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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 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.



Learning a new dance

BY DEAN CRUMPACKER

Following is Dean Crumpacker's story of his journey toward better quality of life, as told to his sister, Abby Crumpacker.

In every life there comes a defining moment that alters the landscape in a permanent way. Mine came 17 years ago—at age 40—while I was sitting in a chair quietly reading. My little finger began to dance as if it were hearing its own music.

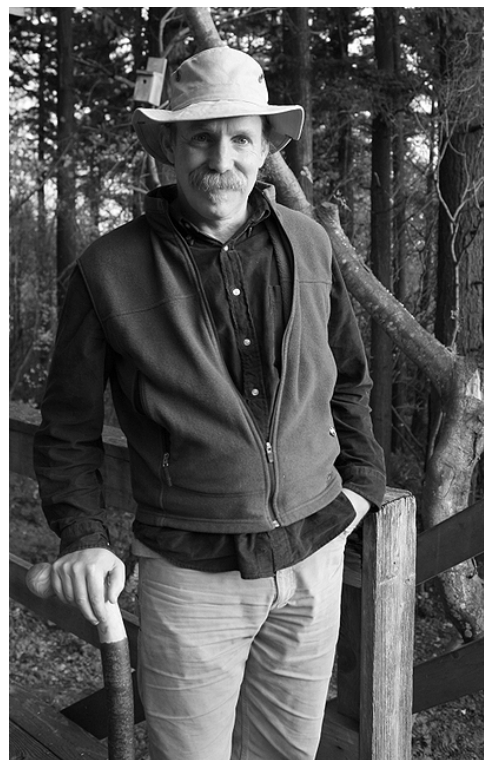
I had no idea my mind was beginning to compose a personal musical score. My body became the blank pages with the notes, tempo, and rhythm inked in by my brain. I was simply a conduit for this process, never asked for my input as the composition choreographed my body's movements.

It took four years for the score to reveal its title: Parkinson's disease.

From a musical perspective, Parkinson's comes in variations, with unique styles and tempos, and a melody that differs from person to person. Our bodies move to their own changing rhythms that we must adapt to.

Facing the music

For years my symptoms have been managed with the traditional Parkinson's drugs. Because the disease's symptoms are progressive and ever-changing, the drug treatment is often a lot of trial and error.



Courtesy photo

The author on a recent walk.

I have been undermedicated. I've also been overmedicated to the point of a doctor describing me as "drunk on Parkinson's drugs."

Like a silent thief, Parkinson's has stolen from me over the years. I had built a home in Santa Fe, NM, supporting myself as an artist and blacksmith. Baking pies and breads to sell at the local farmers market was also a means of support.

Playing banjo, piano, and other instruments, as well as restoring vintage cars, trucks, and motorcycles, kept me

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occupied in any spare moments.

As the disease progressed, managing life became increasingly difficult and I was forced to relocate to Portland, OR. My family would help me, and there was a nearby Parkinson's center that would provide care. This move brought me to the humbling realization that my independent life was gone.

Because I wanted to do something to help the Parkinson's community, I volunteered for an experimental drug trial known as the "GDNF Study." My participation required "open-head" surgery and the implantation of pumps on either side of my abdomen. Tubes were run under my skin from the pumps to an area of the brain called the putamen. Once a month tanks in the pumps were filled with the study drug, liatermin, or a placebo.

Whether it was reality or wishful thinking, I began to experience subtle relief. But within a year the study was cancelled due to safety issues. I went in for another open-head surgery to remove the hardware from my brain and the pumps from my belly.

'A new lease on life'

With Parkinson's, when the prescribed drugs, rest, and food are all working together, when one can basically function, it is referred to as being "on." The opposite is being "off."

My unpredictable, but increasingly frequent, off periods incapacitated and exhausted me. My social interactions and ability to venture out into the world began to shrink as my time was spent anticipating and managing symptoms.

A true miracle occurred during these dark days. I fell in love with Jennifer, a lovely and truly amazing woman. Jennifer's caring embodies unconditional love, and our life together is filled with laughter and joy despite Parkinson's and everything in its wake.

Jennifer supported my decision to undergo deep brain stimulation (DBS)

surgery. My doctors had suggested I was a good candidate for the procedure, and it seemed the logical—if not the only—option left to improve my quality of life.

My frustrations with the disease had become greater than my reluctance to undergo my third open-head procedure, and I scheduled surgery.

A disappointing reality

From all reports my surgery went perfectly, and I went home with high expectations. An appointment was scheduled with my neurologist, who would determine which settings would give me the greatest relief with the fewest side effects.

I was flirting with disappointment when I left this first session because my voice had started to weaken and swallowing felt strange. But I kept the faith my body would adjust.

But the outcome of each monthly session seemed to follow a pattern. Benefits achieved with a new setting disappeared within days. When I expressed concern about my nearly inaudible voice and difficulty swallowing, I was referred to speech therapy.

At the same time my left side was becoming weaker and dexterity was disappearing in my left hand and arm, rendering it mostly useless. My Parkinson's symptoms seemed to be accelerating at a very rapid pace.

Because my tremors would increase when the DBS device was turned off, there was continual reassurance that the procedure was working, and I continued to hold to the hope that the right adjustment would be made. Eventually I was told the programmer had found the optimum settings for me.

