberts is a researcher with the Lerner Research Institute, part of the Cleveland Clinic.

Mind-body link focus of wellness event

THE SECOND ANNUAL Wellness and Parkinson's Conference will take place from 9:30 a.m. to 2 p.m. on March 5, 2011, at the Bellevue Hilton, 300 112th Ave. SE in Bellevue, WA.

The conference will focus on the power of the mind and the connections between how we think and how we feel. Additional presentations will cover exercise and stress management.

This conference is designed to educate and inform people with Parkinson's and their families about practical tools that can be used in addition to proper medication management and specialized care to achieve an optimal quality of life.

Speakers include:

- ◆ Dr. A. Jon Stoessl, a professor of medicine (neurology) and director of the Pacific Parkinson's Research Centre at the University of British Columbia in Vancouver

- ◆ Dr. Monique Giroux, a nationally recognized specialist in movement disorders and medical director of the Booth Gardner Parkinson's Care Center and the Northwest Parkinson's Foundation

- ◆ Sierra Farris, PA-C, a national leader in deep-brain stimulation therapy and member of the Booth Gardner Parkinson's Care Center staff

The cost is \$15 per person, with a boxed lunch provided.

Register online at nwpf.org/events.aspx or by mailing a check to Northwest Parkinson's Foundation, 400 Mercer Street, Suite 504, Seattle, WA 98109.

For more information, call 1.877.980.7500.

Conference draws crowd, instills hope

CELEBRATING ITS FIFTH YEAR, the HOPE Conference on Parkinson's has grown into the largest gathering of its kind in the Northwest and the largest such one-day event in the country. Nearly 700 patients and families from 10 states came together in Seattle on November 6, 2010, to connect with one another and learn from a distinguished group of national experts about living well with Parkinson's.

Speakers included Dr. Jay Alberts, associate in biomedical engineering at the Cleveland Clinic; Dr. James Leverenz, associate professor of neurology and psychiatry at the University of Washington; Dr. Monique Giroux, movement disorders specialist and medical director of the Booth Gardner Parkinson's Care Center and the Northwest Parkinson's Foundation; Dr. Matt Ford, assistant professor of physical therapy at the University of Alabama, Birmingham; and Peter Dunlap-Shohl, a cartoonist and blogger living in Alaska who shared his personal journey with Parkinson's.

A recurring theme at the 2010 conference was the benefit of wellness and lifestyle activities in moderating or slowing symptoms of Parkinson's disease.

Dr. Alberts highlighted the importance of exercise in slowing the loss of dopamine-producing neurons and, as a result, the decline in motor function in those with Parkinson's.

Dr. Ford showed the effects of music in minimizing Parkinson's symptoms. And Dr. Giroux discussed the importance of a comprehensive approach to wellness in addressing the many peripheral effects of Parkinson's disease.

The conference attracted 36 sponsors, exhibitors and artists who shared valuable information, resources and beautiful art with attendees throughout the day.

Feedback on the day was uniformly positive. "I come to the conference as a family member," one attendee shared. "It is an excellent conference ... warm, welcoming and hopeful." Other attendees remarked that the conference gets better each year and that it is an event they always look forward to.

Special thanks to Teva Neuroscience, Novartis, Boehringer Ingelheim, Evergreen Medical Center and UCB for their generous support of the event.



Staff photo
Dr. Monique Giroux presents to a full room at the 2010 HOPE Conference on Parkinson's.

Rider honors dad, fosters hope on road to Portland

BY MATT RAMERMAN

I moved home to Seattle from Atlanta in 2000 to be closer to my dad, Wayne Ramerman, who was starting his 13th year with Parkinson's disease. My father retired as a beloved small-town doctor of nearly three decades—a doctor who, in his younger years, would never have believed he'd be the patient someday.

Dad has managed his physical challenges with great determination, continuing to push himself physically and mentally at every turn and maintaining constant optimism about the future—all of which I believe has kept him moving to this day, 24 years into his experience.

Shortly after returning to Seattle, I became interested in two things—riding the Seattle-to-Portland Bicycle Classic (STP) and looking for a way to get more involved in advocacy and care for people with Parkinson's disease.

I found a reference online to a group called Team Parkinson's that was riding the STP in support of the Northwest Parkinson's Foundation.

I called the foundation and introduced myself to the executive director, who suggested we meet for lunch.

