Forging ahead: Ups and downs on the journey

The last time you heard from Dean Crumpacker—in the January/February 2009 issue of this newsletter—was after a series of trials and tribulations leading to the reconfiguration of his deep-brain stimulation device at the Booth Gardner Parkinson’s Care Center in Kirkland, Wash. After reconfiguration Dean decided to pick up where he’d left off as a blacksmith. In June 2009—with mind, body and spirit greatly restored—he set off from Portland, Ore., to his former home in Santa Fe, N.M., to retrieve his tools. Here’s the story in his words.

BY DEAN CRUMPACKER

It was August and my former blacksmithing shop was loaded onto a trailer headed toward the Northwest while I, driving the 1994 Chevrolet decommissioned police cruiser I had once left behind, began the trek home.

Early in the morning the second day after leaving Santa Fe, as I was nearing the Utah border, I was overtaken by a highway patrol officer who appeared out of nowhere then disappeared into my Chevy’s blind spot. Trying to determine his position, I swerved enough to cause him to pull me over.

During the course of our exchange, the officer decided my speech was sufficiently slurred to warrant a field sobriety test, which I failed. He asked about any recent use of alcohol or illegal drugs. I told the officer I have Parkinson’s disease and that the only drug I was on was Sinemet, used to treat its symptoms. He didn’t believe me, and into the handcuffs, police car and jail I went.

At the jail a blood sample was taken to ascertain what drug I was on. To make a long story short, this jail cell was my home for the next 24 hours until I was released with a DUI citation in hand.

That was not the end of the matter. It took eight months for the crime lab to process my blood, and the results showed the only drug in my system had been the Sinemet. It was determined my slurred speech and failure of the sobriety test...
were due to Parkinson’s, not the influence of alcohol or illegal drugs, and the case was dismissed.

Moving on

My container of tools arrived in Portland days before I did and was unloaded by friends and family at its new home on the Dinihanian Farm in Beaverton, Ore. The farm is owned and operated by my neighbor and friend, Vahan Dinihanian.

Vahan is one of the people in my life who encouraged me to get back to the work I love. He offered me space in one of the buildings on his farm, and this is where I have set up my new shop. I can’t overstate how instrumental my friend’s support has been in making this next phase of my life possible.

It took a few months, but my shop is now up and running and I’m preparing to teach the art and craft of metalworking. It’s a real joy to be reunited with my tools, which I’d been away from for many years, and I was heartened to discover muscle memory fairly intact as I started to use them again.

In my previous article I described the “music” and “dance” of Parkinson’s. Through these terms I sought reframe the disease-related experiences that on some days drove me to despair.

Getting to this new, more positive mental space involved stepping outside myself for a different view of things, being more curious and objective about where I was, working to be less sad and emotionally stricken, and cultivating compassion toward myself and others.

I also mustered as much creative energy as I could, beginning with smaller projects such as woodcarving, until I felt ready to take the plunge back into blacksmithing.

I still see myself as a dancer, music-maker and blacksmith, albeit one who is now more effective at teaching metalwork than taking the large-scale projects as I once did.

The journey through the land that is Parkinson’s is not for the faint of heart. There aren’t definitive maps or guidebooks to go along with the territory, even as medical science continues to unravel the mysteries of this disease.

Treatment itself can be full of false trails and rough roads. The learning curve is steep and one can be thrown for a loop. (This is literally so in my case. I once executed an unanticipated backward somersault while gardening!)

Coping with and adapting to the challenges sometimes feels beyond our best efforts, but somehow we persevere and move forward. Sometimes we even recover lost ground. This has happened for me, the blessing of progress made possible by a Parkinson’s specialist, sheer determination and the input of many fellow travelers, to whom I give thanks as I forge ahead.

Dean Crumpacker lives in Beaverton, Ore. He can be reached at forgedahead@gmail.com or (505) 690-9941. Jennifer VanOrsdel and Kirk Wilson, friends of the author, also contributed to this piece.
The American Parkinson Disease Association, Washington Chapter, and the Northwest Parkinson’s Foundation are co-hosting the region’s largest educational symposium for patients, family, friends and caregivers on **Saturday, November 6, 2010**.

**PROGRAM**

**9:15**  Welcome and opening remarks  
*Craig Howard, Chairman of the Board, Northwest Parkinson’s Foundation*

**9:30 – 10:30**  Is Exercise Medicine for Parkinson’s?  
*Dr. Jay Alberts, Biomedical Engineering Assistant Staff, Lerner Research Institute, Cleveland Clinic*

**10:30 – 10:45**  Yoga break  
*Tim Seiwerath, Certified Yoga Instructor, Northwest and Swedish Hospitals*

**10:45 – 11**  Research Update: Biomarkers and Parkinson’s Disease  
*Dr. James Leverenz, Associate Professor of Neurology and Psychiatry, University of Washington*

**11 – Noon**  Wellness Choices for Brain Health  
*Dr. Monique Giroux, Movement Disorder Specialist and Medical Director, Booth Gardner Parkinson’s Care Center and Northwest Parkinson’s Foundation*

