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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.



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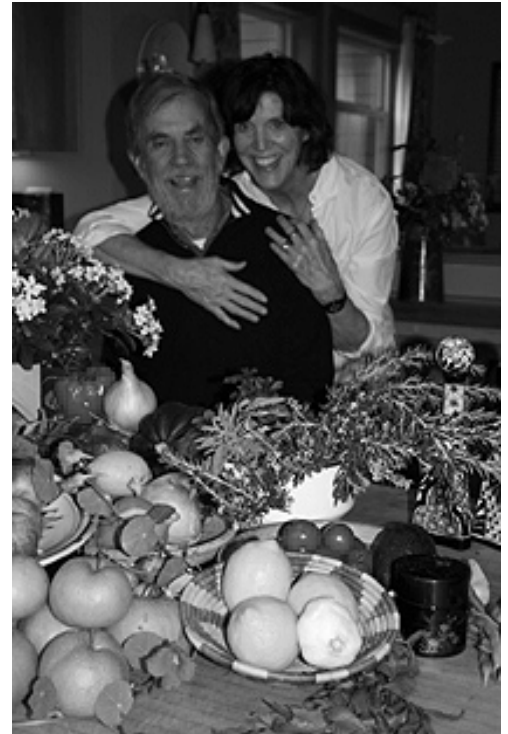
New book a roadmap for living well with Parkinson's

BY ANNE CUTTER MIKKELSEN

It was during the 2006 HOPE Conference that my husband Mike and I realized there was something we could do every single day to improve the quality of our lives, even with Mike's advancing Parkinson's disease along for the ride. The conference message was clear: There's no magic bullet, but there is a lifestyle—including proper nutrition and exercise—that just might make a difference.

Mike is a lifelong artist—a potter and sculptor. He was diagnosed with Parkinson's in 1993 but recognized his first symptoms in 1981. I am a cook, trained in France. Our formula for taking charge includes adapting our individual skills to meet evolving challenges and embrace emerging science.

We decided to write a book, *Take Charge of Parkinson's Disease*. It blends the "delicious science" of nutrition with the story of our personal journey. One of our primary purposes in writing this book was to spread the excitement about our newly discovered low-fat, brain-healthy pantry.



Courtesy photo

Mike and Anne Mikkelsen

We introduce the reader to an array of delicious, nutrient-dense meals loaded with antioxidants and anti-inflammatory substances known to contribute to brain health. Through our story and recipes, we hope to inspire you to stock your pantry well and wisely, and to create your own recipes using the dynamic list of colorful, nutritious ingredients.

Expert voices join us by way of sociologist and writer Nanette J. Davis, Ph.D., and Cleveland Clinic researcher Jay Alberts, Ph.D. Dr. Davis shares her perspective on strategies for successful caregiving and outlines a plan for how to safely navigate the unfamiliar circum-

> CONTINUED ON NEXT PAGE

BY COLLEEN CROWLEY, J.D., CFRE



DEAR FRIENDS OF THE PARKINSON'S COMMUNITY, The holiday season is fast approaching and, with it, the many joyous occasions to connect with friends and family to share in the warmth and spirit of the holidays.

While these experiences are positive for most, they can also produce feelings of stress, anxiety and loneliness in others. These

feelings can be particularly acute for people with Parkinson's and their caregivers.

That's where the Northwest Parkinson's Foundation online Wellness Center comes in. The Wellness Center provides helpful tips and ideas on how to manage the stress associated with the holidays—and so much more.

“Research shows that lifestyle habits make a big difference in our ability to manage stress,” notes Monique Giroux, M.D., medical director of the Northwest Parkinson's Foundation and creator of the Wellness Center. “The challenge for some of us is how and where to get started. Once we get started it can be just as difficult to stick with the personal changes we have made.”

(See Page 4 for more on the Wellness Center.)

In the coming year we will be enhancing the content of the Wellness Center by including interactive features and a personalized section called *My Wellness*. The *My Wellness* section will provide opportunities to download and organize your medical chart, set personal goals, and track your exercise and diet. Other opportunities such as community blogs are being considered.

