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A B O U T U S

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NORTHWEST
PARKINSON'S
FOUNDATION

Parkinson's, step by step

BY DOUG MANUEL

Walking on a gravel beach you feel that you are standing still—the headland that must be rounded before the tide rushes in no closer, the pebbles slipping, offering no purchase, your backpack heavy with rain and sweat, knowing that if you stop muscles will tighten. One step at a time seems not enough.

I was a math teacher at the time I wrote those thoughts. Now I have Parkinson's. I was diagnosed in 2004, when I was 55—same age, same symptoms as my mother 30 years earlier. I knew too much and that day I cried.

Now I play pickleball, fake my way to the spice dance of zumba, lean off-balance in tai chi, teach a Parkinson's movement class without a lesson plan, run a support group without a curriculum, pedal a stationary bike to exhaustion, walk a 2.7-mile loop with two 200-foot hills, attack the persistent salmonberry briars interlaced with stinging nettles—and know that the tide of Parkinson's is unrelenting yet somehow feel that, around the next headland, there is a beach of great beauty.



Courtesy photo

Doug Manuel and his wife, Josie.

We begin with irritation—the foot that trips us on a flat surface, the dry eye from a slow blink rate, the half-complete sentence that hangs in the air, the arm that does not swing, the hand that does not write, the bowels that do not move, the sexual dysfunction, depression, anxiety, fatigue. Denial is good medicine.

We move to the drugs—Mirapex, Requip, amantadine, selegeline, Azilect, Stalevo. We switch doctors, take disability from work, join the Y, attend the annual HOPE conference, sign up for a double-blind drug trial that works wonders, see many headlands that must be rounded on an incoming tidal wave.

And yet, there is always the option, the choice to turn back, to stop—or better yet, to crawl, to climb, up and over to the next beach.

Doug Manuel lives in Bremerton, WA, and is a man of adventure and pickleball champ.

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

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The team needs *you*

BY FOREST LANE

FIFTY YEARS AGO, the lead character in a popular TV western advertised his services with a four-word statement of qualifications: *Have Gun, Will Travel*. His name was Paladin. True to the significance and meaning of his name, Paladin was “the champion of people in need and a protagonist of good causes.”

These days, the Northwest Parkinson's Foundation has a whole team of champions with their cleats to the pedal, each one with a similar statement of qualifications: *Have Bicycle, Will Ride (for Parkinson's)*.

I'm talking about the members of Team Parkinson's—54 and growing—who have signed up to ride from Seattle to Portland this July while pledging to raise



\$500 or more each.

We need you to join the team as a champion and sponsor of individual team members. You are fully qualified to be an *official encourager* of Team Parkinson's by helping to fulfill the pledge goals of each team member. Your qualifications? *Have Funds, Will Encourage!*

Visit Team Parkinson's online at nwpf.org and start clicking on the names of team members. Find someone who needs your “encouragement.”

Your donation—whatever you can manage—will be like a gentle wind on the backs of our riders as they make the 60,000 pedal revolutions to Portland.

“Have Bike, Will Ride,” said the paladin, Excuses won't help you to win!

No hired-gun skills,

We need dollar bills!

And for people to do what they kin!

P.S. As a first-time STP rider last year and as a Parkinson's man myself (diagnosed in 2003), I have experienced a reduction of Parkinson's symptoms while cycling. Albeit temporary, it's real. I'm hoping research in this direction will provide more clues to solving Parkinson's.

Forest Lane lives in Seattle.

Climbing to new heights

TEAM PARKINSON'S KILIMANJARO numbers have grown significantly since the January 2011 kick-off event at the Mountaineers. The team's purpose is to encourage people living with Parkinson's and their families to reach new heights by setting a personal exercise goal and logging their activities along the way to that goal.

Our team's 64 members have logged more than 700,000 activity points and are well on the way to reaching their collective goal of a million points by July.

People with Parkinson's and their

families are taking the challenge to increase physical activity and find better energy and wellbeing. Monthly meetings are ongoing to bring support and education about exercising with Parkinson's. Sierra Farris, PA-C, is leading the effort to sustain, train and motivate team members.

