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ABOUT US

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NORTHWEST  
PARKINSON'S  
FOUNDATION

## Art, laughter are therapy for PD group

BY ANNE ATKIN

I was diagnosed with Parkinson's disease six years ago, when I was 55. I'd had symptoms for the previous seven years and been misdiagnosed as I searched for an answer.

A year after my diagnosis, and with help from a close friend, I started a support group—"Painting with Parkinson's"—focused on art as therapy for Parkinson's disease.

Over the last couple of years I have expanded what this support group does. Creativity is the main focus, but now I use exercises, socialization and, most recently, cognitive activities. This is all in a safe, supportive and loving setting.

It is wonderful to see emotional baggage left at the door when people arrive and not picked up when they leave. One man calls our group an oasis of sanity in an otherwise difficult world.

Many people with Parkinson's experience difficulty with motivation and apathy, two very difficult aspects of the disease that have to be overcome. I am gently encouraging to all in our group.



Courtesy photo

A "Painting with Parkinson's" group at work.

I also love making people laugh. We all work hard to make meetings as much fun as possible, with lots of laughter.

Our efforts are focused on exercising and on striving to "retrain" the brain. We also incorporate visualization, wellness and mindfulness—in other words, a package-deal of things that can help us feel we are taking some control back in life.

Last week I saw my neurologist. He thought it was time to have a look at my mobility and functionality. Three years ago I had a score of 15 (whatever that is!) on his tests, and last week I got a top score of 0. My doctor said that whatever I'm doing, I'd better not stop!

*Anne Atkin is a volunteer, public speaker, ambassador and librarian with the Canadian organization, Parkinson's Victoria. She began her first "Painting with Parkinson's" group in 2007, parlaying her love of art and experience as a teacher into benefit for others with Parkinson's.*

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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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## FROM THE EXECUTIVE DIRECTOR

BY COLLEEN CROWLEY, J.D., CFRE



AMAZING THINGS HAPPENED this year!

Thousands of you learned to live better with the challenges of Parkinson's. You read the bimonthly *Parkinson's Post*, full of inspiring real-life stories, valuable medical information and plain old common sense. You attended one of the many educational programs we presented throughout Washington, Idaho, Montana and Alaska. You learned to improve your brain health through exercise, good nutrition and mindfulness. You looked forward to the weekly email update with all the latest news in research and more stories of people choosing to find a

better way to address the everyday symptoms of Parkinson's. You surfed our website to find support group locations, the time and date of the monthly telehealth presentations and up-to-date information at the Wellness Center.

Your doctors, nurses and case managers also learned from the Northwest Parkinson's Foundation and our medical director, Monique Giroux, M.D., and physician assistant, Sierra Farris, PA-C. Along the way you cheered them on as they made a historic climb up Mt. Kilimanjaro with four people with Parkinson's all reaching the top.

Nearly 1,000 of you came together to mix, mingle and move at the 2011 Wellness Conference and 2011 HOPE Conference. It was so inspiring!

The Northwest Parkinson's Foundation is committed to bringing you all of this and so much more. Every day we focus on how to best reach thousands of people with Parkinson's throughout our region. We *can* do this with your support.

This holiday season, I hope you'll consider making a gift to the Northwest Parkinson's Foundation. Amazing things will happen! Thank you.

## Put some new tools in your coping toolbox

ONE OF THE MANY WAYS to enhance the quality of life with Parkinson's is to use all the tools available to meet your needs.

Adaptive mobility equipment and devices can be among the tools at your disposal. They can be as simple as canes and walkers and as technologically advanced as voice-activated computer software.

Whatever your stage of Parkinson's, being open to taking advantage of these tools will increase your comfort and ability to be active and engaged in life.

One program that meets this need is Donor Closet in Edmonds, WA. This program has new and refurbished durable medical equipment and mobility

equipment for people with Parkinson's. A wide range of equipment is available, from shower chairs to hospital beds.

A minimum donation is requested, which is less than the cost of renting the equipment from a medical-supply company. Financial assistance is available.

For more information on Donor Closet, call 425.712.1807.

Many senior centers also maintain a similar program of lending equipment. Donor Closet and most senior centers will also accept medical equipment you are no longer using.