Little did I know that one lunch would lead to nine years serving on the board of directors, five trips to Portland on my bicycle and my father's quality of life dramatically improving as a result of being connected to the Northwest Parkinson's Foundation and



Courtesy photo

The author's father, Dr. Wayne G. Ramerman, with granddaughters Madison and McKenna.

the Booth Gardner Parkinson's Care Center—an amazing amount of life change from a simple connection around a bicycle.

What is Team Parkinson's? It's a group of remarkable people not just committed to raising money for a common and noble cause—but who are pushing themselves, stretching beyond their comfort zone and reaching a remarkable goal of pedaling a seemingly impossible 200 miles.

Folks from every corner of life join the team each year, united by a common experience with Parkinson's.

This fellowship yields a powerful connection as well as a sense of unity and optimism.

Each year the Seattle-to-Portland event attracts between 8,000 and 10,000 riders of all abilities, riding all types of pedal craft—from expensive carbon fiber racing bikes to unicycles!

The course is packed with an endless peloton of cyclists. Despite the vast number of cyclists, over the course

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STP an annual rallying point for one rider

BY CHRIS JEWELL

I was sitting on my neighbor Paul's front deck 11 years ago, enjoying a beautiful Seattle spring day after an early morning ride. Paul and I were talking about upcoming bike rides, and the topic of the 200-mile Seattle-to-Portland Bicycle Classic (STP) came up. Somehow a challenge got thrown out: "If you'll ride it, so will I."

At the time I was 40 and, although I was a recreational biker, my longest bike ride had been maybe 10 miles. I considered myself in fairly good physical shape, having been a commercial fisherman and construction worker all my life.

I only had one small health issue: Two years earlier, I had been diagnosed with Parkinson's disease.

Since my diagnosis, I'd been determined to stay in shape. Riding my bike was part of the plan, and the STP seemed like a good idea.

Paul and I began doing regular training rides around our hilly neighborhood of Magnolia. I quickly got used to telling Paul, "I'll see you at the top."

It soon became apparent to me that this was going to be a little harder than I'd thought.

I can't tell you many details about my first STP, except that by the time we got to the 50-mile mark, we'd come to the realization that our bikes were not the speed machines we'd thought. We inhaled

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our lunch and drank enough water to do a good impression of camels.

After lunch, time seemed to slow to a crawl. By the time we got to McKenna, WA, the sun was out and it was hot. The scenery was beautiful, but I was not having much fun and my Parkinson's wasn't doing me any favors.

When we pulled into the rest stop, the little shade available was being put to good use. That's where I met Bill Bell, founding executive director of the Northwest Parkinson's Foundation. He told me he was putting together a team to raise funds for a cause I was intimately familiar with. I decided to sign up for the following year's ride as a member of the team—but for now I had an STP to finish.

The single most valuable tool I had in my corner was my friend Paul's encouragement and confidence. It didn't hurt that he pulled lead for most of the ride, but what kept me going

were Paul's encouraging words—"You're doing great!" and, "Only 20 more miles," and, a while later, "Only 10 more miles." Those words kept me going. This is when I learned the true value of the support of a good friend.

When we arrived in Centralia, WA, the midpoint, our families were there holding banners and cheering—one of the best sights I've ever laid eyes on.

It's hard to articulate the feeling of accomplishment that came with crossing the finish line the next day. It had been well worth it.

In the 12 years since, I haven't missed a ride. The STP is a yearly rallying point for my family and many of my friends. My sons, 19 and 21, are avid riders and we train together.

My wife Suzanne caters fabulous meals for the team. She is joined at rest stops by bike mechanics from Alpine Hut and message therapists, all volun-



Courtesy photo

The author with Malu the dog at the STP.

teers. Their presence makes all the difference in the world.

Over the years Team Parkinson's has raised hundreds of thousands of dollars and spread awareness for an important cause, but we can't stop riding yet. We can use all the riders we can get.

So if you want to make more of your STP, consider joining Team Parkinson's. We'll see you on the road!

Team Parkinson's looks to new heights in 2011

JOIN THE EXCITEMENT as the Northwest Parkinson's Foundation and Empowerment through Adventure join forces to encourage people with neurologic disease to raise the bar for personal accomplishment.

In an effort we're calling **Team Parkinson's Kilimanjaro**, the Northwest Parkinson's Foundation is partnering with Empowerment through Adventure's **Leap of Faith** to climb Mt. Kilimanjaro this summer.

The climb will be led by Lori Schneider, an experienced climber and the first woman with multiple sclerosis to summit the highest peak on each of the seven continents. The Kilimanjaro climb, set for July 13 to 18, 2011, will be made by a group of people with multiple sclerosis and Parkinson's disease.