Farris, along with Monique Giroux, M.D., will climb Mount Kilimanjaro in July with a group of people who have Parkinson's or multiple sclerosis. Their goal is to bring awareness that a diagnosis of Parkinson's doesn't mean life is over—it's just beginning.

As life takes a new course with Parkinson's, so does the importance of living every day with as much spontaneity and vitality as possible.

Support groups: those threads that bind

BY LEONARD M. ZUNIN, M.D.

We cannot live by ourselves alone. Our lives are connected by a thousand invisible threads.

—Herman Melville

IN THE 1960s, they were revolutionary. In 2011, support groups are a mainstay in a multifaceted approach to Parkinson's disease.

Parkinson's support groups promote a focused social interaction in which a small group of people with Parkinson's (and perhaps their caregivers or friends) meet regularly with a facilitator.

The purpose? To share information, address common problems, improve coping strategies and foster camaraderie. The very act of listening and sharing offers the opportunity to function more effectively and continue to grow emotionally.

Sharing challenges, sharing solutions

Individuals respond to a Parkinson's diagnosis with a variety of emotions: disbelief, anger, fear, embarrassment, depression and anxiety among them.

Participants come to a support group hoping to improve their lives.

Each participant is unique, as is the nature of that individual's disease. Each brings to the table different coping skills and life experiences. They benefit from the group in different ways and at different rates.

Watching others cope well with similar problems often instills hope.

Moving out of isolation

A common feeling among people with Parkinson's is isolation from others. Many experience great difficulty sustaining interpersonal relationships. They may feel unlikable and unlovable.

Support groups often provide the first experience of being understood, the first opportunity to identify with others who are coping with Parkinson's. Enormous relief often accompanies the recognition that one is not alone.

Frequently, people with Parkinson's feel their behavior and responses in the face of the disease are abnormal. Helping people see that their reactions are a normal response to an unanticipated life-altering illness is called *normalization*.

Support groups can provide normalization, which can be a powerful healing factor as individuals replace their feelings of separateness with a sense of acceptance and sharing.

Gaining knowledge enhances coping

Most participants leave the group far more knowledgeable about their particular symptoms and challenges than when they entered. This makes them increasingly able to help themselves and others.

How is this accomplished? By group sharing and through presenters and speakers from outside the group, often professionals in specific areas such as voice therapy and medications.

Reaching out, reaching in

One of the greatest strengths of Parkinson's support groups is that they offer members a unique opportunity to help others.

Too often those with Parkinson's

believe they have little to offer others because they need so much help themselves. Profound feelings of inadequacy may result.

The process of helping others is a powerful therapeutic tool that greatly enhances feelings of self-worth.

In addition, caregivers in the group not only learn about Parkinson's disease, but receive support for their efforts and share coping strategies with one another and with those for whom they are caregivers.

Support groups often provide the first experience of being understood, the first opportunity to identify with others who are coping with Parkinson's.

Support groups vs. psycho-therapy groups

A skilled support group facilitator models active listening, gives non-judgmental feedback and offers positive support.

Facilitators strive to create a safe environment for group interaction and coordinate activities to help provide avenues of involvement for each participant. The facilitator is typically not a professional therapist.

Therapy groups often include the issues noted above, but the focus of the group and qualifications and role of the therapist are different.

The therapist uses a range of techniques based on experiential relationship-building, dialogue, communication and behavior change.

Some Parkinson's patients may find value in participating in both a support group and psychotherapy.

The mystery of an unimagined life

No one's life unfolds exactly as they'd imagined. No one asks for a

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INFORMATION WON'T CURE PARKINSON'S, but it's the first step to better understanding its many challenges as well as to discovering the possibili-

ties of living well. Here are a few informational opportunities happening around the Northwest. You can find more on our Events page at nwpf.org or by calling us at 877.980.7500.

In Washington

◆ Caregiver conference. 9 a.m. to 4 p.m. on June 6 in Tukwila. Cost is \$30. Call 800.422.3263.

◆ Brain Health for Parkinson's. 11:30 a.m. to 2 p.m. on June 15 at the Kitsap Conference Center in Bremerton. No cost. Call 877.980.7500.