*Adapted from the Seattle Times Community Giving Supplement, Sept. 28, 2011*

# Generosity of many makes SoDo event a big success

THANK YOU TO ALL of our guests, sponsors and contributors for spending **An Evening in SoDo** with us. While paying special tribute to Gov. Booth Gardner and celebrating the Northwest Parkinson's community, this September 28 benefit dinner raised more than \$65,000 to support our programs and services that improve the quality of life for people with Parkinson's disease.

**Guests & Contributors:** Juan Aragon, Elizabeth Bacher, Dan & Pam Baty, Bill & Margo Bell, Buz & Carol Bell, Jennifer Bell, Bill & Ruth Benfield, Craig & Sue Bohman, Steve & Karen Boone, Don & Meg Briggs, Dan & Pat Brzusek, Mr. & Mrs. Daniel Burdick, Carese Busby, Jean Ciesynski, Chris & Linda Clark, Robert & Kristina Clawson, Dan Unti & Colleen Crowley, Keely Dailey, Brian Devereaux, Ron Dotzauer, Vasiliki Dwyer, Steve Esola, Sierra Farris, Brad Fisher, Jean Gardner, Gail Gardner Gant, Monique Giroux, George Grader, Jim & Wendy Griffin, Bob & Joanne Hacker, Dick & Karen Hadley, Eric & Gina Hadley, Marilyn Hall, Sandra Harui, Loryn Heath, Katie Henry, Craig Howard, Gail Howard, Gretchen Hull, Tom & Julie Hull,



**Board members Bill Bell and Craig Howard enjoy An Evening in Sodo with (from left to right) Perri Lynch, Margo Bell and Gail Howard.**

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## AROUND THE REGION



INFORMATION WON'T CURE Parkinson's, but it's the first step to discovering the possibilities of living well. Here are a few informative events around the region.

### Telehealth—multiple viewing sites

- Telehealth talk on case-management strategies | 2 p.m. | November 14 | Coeur d'Alene and Grangeville, ID; Anchorage, AK; Billings and Miles City, MT; Pendleton, OR; and various locations in Washington | Visit [nwpf.org/telehealthnet.aspx](http://nwpf.org/telehealthnet.aspx) or call 877.980.7500 to learn more.

### Washington

- Dance for Parkinson's | Mondays from 2 to 3:30 p.m. | November 7 to 28 | Des Moines Senior Center, 2045 S 216<sup>th</sup> Street, Des Moines | No charge | Call 206.748.9481 to register.

- New Tremble Clef singing group starting on the north side of Spokane | 2:15 to 3:15 p.m. | November 2 and continuing 1<sup>st</sup> Wednesdays | Call Walt at 509.448.3535 or the Parkinson's Resource Center at 509.473.2490.

### Idaho

- Holiday social for Boise support group | Early December | Call Betty Boone at 208.336.7137.
- Meridian support group starts each session with singing | Call Sharon at 208.890.1224.

### Montana

- Presentation by Eliad Culcia, M.D., neurologist and medical director of the APDA-Montana Information and Referral Center | 1 p.m. | November 11 | Hilton Garden Inn, Great Falls | Call Lydia Skoog at 406.455.2964 to register.
- Billings Clinic social worker Diane Kersten will talk about Parkinson's and depression | 4 p.m. | November 2 | Call Ruth Normand at 406.256.5235 to register.

*Check our website ([nwpf.org](http://nwpf.org)) for more event listings.*

# In marketplace of options, maximize and prioritize

BY SUSIE RO, M.D.

Conventionally trained neurologists, including myself, are generally undereducated about complementary and alternative medicine (CAM) as well as unfamiliar with the education CAM providers experience regarding neurologic conditions. And so, while hearing apparently conflicting information from multiple sources is daunting to patients, to be asked by patients for advice on CAM can be equally intimidating for physicians.

Unfortunately, many of our limited experiences with some CAM treatments have involved adverse outcomes. We have all had the experience of having patients looking for the “miracle cure”



spend large amounts of time and money on treatments that have little clinical evidence to support their use, sometimes sacrificing conventional treatments to accommodate them or, worse, subjecting themselves to risky, invasive and unnecessary procedures.

Some people are uncomfortable philosophically with the idea of ingesting “unnatural” substances and believe what is “natural” is intrinsically better.