The climb is about awareness—including challenging misconceptions about the limitations of disease. It is also about empowering people to take off the labels that come with illness and to set and achieve their

highest personal goals.

As part of this adventure, the Northwest Parkinson's Foundation is creating a larger team—Northwest Team Parkinson's Kilimanjaro—that *everyone* can join. You set personal physical activity goals, work toward them, and "summit" with the team in July.

Northwest Team Parkinson's Kilimanjaro will come together through blogs, emails, online educational material and monthly meetings. Members will benefit from education, encouragement, support and inspiration each step of the way.

Join the fun and get more information at a kick-off seminar on January 22, 2011, in Seattle. For details on the seminar, which will be recorded and posted online for those unable to attend, call us at 1.877.980.7500. To register for Northwest Team Parkinson's Kilimanjaro, visit nwpcf.org/events.aspx or call us.



TRIBUTE GIFTS

Gifts to the Northwest Parkinson's Foundation support our educational publications and self-care tools, including this newsletter, weekly email news updates, a content-rich website, patient-education programs and our annual HOPE Conference on Parkinson's. In addition to sustaining existing programs, donations support our efforts to develop and implement innovative new programs that respond to the changing needs of the Parkinson's community.

We are privileged that so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year. In each issue we list tribute contributions made in honor or memory of loved ones touched by Parkinson's.

Those wishing to establish a permanent memorial may create a family fund with a minimum donation of \$2,500, either from a single gift or many. New family fund donors are listed below. To learn more, contact Joseph DiChiaro at 1.877.980.7500 or joseph@nwpf.org.

Listed here are tribute gifts received between **October 9** and **December 16, 2010**.

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2010 to prevent us from signing up—but we found ourselves on our way to Tyler, Texas, in June to go through Mercy Ship’s “Gateway” training for long-term staff.

I was told that, because of my Parkinson’s, I would not be able to live on the ship at length.

But the staff said they were “intrigued” by our qualifications and asked us to consider becoming part of the staff of the Gateway program. This would involve going through the program ourselves, which in essence meant an eight-week job interview.

Those eight weeks included classroom instruction and maritime basic safety training. (While I won’t be joining a firefighting team anytime soon, I did successfully flip a 12-person life raft from upside down to right side up!)

Our adventure continued as we traveled to Africa to continue our training. In August I found myself on the back of a motorcycle taxi in Benin, West Africa.

No helmet, in a skirt and flipflops at the age of 55, with stinkin’

Parkinson’s disease!

Women’s knees are not allowed to show in Benin, so I’m sure I committed a serious faux pas by accidentally showing some thigh as we buzzed through the city and countryside.

That motorcycle taxi ride came at the end of two weeks in Benin, where we served in an appalling prison and a well-run orphanage.

After our time in Benin we spent 10 days on the Africa Mercy, in port at Lome, Togo.

By early September we’d rented our house, packed the car and headed for East Texas to start a new era.

I have felt especially good since the spring. Dr. Monique Giroux, my movement disorders specialist, would say that new adventures restore zip to life with Parkinson’s, and I agree.

For me there is also a strong sense that I’m living the Bible verse about the power of Christ being made perfect in weakness.

I need to take good care of myself but I’m going to “live large” for as long as I can.

Gotta run ... the motorcycle taxi’s waiting!

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of a day you frequently encounter fellow Team Parkinson’s riders, clearly identified by the team jersey.

At rest stops along the ride, and even during training rides, you’ll find yourself approached by strangers curious about Team Parkinson’s. Inevitably you will discover that your new acquaintance has a family member or friend or colleague with Parkinson’s.

In these moments you discover your most important role with Team Parkinson’s—that of ambassador. These are your moments for making a connection between someone with Parkinson’s and the Northwest Parkinson’s Foundation, your chance to share the potential for living better.

Unfortunately, Dad never had the chance to ride with me to Portland.

But I pedal each mile for him, knowing that perhaps I can provide an important connection to someone seeking answers—seeking hope and a better quality of life—just as that fateful lunch provided me so many years ago.

Matt Ramerman is a Northwest Parkinson’s Foundation board member.

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NWPF remembers grace and service of founding board member

It is with great sadness that we note the passing of Paula Rose on December 1, 2010. Paula was a founding board member of the Northwest Parkinson's Foundation.

Paula, who lived for many years with Parkinson's disease, was a driving force in the growth and development of the Northwest Parkinson's Foundation during the course of more than 10 years of volunteer service.

Paula was a gracious and inspiring woman who lived life to the fullest and was an inspiration to many. She will be greatly missed.