This holiday season we are asking for your support of this very special resource. Supporting the expansion of the services offered through the Wellness Center will empower you and thousands of other people with Parkinson's to become fully engaged in living well every day.

Your gift of \$25, \$50, \$100 or your most generous contribution will help us expand this valuable service and make it accessible to all who need it.

Thank you, and happy holidays!

Lonnie Ali inspires, encourages with talk geared to caregivers

By Sharon Pasko

I recently went to a Northwest Parkinson's Foundation symposium for caregivers, and what a treat it was to hear from Lonnie Ali, wife and caregiver to a pretty well-known person with Parkinson's—Muhammad Ali.

A gifted speaker, Ali laced her talk about the ups and downs of caregiving with generous humor. She offered sage advice for caregivers, including these nuggets:

Caregivers must: 1) have a positive attitude, 2) carve out time for themselves and the things they enjoy, 3) rest, 4) eat a healthful diet, 5) exercise, 6) indulge in things they want from time to time, 7) surround themselves with good friends and close family, 8) educate themselves so they can be realistic about what they are facing, 9) attend to their own health, and 10) be organized.

Being organized is especially important, she said. It helps to keep a notebook of questions for your loved one's doctor, a list of medications and dosages, and notes about any changes you see. Exercise, too, is essential—not just for the caregiver but for the person with Parkinson's. Even her husband indulges in what he calls “girly” exercise—yoga. (Clearly, a sense of humor is also vital.)

It was a very inspirational and informative talk by a great and caring lady.

Sharon Pasko and her husband, Rick, live in Black Diamond, Wash. They have three children and five grandchildren.

> FROM PREVIOUS PAGE

stances of Parkinson's with optimal results. Exercise is another key element in our formula for taking charge. Dr. Alberts adds his exciting research on “forced exercise” using the tandem bicycle. Our book also presents practical information about symptom management and healthy coping strategies for boosting physical and emotional resilience.

Quality of life is really as much about choosing an attitude of wellness as anything else. The most empowering message Mike and I have heard along the way is that if we dare, we can take control of Parkinson's by changing our lifestyle. You will see how we ultimately learned to move Parkinson's to the back seat so that we could see the road ahead.

Take Charge of Parkinson's Disease: Dynamic Lifestyle Changes that Put YOU in the Driver's Seat—by Anne Cutter Mikkelsen with Carolyn Stinson and published by Diamedica—will be in bookstores and online in December. The author lives in Bellingham, Wash.



Jeff and Lynley Shaw dressed in the spirit of the “Take Flight for Parkinson’s” dinner at the Seattle Museum of Flight in September. The dinner honored Bill Bell, center, retiring executive director of the Northwest Parkinson’s Foundation. Jeff Shaw is a neuropsychologist at the Booth Gardner Parkinson’s Care Center and Lynley Shaw is an oncology nurse at Evergreen Hospital in Kirkland, Wash.

Photo by Mary Jane Lane

‘Take Flight’ event salutes NWPF founder

FRIENDS, FAMILY and colleagues gathered at Seattle’s Museum of Flight in September to celebrate and salute the accomplishments of Bill Bell, founding executive director of the Northwest Parkinson’s Foundation, and to launch the organization into a new future of growth and opportunity.

Craig Howard, cofounder and board chairman, spoke passionately about the impetus for the foundation’s launch in 1998. Their inspiration came from having mothers with Parkinson’s. But while research was underway to find a cure for the disease, Howard said he and Bell found few resources to assist and support people living with Parkinson’s from day to day. Their vision was to help people with Parkinson’s live their best possible lives today, anticipating the cure tomorrow.

Twelve years later their initial vision has blossomed into a far-reaching and comprehensive program of support for people with Parkinson’s and their caregivers. Today thousands of people in the Parkinson’s community are able to access inspiring, timely and helpful information and advice. The Northwest Parkinson’s Foundation provides this information through a content-rich website, the bimonthly *Parkinson’s Post* newsletter, weekly email updates and a variety of symposia on Parkinson’s.