**Noon – 1**  Lunch and Panel Discussion with Q&A  
*Dr. Mike Kim, Movement Disorder Specialist, University of Washington; Susanna Eller, Geriatric Social Worker, Providence Mount St. Vincent; Dr. Kristoffer Rhoads, Neuropsychologist, Virginia Mason Medical Center; John and Suzanne Schofield, Patient and Caregiver; Forest Lane, Marathon Cyclist and Patient*

**1:15 – 1:45**  Homemade Hope – How to Thrive Today with Parkinson’s Disease  
*Peter Dunlap-Shohl, Patient*

**1:45 – 2**  Smile break  
*Irene Pasternak, Certified Feldenkrais Instructor*

**2 – 3**  Music is Exercise for the Parkinson’s Brain  
*Dr. Matt Ford, University of Alabama at Birmingham*

**REGISTRATION FORM**

Register online at [nwpf.org](http://nwpf.org) or toll-free at **877.980.7500**—or complete and mail this portion of the page to:

Northwest Parkinson’s Foundation  
Attn: Conference Office  
400 Mercer Street #504  
Seattle, WA 98109-4641

**ATTENDEE INFORMATION**

Please supply the name of each attendee. This form may be copied for additional attendees.

**Attendee 1:**  
Mr.  O Ms.  _________________________  
I am a:  O Patient  O Caregiver  O Family  O Friend

**Attendee 2:**  
Mr.  O Ms.  _________________________  
I am a:  O Patient  O Caregiver  O Family  O Friend

**Address**  
_____________________________________

**City**  
_________________________________________

**State**  
_____________  **Zip**  ___________

**Telephone**  
___________________________________  
O Home  O Work  O Cell

**Email address** (for your registration confirmation)  
________________________________________________

**LUNCHEON SELECTION**

**ATTENDEE**

1  2
O  O Grilled chicken with pomegranate sauce
O  O Mushroom risotto (vegetarian)

**OTHER REQUESTS**

O Escort at drop-off entrance  
O Scholarship request—limited number available  
O Special dietary request:  _________________________  
O Other:  _________________________
CONFERENCE FEE

The conference fee includes conference speakers, group activities, continental breakfast, lunch, afternoon snack and vendor exhibits.

**On or before October 29—$30.00**
**After October 29 and on November 6—$35.00**

Please mail this completed registration form with your payment. If you are unable to attend, please consider making a gift to support a scholarship for a person in need. Thank you!

- O Enclosed is my check for $____________________
  (payable to Northwest Parkinson’s Foundation)
- O Master Card  O Visa
- O Please bill my credit card $___________________
  Card # ____________________________________
  Expiration date (month/year) ________ /_________
  Name on credit card (please print) _______________________________
  Signature __________________________________
  Address of cardholder:  O Same as attendee
  Address ___________________________________
  __________________________________________
  City   State   Zip

Volunteers needed: This conference relies on a team of volunteers who assist the event coordinator for all or part of the day. We especially welcome teens, who are eligible to earn community service credit for school. To learn more about volunteering, contact Alecha Newbern at alecha@nwpf.org.

Questions? Call 877.980.7500 or email info@nwpf.org.

CONFERENCE DETAILS

**What time?** 9:15 a.m. to 3 p.m.

**What date?** Saturday, November 6, 2010

**Where?** Hilton Seattle Airport & Conference Center, 17620 International Blvd., Seattle, WA 98188

Free parking is available in the Conference Center garage and designated parking facilities only. Drop-off accessibility is at the north Conference Center main entrance on 176th Street.

The 2010 HOPE Conference will offer information on exercise, diet, medications, movement, speech and research that patients and families can use.

Exhibitors will include a variety of organizations and companies that will share information and resources for people with Parkinson’s disease and their care providers. Additional exhibits will feature information on medications, research, treatments and care options.

If you are unable to afford the conference fee, please let us know on the registration form. Scholarship requests will be reviewed for approval.

Special thanks to our sponsors:
Agonist side effects vary but can be addressed

Q: I take Requip but am told this drug has a lot of side effects. What side effects should I watch out for?

A: Requip—or, generically, ropinirole—is a dopaminergic agonist used to treat motor problems in both early and advanced Parkinson’s disease.

This class of medicine acts like dopamine in the way it activates brain nerve cell receptors. The benefit of dopamine agonists are many and include:

- A long half-life (the length of time a dose is measurable in your system), reducing the wearing-off effect of medicine such as is seen with levodopa.
- A low incidence of dyskinesias when used as an initial therapy.
- A reduced wearing-off effect when used with levodopa in advancing disease.

The benefits of agonists must be weighed along with the potential for side effects to determine if these medicines are right for you. They can be a key strategy in relieving movement symptoms. But for some, they come at the price of increased side effects.

Some side effects can be reduced or eliminated by starting at a very low dose and slowly increasing it to find the lowest effective dose for your symptoms.