Conversely, it is temptingly intuitive that removing a substance linked to

increased risk of developing Parkinson’s should slow down the disease, and that is more appealing than adding more outside substances to merely “control symptoms.”

Just because there is a strong theoretical basis or compelling animal data for the benefit of a substance or intervention, or even a single suggestive

study, does not mean it applies to humans with actual Parkinson’s disease, or that it is safe.

Because the supplement industry is not

regulated with the same rigor as FDA-approved medications with regard to safety or efficacy, it can be challenging to know optimum doses, purity and potential interactions. With supplements,

claims can be made but do not have to be backed up.

How reliable is experimental data? There is considerable debate as to whether the data obtained in conventional clinical trials should be the “gold standard” guiding our prescribing practices.

Many studies on potentially beneficial, naturally occurring substances will never happen because there is no financial incentive for the marketplace to undertake these studies.

Supplements can be costly, and how can one measure their monetary value relative to conventional pharmaceuticals when they have not been directly compared?

We are seeing with increasing frequency proof that nonconventional interventions can have a marked positive impact in improving the lives of Parkinson’s patients in a variety of areas.

But, just as we should not dismiss alternative therapies due to lack of evidence, neither should conventional therapies be dismissed due to the limitations of clinical trials.

Both conventional and CAM providers aim to maximize the health and quality of life of the people they treat, and both hope that Parkinson’s progression can be halted and possibly prevented or reversed.

However, that does not minimize the importance of maximizing the impact of the treatments we have available now despite their limita-

tions, and prioritizing the available treatments in a

world of limited resources rather than accepting only the definitive.

Collaboration and communication between providers of different backgrounds will give patients more options without sacrificing the benefits of either.

*Susie Ro is a neurologist with Northwest Neurological PLLC in Spokane, WA.*

The terms **conventional** and **alternative** have different connotations, both positive and negative. For a patient struggling with ongoing symptoms and treatment-related side effects, it’s important to consider whether the prescribed path is truly the best.

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**Just as we should not dismiss alternative therapies due to lack of evidence, neither should conventional therapies be dismissed due to the limitations of clinical trials.**

# Offense + defense may be best formula against PD

BY LAURIE MISCHLEY, N.D.

Complementary and alternative medicine (CAM) means a lot of different things—herbs, chiropractic, supplements, acupuncture, exercise, prayer and special diets, to name a few.



Alternative can have a lot of negative. For the Parkinson's symptoms or unpleasant is only natural to question truly the best path.

Some individuals prefer to use CAM in addition to conventional medicine (complementary), while others use it instead (alternative).

Given the diversity of how CAM is used and defined, it's virtually impossible to make sweeping comments about whether or not CAM is useful in Parkinson's disease.

Conventional medicine, the current standard of care, excels in its ability to relieve symptoms of Parkinson's disease, but has repeatedly failed in attempts to prevent, slow or reverse the disease process.

I like the analogy of a sports team: Conventional medicine plays excel-

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**It's important for patients to become educated and to establish a team of trusted providers with diverse areas of expertise, who are willing to communicate with one another.**

lent defense in Parkinson's. If you are looking for symptomatic relief, the pharmaceutical and surgical options are the best.

But who on your team is playing offense? Who is trying to figure out how to stop your disease from progressing? Who is trying to reverse the process?

These questions get at the heart of neuroprotection, an offensive strategy that is currently an unmet need for those with Parkinson's.

It is accurate to say, "There are no established ways to slow or reverse the disease process." It is also reasonable to wonder, "Do therapies exist that have the potential to slow or reverse the disease, but for which the research has not yet been conducted?"

Research studies require a tremendous amount of time and money. This is especially true in Parkinson's, where the disease progresses slowly. Since natural therapies cannot be patented, it is very difficult to find financial support for research for which there will be no return on investment for the study sponsor.

CAM researchers must rely on government and foundation grants, which are scarce and in high demand. What this means is that less CAM research gets done, and we repeatedly find ourselves saying, "I don't know. The research has not been done."

As a CAM researcher and clinician, I believe there are dozens of therapies for which preliminary data suggest they may have neuroprotective potential in Parkinson's.

For each CAM therapy it's necessary to weigh the risks and benefits. What are you hoping to gain? How well-informed is the prescriber? What is known about product purity and stability? What are the potential side effects? What will it cost? What impact will it have on my family? How long will I try it before reevaluating?