◆ Non-motor Issues Associated with Parkinson's. 1 to 3:30 p.m. on June 24 at the Educational Center at Evergreen Hospital in Kirkland. No cost. Call 800.887.8100.

◆ Brain Health for Parkinson's. 11:30 a.m. to 2 p.m. on August 17 at the Lynnwood Convention Center in Lynnwood. No cost. Call 877.980.7500.

In Montana

◆ Brain Health for Parkinson's. 2 to 3:30 p.m. on May 23 at Benefis Hospital in Great Falls. Call 877.980.7500.

In Idaho

◆ Living Well in Idaho. Six weekly classes for people with chronic illness and their care partners. Various locations. No cost. Call 208.908.4990.

◆ Fit and Fall Proof™ Classes. Promote balance by learning strategies for moving safely and confidently. Various locations. No cost. Call 208.327.8591.

◆ Powerful Tools for Caregivers. Six weekly classes for care partners. Various locations. Cost is \$60, with some scholarships available. Call 208.333.1363.

Regional

◆ Tips for Addressing Apathy in Parkinson's. June 13 telehealth presentation. Multiple locations. Call 877.980.7500 or visit nwpf.org/telehealthnet.aspx for a full listing of monthly Parkinson's telehealth topics and broadcast sites.

Wellness conference probes Parkinson's and mind-body connection

BY MONIQUE GIROUX, M.D.

MORE THAN 250 PEOPLE learned about the healing power of thought at the Northwest Parkinson's Foundation's 2nd Annual Wellness Conference on March 5 in Bellevue, WA.

The "Power of the Mind" event, like many supportive offerings of the Northwest Parkinson's Foundation, focused on personal healing and wellbeing for people with Parkinson's disease and their families.

The keynote speaker, Jon Stoessl, M.D., a researcher from the University of British Columbia in Vancouver, dissected the placebo effect and offered unique insight to its cause and role in Parkinson's treatment. It turns out the placebo effect is not only a real and measurable phenomenon, but that dopamine is an important mediator of this phenomenon.

Using imaging techniques that measure brain activity, such as PET scans, Stoessl and his team are able to define specific brain areas associated with the placebo effect.

An individual's expectation of treatment is a strong determinant of brain activity and the strength of the placebo effect, he said.

If you think it, it will happen

In other words, the way we think really can affect how we feel and how a treatment will work.

My own talk further explored the power of the mind and how we might use this power to get more out of our Parkinson's treatment.

I explained the ways in which self-empowerment, positive thinking and stress management influence our



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Advocate finds her voice on PAN trip

BY CATHY OAS

OKAY, I'LL BE HONEST. I hate this disease called Parkinson's—the way it robs you of control over body and mind, slowly but surely, like a cowardly thief in the night. I hate that I can no longer work at a profession I was passionate about—helping children and their families learn the power of communicating. It frustrates me that we have no cure and nothing particularly promising in the pipeline.

So in late February I channeled my frustration and sense of urgency into a trip to Washington, D.C., for the Parkinson's Action Network (PAN) Forum. PAN is the unified voice of the Parkinson's community advocating for better treatments and a cure. In partnership with other Parkinson's organizations and a powerful grassroots network, PAN educates the public and government leaders on better policies for research and improved quality of life for people with Parkinson's.

Armed with little more than a Facebook page as a resource and a sense that surely there were others like me who needed a voice, I flew to D.C.

What I discovered there was nearly as life-altering as my diagnosis in 2002. I met other delegates from Washington state over the two days we learned about the PAN political agenda and the positive and inarguably indelible impact of advocacy—or “telling your story.”

The Washington team consisted of Tom Ryan of Bainbridge Island, Carey Christensen of Stanwood—both, like me, diagnosed with young-onset Parkinson's—and Colleen Crowley, executive director of the Northwest Parkinson's Foundation.

Over two days of fascinating and inspiring education, I learned there are many bright minds working on our behalf.

We spent all of Wednesday in meetings on Capitol Hill. I witnessed the power of our democracy in action and developed a new respect for the First Amendment, the right of all to speak and be heard. Our long day began with appointments with our state's elected officials—Sens. Patty Murray and Maria Cantwell and Reps. Jim McDermott, Norm Dicks and Jay Inslee.