The side effects that are more common with agonists when compared to other medicines include:

- Nausea—This side effect usually improves over time and is best treated by slowly increasing the dose and by taking medicine with meals.
- Lightheadedness—Dizziness when standing is sometimes a symptom of low blood pressure. This problem is often associated with Parkinson’s and can worsen with medicines including agonists. You might want to take your blood pressure at times you feel dizzy (a recording both sitting and standing can be helpful). Share these recordings with your healthcare provider to determine if treatment changes are in order. Avoid dehydration, which further lowers blood pressure. One way to do this is to be sure you take a full glass of water with each medicine dose.
- Leg swelling—This problem has many causes including heart disease, inactivity, Parkinson’s and medicines. Be sure to report the problem to your primary doctor. Don’t assume it is from your medicines, especially if you have been on an agonist for some time and leg swelling is a new problem. Elevate your legs when sitting and avoid sitting for extended periods without getting up to walk around.

- Cognitive problems and hallucinations—Agonists can worsen thinking problems associated with Parkinson’s and contribute to visual hallucinations. It is important to report these changes to your provider so that they can be addressed.
- Impulsivity-control disorders—Hypersexuality, pathologic gambling, binge eating and compulsive spending are just a sample of impulsivity behaviors sometimes brought out by agonists. Many people have a craving for sweets or enjoy shopping or occasional (and controllable) gambling as a source of entertainment. These problems are far more serious when you lose control. Discuss this risk with your family or caregiver and inform your healthcare provider of any problems. Medication adjustments can be made.
- Sedation—Almost all Parkinson’s medicines can worsen sedation. A specific form of this problem—falling asleep during active times such as driving, eating or talking—is a serious concern.

It is important to be aware of these potential side effects, and to know that some people may be at greater risk for them than others.

Despite their potential side effects, agonists are an important part of many people’s drug regimen, effectively treating movement problems and off symptoms.

Do not stop your medicine on your own, even if you are concerned about a side effect. Abruptly stopping these medicines can worsen movement, increase the risk of falls and cause a withdrawal syndrome.

Be wise and be safe. Talk to your doctor and review the need to make a medicine change. Remember, many people with Parkinson’s are on more than one medicine, and more than one medicine can be the culprit.
Gifts to the Northwest Parkinson’s Foundation support our educational publications and self-care tools, including the Parkinson’s Post newsletter, weekly emails news updates, a content-rich website, patient-education programs and the annual HOPE Conference on Parkinson’s.

In addition to sustaining our existing programs, your thoughtful donations also 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 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, and the donations page of our website (nwpf.org) lists all-time donors to these funds. Contact Keri Kellerman (877.980.7500 or keri@nwpf.org) to learn more.

Listed here are those who made tribute or family fund gifts from June 17 to August 6, 2010.

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Thank you, members and volunteers!

We thank our 2010 Team Parkinson’s members, who together raised funds and awareness for the Parkinson’s community. Congratulations on making the journey toward hope and wellness!

We are also grateful to the volunteers who lent time and talent along the trail of the 2010 Group Health Seattle-to-Portland Bicycle Classic, the 204-mile ride favored by most of our team.

Volunteers in Spanaway, Wash., and Lexington, Ore., were: Suzanne Cameron of Cameron Catering, who kept the team nourished with healthful and energizing food and beverages; Kyle Fisher of Alpine Hut, who resolved a range of bike problems; and Meghan Hintz and Shanti Sivadas, who massaged our cyclists’ tired muscles.

Centralia, Wash., volunteer crew members were: Jacque Beason, Beth Hardison, Gretchen Stronks, Kapri Fleming and Mary Jane Lane, who made their refueling station like home with good food, ample shelter, comfy chairs and great big smiles.

Volunteers at the finish in Portland, Ore., were: Sue and Mark Petersen, Chris, Ann and Karen, who designed their welcoming station with palm trees, wore hula skirts and handed out Hawaiian leis.

Last but not least were the team members themselves: Robert Allen, Maureen Atkins, Riley Atkins, Phil Augustavo, Bill Bell, Lynne Birming-


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The Northwest Parkinson’s Foundation is a cofounder and partner of the Booth Gardner Parkinson’s Care Center. This comprehensive care facility is home to physicians, neuropsychologists, physical and occupational therapists, and speech pathologists, all specialists in Parkinson’s. To make an appointment, call 425.899.3123.

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Safeway raises funds and awareness for PD

Safeway selected the Northwest Parkinson’s Foundation as a 2010 Charity of Choice. During March, all Safeway stores in Washington, Montana, Idaho and Alaska had canisters at every check stand with an opportunity for customers to donate spare change to the Northwest Parkinson’s Foundation.

We are honored to be a beneficiary of this effort, which raised $20,000 for the Parkinson’s community. “Our goal is to offer customers an easy way to lend their support while increasing awareness about Parkinson’s disease at the same time,” said Cherié Meyers, Safeway’s director of governmental and public affairs.

If you’d like to thank Safeway for supporting the Northwest Parkinson’s Foundation, mail cards and letters to Cherié Meyers / Director, Governmental and Public Affairs / Safeway / 1121 124th Ave. NE, Bellevue, WA 98005.