We thank all those who joined the celebration and

and who made gifts in honor of Bell, which will benefit the Tina Bell Torrance Family Foundation. These gifts will be used to develop tools and resources that inspire and inform people with Parkinson’s and their families to carry on the legacy that Bell and his mother brought to the Northwest Parkinson’s Foundation. Our thanks to the following generous donors:

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Online community lays out path to wellness with Parkinson's

By **Monique Giroux, M.D.**

The Northwest Parkinson's Foundation online Wellness Center—nwpf.org/wellness—is coming up on its first anniversary. We are grateful to the many people who are participating in this online community and shaping its future.

What is the Wellness Center?

The Wellness Center is a website designed to inspire people with Parkinson's and their loved ones to make positive personal changes that contribute to living their best with a chronic disease.

The program is the first of its kind, coupling up-to-date education on Parkinson's with information on holistic health, self-care and personal healing to enhance wellness.

Researchers, clinicians and national experts are invited to contribute and a new edition is posted monthly.

The Wellness Center features articles that have a focus on subjects important to *you*. Our topics are diverse to meet the needs of everyone we serve.

For instance, some people are interested in exercise and the positive role this plays in Parkinson's wellness. Others are more interested in a holistic approach to improving everyday life—one that focuses on nutrition, stress reduction, creativity and spirituality.

The Wellness Center brings together current information and scientific discoveries about these approaches as well as helpful tips to get you started on your wellness journey.

An important part of the program is the support gained from the creation of a virtual wellness community. The collective voice of our community is a unique and important part of the Center. Members are encouraged to submit comments, tell their stories, inspire and motivate others, and shape the future of the Center.

By joining this group you become part of a growing trend of people—joining forces with others to reach beyond the old idea that a prescription pad and pills are the only way to treat Parkinson's. Medications are important, but they are just not enough.

How did the Wellness Center get started?

My first initiative as Northwest Parkinson's Foundation medical director was to expand knowledge about holistic

approaches to wellness for people with Parkinson's.

I care for thousands of people with Parkinson's and

I have listened to my patients—from recent diagnosis to advanced disease—tell me, 'I am blessed and life is good, even with Parkinson's.'

have learned quite a bit from my patients throughout the years. They have taught me what works or does not work for them, what their biggest struggles or obstacles are and, most importantly, their successes.

I have listened to my patients—from recent diagnosis to advanced disease—tell me, 'I am blessed and life is good, even with Parkinson's.'

Hearing from my patients gradually changed my thoughts about treating Parkinson's—so much so that I chose



Join us for "Empowerment through Adventure," an inspirational presentation on self-empowerment by **Lori Schneider** (at left), a mountain climber, adventurer and multiple sclerosis patient. Her talk will take place from 1 to 4 p.m. on **Saturday, January 22, 2011**, at the Mountaineers Program Center in Seattle's Magnuson Park.

You'll also find out how to get involved with **Team Parkinson's Kilimanjaro 2011**, an expedition in support of programs for people with Parkinson's disease and muscular sclerosis.

To learn more about the talk or Team Parkinson's, contact Alecha Newbern at alecha@nwpf.org or **206.728.9481**.

to return to school to complete fellowship training in integrated medicine, a field that combines an array of approaches to achieving holistic health and wellness.

Research supports this holistic approach to care. New research finds that certain foods and exercise play a role in lowering the impact of Parkinson's and may even lower the risk of developing the disease to begin with.

The importance of exercise cannot be overstated; it is not only physically benefi-

cial but may also be *neuroprotective*—meaning it is thought to protect and possibly regenerate the dopamine-producing neurons that are diminished with Parkinson's disease.

The importance of looking at new ways to treat Parkinson's is crucial as our medical and surgical therapies have limitations over a person's lifetime with Parkinson's. In other words, research now supports what we have known all along—a prescription and medication are important, but not enough alone to optimize health.