The team worked well together in presenting our case. The combination of Carey's passionate breadth of knowledge and experience, Tom's quiet and steady intelligence, and Colleen's ability to calmly summarize and speak for the people of the Northwest made us a powerful presence.

We included some critical talking points—that Parkinson's is expensive in terms of income lost due to disability, that aging Baby Boomers will be tapping into the healthcare system, and that Parkinson's is a bipartisan issue—no one is exempt from its ravages.

By the end of the day, we were exhausted yet exuberant knowing we had secured continued and increased support for PAN's legislative policies:

- ◆ Continued funding for the National Institutes of Health to fuel Parkinson's research
- ◆ Support for the National Neurological Diseases Surveillance System Act
- ◆ Funding for the Department of Defense's Neurotoxin Exposure



Photo by Colleen Crowley

From left, Tom Ryan, Cathy Oas and Carey Christensen.

Treatment of Parkinson's Research program.

We also encouraged our elected officials to join the Parkinson's Disease Caucus.

We felt heard. And, in this era of healthcare reform and tightening budget restrictions, we believe our elected officials will do their best to keep the interests of people with neurological disorders in the front of their minds.

This experience showed me that the “power of one” is real—that one voice can make a difference. Despite our country's many challenges, it is still a beautiful place of democracy, as wonderfully messy and chaotic as that may seem at times. That there are many talented, intelligent and articulate people here who are passionate about finding a cure as quickly as possible, and they are working diligently on our behalf.

Perhaps, most important, I learned this: When you become an advocate, you cease being a Parkinson's victim.

Cathy Oas lives in Seattle. She can be reached at cathyoas@yahoo.com. She is grateful to PAN and her fellow delegates, her family (including her daughters, who she says at times still must wonder what Parkinson's has done to their mom), her friends, and the people with Parkinson's and their caregivers in her yoga and support groups.



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, your 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 **February 11 and April 13, 2011.**

Please notify us of any errors in spelling or attribution.

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This means that every dollar raised by our STP riders will directly support programs and services for people with Parkinson's and their loved ones.

Visit the Team Parkinson's online headquarters today—at nwpf.org—and sponsor a member. Your contribution will make a world of difference!

We thank our Team Parkinson's 2011 sponsors:

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SUPPORT GROUPS | CONTINUED FROM PAGE 3

Parkinson's diagnosis. No one puts "support group" on his bucket list of things to do. Yet, in Melville's words, "Our lives are connected by a thousand invisible threads."

The people we meet in Parkinson's support groups are connected by some of those previously invisible threads. In support groups, these unique threads are woven together as we share our stories. The groups help us to make connections, to remind us of the preciousness of each moment, and to appreciate more fully the deeper dimensions of giving and receiving.

Some of what we learn in groups is immensely practical. Yet, when things are just as they should be, support groups also provide a portal to the mystery and wonder of life and the positive aspects that can be found in all things.

Dr. Zunin facilitates a Parkinson's support group in Napa, CA. He is a retired psychiatrist, artist and bonsai enthusiast, as well as a devoted husband, father, son and grandfather. He has had Parkinson's for 15 years.

WELLNESS CONFERENCE | CONTINUED FROM PAGE 4

experience and expectation of therapy.

We can optimize how our bodies respond by coupling these thoughts with traditional medical and surgical therapy.

Mindfulness-based therapy may be one way we do just that. As clinical psychologist Jan Fite, Ph.D., reminded us, "We may not always be able to change our situation, but with mindfulness therapy we can change how we look at it, feel about it or respond to it."

Guided imagery, meditation, positive thinking and yoga are just a few of the ways a person can practice mindfulness.

We ended the day on a high note as psychotherapist and performance coach Susan Parker guided us through a laughter exercise.

The Northwest Parkinson's Foundation's online Wellness Center offers information and tips for personal healing and optimal living with Parkinson's. Conference videos and handouts, as well as more information on the placebo effect, mindfulness and the power of positivity, are available at nwpf.org/wellness.

Dr. Giroux is medical director of the Northwest Parkinson's Foundation.