It's important for patients to become educated and to establish a team of trusted providers with diverse areas of expertise, who are willing to communicate with one another. If any of us had "the answer," we'd have cured all our patients. We don't. We're all doing the best we can with the tools in our boxes.

One of the nicest parts of working with Parkinson's as a naturopathic physician is that CAM therapies and conventional therapies are rarely in conflict; rather, the combined

strategies, when appropriately used, tend to complement one another nicely.

Regardless of your provider's philosophical

beliefs, we are all trying to improve your quality of life to the best of our ability.

With increasing frequency, we are coming together, bridging ideas and understanding, with the common goals of treating, reversing and preventing Parkinson's disease.

*Laurie Mischley is a naturopathic physician with Seattle Integrative Medicine.*



## 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](mailto:joseph@nwpf.org).

Listed here are tribute gifts received between **July 29** and **October 13, 2011**.

*Please notify us of any errors in spelling or attribution.*

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# Maximize your gifts and time with employer matching programs

For many Northwest Parkinson's Foundation supporters, there is a simple way to increase—and in some cases double—the impact of your gift or volunteer time.

Many companies generously give back to the communities in which they do business and the causes that their employees support.

In addition to providing direct grants and sponsorships, these companies match their employees' donations and volunteer hours to nonprofit organizations.

Several prominent Northwest employers are especially generous in this regard, as the grid to the right shows.

But company matching gift programs are not limited to large corporations like those shown in the illustration; many small and mid-sized companies also have generous matching gift programs.

	Boeing	Expedia	Microsoft
Annual match	Up to \$6,000 per employee	Up to \$5,000 per employee	Up to \$12,000 per employee
What's matched?	Cash gifts, volunteer hours, event participation	Cash and stock gifts	Cash and stock gifts, volunteer hours, software donations
Minimum donation matched	\$100	\$25	\$25
Volunteer hours matched	\$500 for each block of 50 hours volunteered	n/a	\$17/hour
Other	Contributes \$100 per run/walk/bike event, 2x/year max	n/a	n/a

If you are unsure whether your company has a matching gift program or how to participate, contact your human resources department.

If you have further questions or need assistance in determining or processing a matching gift, please contact Northwest Parkinson's Foundation Development Director Joseph DiChiaro at 206.218.9414 or [joseph@nwpf.org](mailto:joseph@nwpf.org).

Thank you for your support!

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## Take part in research to help speed discoveries

YOU CAN BE PART of an ongoing research project that could help speed the progress of improved treatments for Parkinson's disease.

Two years ago, personal genetics company 23andMe created a web-based Parkinson's research community to examine how genes and environment are related to the disease. In a fraction of the time of traditional research, the 23andMe study has verified many of the genes associated with Parkinson's.

23andMe is now participating in the largest genetic analysis of Parkinson's to date, as one of four international research groups. The groups have identified a target that may modify risk for Parkinson's and are working with an

external academic partner to explore this possibility. More than 5,000 people are signed up to participate in the study, making important progress possible.

23andMe is halfway to enrolling 10,000 people with Parkinson's in the research community. A cohort of this size has the potential to enable breakthroughs and reveal treatment targets. The 23andMe approach enables these discoveries to happen rapidly. The more people who enroll in the project, the more powerful it becomes.

Participation is free and open to anyone who has been diagnosed with Parkinson's by a physician. The study is conducted online, so you can take part from any location. As a participant, you will provide a saliva sample for DNA testing and fill out online surveys about your symptoms, experiences and environmental exposures.

In return, you will be able to see your own genetic information, including whether you carry certain mutations associated with Parkinson's. You can also choose not to view these results. If you choose to see results, 23andMe provides knowledge and support to put them in context through online tutorials, videos and a patient liaison ([pd-help@23andme.com](mailto:pd-help@23andme.com)).

Additionally, community members are informed of discoveries made possible by their participation.

To learn more, enroll, and see the discoveries charted to date, visit [23andme.com/pd](http://23andme.com/pd). Members can also see new genetic data in the Parkinson's report and fill out new surveys on factors that might play a role in Parkinson's, such as caffeine use and pesticide exposure.

*Source: 23andMe Inc.*