As with any chronic disease, there are times when it is difficult to avoid the stressors that come from day-to-day living. However, the ability to see more positives than negatives in life builds a strong foundation for coping.

We built a program that can support and engage people through their years of living with Parkinson's and offer the knowledge and tools to promote wellness.

The Wellness Center is designed to bridge the gap between everyday medical treatment, alternative therapies and how to make it all work together.

How is the Wellness Center unique?

The Wellness Center is unique in that the focus is truly on *you*, the person with Parkinson's, and not the disease. This approach emphasizes what the person with Parkinson's *can*—rather than *can't*—do.

This means a focus on patient engagement, proactive and



Courtesy photo

Monique Giroux, M.D., has served as medical director of the Northwest Parkinson's Foundation since November 2009.

preventative care, and motivation for positive change. Much of our content is designed around improving your medical care by supplying tools and worksheets so that you can stay organized, build your own healthcare team based on your needs, prepare for your doctor and hospital visits and educate your primary physician on Parkinson's.

We include information on specialists and other professionals in your community and how they may benefit you, helping you advocate for yourself no matter where you live.

Based on feedback to date, we have added new features such as a recipe book, tools to organize your medical records, stories of inspiration and motivational tips submitted by community members.

What can you expect in 2011?

We will continue to enhance the Wellness Center over time, increasing the interactive nature of the site by developing a personalized section called *My Wellness*.

The *My Wellness* section will include opportunities to download and organize your medical chart, set personal goals and track your exercise and diet. Other opportunities such as community blogs are being considered.

How can you get involved?

First, go to nwpf.org/wellness and become a member by signing up.

Second, help us grow. Spread the word and tell others. Our goal is to be 5,000 strong by the end of next year.

Content is designed around improving your care by supplying tools to help you stay organized, build a healthcare team, prepare for doctor visits, and educate your primary physician.

Third, get involved and be heard. We encourage you to shape the development of the Wellness Center by submitting your own interesting stories, exercise routines that work, top foods for Parkinson's, and what you find important for personal wellness.

Fourth, make the online Wellness Center your own. Tell us what you'd like it to look like by completing our member's survey. You can do this by visiting nwpf.org/wellness and selecting the "Wellness Survey" button on the left-hand sidebar.

Dr. Monique Giroux is a movement-disorders specialist and medical director of the Booth Gardner Parkinson's Care Center in Kirkland, Wash.



Gifts to the Northwest
 Parkinson's Foundation support our educational publications and self-care tools, including the *Parkinson's Post* 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 thoughtful 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 877.980.7500 or joseph@nwpf.org.

Listed here are those who made tribute gifts between **August 7 and October 8, 2010.**

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*See Page 3 for a full listing.

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Email campaign is a resounding success, thanks to a generous community (you!)

IN SEPTEMBER we launched an email campaign in support of our weekly *Parkinson's News Update*, which reaches more than 18,000 readers around the world. We are happy to report that the campaign was a great success! We reached our goal of raising \$10,000 in just one month. Gifts poured in from far and wide—including from Canada, New Zealand and Japan!

The goal of the *Parkinson's News Update*, which is delivered by email each Friday, is to empower readers with information about the latest advances in treatment and care and to provide that information free of charge to anyone who signs up to receive it.

The gifts we received during our campaign will help to underwrite the annual cost of producing and distributing the weekly news update and directly benefit the many thousands of people

who read it each week.

Our thanks and appreciation go out to the following individuals, who gave generously in support of this valuable service:

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New development director joins NWPF staff



The Northwest Parkinson's Foundation is pleased to welcome Joseph DiChiaro to its staff.

DiChiaro began his role as development director in October, bringing with him an extensive and varied development background built through positions

with the American Diabetes Association and the University of Washington. Before moving to Washington, DiChiaro worked for social service and environmental agencies in New Mexico.

DiChiaro says he looks forward to getting to know the Northwest Parkinson's Foundation community. He can be reached at joseph@nwpf.org and 877.980.7500.