By this point, carrying on conversations was all but futile since my voice was so soft that nobody could hear me. Eating and drinking were becoming

more and more uncomfortable and dangerous as my swallowing reflex was weak and unreliable.

I could barely use my left hand or arm, so operating a computer was extremely difficult. I used a wheelchair to get around but needed to be pushed since my left side was so weak.

I was mentally and physically exhausted each moment of every day. I continually questioned the doctors about what else might be done for me. Eventually, my doctor looked me in the eye and told me I needed to face the

My frustrations with the disease had become greater than my reluctance to undergo my third open-head surgery.

fact that I had advanced Parkinson's and learn to live with it.

These words devastated me. Not only was the DBS a major disappointment, I was more debilitated than I'd been before the surgery. And I appeared to be out of options.

Everything changed for me that afternoon. The lights went off and the darkness covered me with a cloak of blackness so thick and deep I could not see. The one thing that had kept me going—hope—had been taken away.

Getting it back

Running in the background here is another story. My sister, a big believer in options, had begun questioning my predicament. Turning to the Internet, she began a search for information on DBS results and discovered a list of licensed DBS programmers by state.

No programmers were licensed in Oregon, but there were three in Kirkland, WA, at the Booth Gardner Parkinson's Care Center, a three-hour drive from Portland.

She called the center and I was

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Get moving for your body, mind, and soul

By **Amanda M. Herges, M.A.**
and **Jeffrey A. Shaw, Psy.D.**

People with Parkinson's commonly experience loss of energy and depression from time to time. And they tend to experience the most significant emotional distress when their physical symptoms are at their worst.

The relationship between mental health and physical energy is clearly circular: A decrease in physical activity typically results in a similar decline in mood, which can in turn decrease your motivation to initiate physical activity.

It's not surprising that the word for feelings—*emotion*—seems to be about movement. (In numerous languages, in fact, the word for “emotion” contains a reference to movement.) Human beings realized early on that emotion and movement are related.

The structure of the brain mirrors this connection between feeling and moving—the regions of the brain affected by Parkinson's play a role in both the physical and the emotional. Studies suggest that the prevalence of depression in people with Parkinson's ranges from 30 percent to 50 percent or more.

Symptoms of depressed mood include increased irritability, loss of pleasure in activities that were previously rewarding, difficulty sleeping, difficulty concentrating, significant weight change, and depleted energy.

Movement therapy is a common treatment for addressing sadness and anxiety. For example, seasonal affective disorder—depression that is common in the dark winter months—has been shown to improve with both increased light exposure and physical exercise.

And recent research involving people with Parkinson's enrolled in a strength-training program suggests that increased physical activity can result in benefits beyond the physical. Study subjects reported significant improvements in their overall quality of life after completing the program.

Physical activity has been shown to increase production of brain chemicals called endorphins, which produce a feeling of well being.

Additionally, physical activity may counteract stress-induced chemicals and hormones that can inhibit immune system functioning.

Getting started

The value of physical activity is clear. So what are you waiting for? Easier said than done, right?

Most people struggle with motivation—and not just people with Parkinson's. But the low mood and depleted

energy common in Parkinson's may contribute to difficulty initiating physical activity.

The following ideas may get you going.

First, your treatment team—which may include you, your physician, and your physical therapist, occupational therapist, and/or speech therapist—should develop an activity plan that is appropriate for you and your abilities and goals.

Specific goals—for exercise and other activity—should be established. You should think about, and clearly state, the activities you want to do. Ideally, each day should include:

- ♦ Physical activity
- ♦ Social activity with family members and friends
- ♦ Connecting to your community and helping others
- ♦ Spirituality
- ♦ Mental stimulation and intellectual challenge
- ♦ Mastery and improvement of existing skills

Second, researchers suggest making changes to your environment that will motivate you to get moving.

For example, posting reminders or cues will help you stick to your goals. For inspiration, consider decorating your home with pictures of you at your best, or simply doing the things you love.

Third, choose activities you enjoy or are interested in trying. If being physically active is too difficult for you or simply not

appealing, choose a captivating hobby instead. Choosing an activity that can include friends or family will keep you on a schedule and provide you with an opportunity to socialize.

Lastly, reward yourself. Setting small goals and rewarding yourself for reaching them can help keep you motivated. You will be most likely to continue to pushing yourself to the next level if you set incremental goals and enjoy your achievements along the way.

Pictured here: Amanda Herges is a Ph.D. student doing an internship with Evergreen Healthcare in Kirkland, WA. Jeff Shaw is a neuropsychologist at the Booth Gardner Parkinson's Care Center, which is part of Evergreen Healthcare.



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soon scheduled to see the center's DBS programmer, Sierra Farris, MPAS, PA-C, as part of a multi-day appointment.

During my first day, Farris and the center's medical director, Monique Giroux, M.D., spent more time with me than my previous team had in the entire year and a half post-surgery.

Farris evaluated my abilities and tested my DBS system on every possible setting while checking the parameters and observing where my side effects began. A CT scan showed the system was intact but that something was not functioning correctly.

"If you have to turn the settings up to a point that you experience debilitating side-effects, the probes are not in the target area," Farris explained.

For nearly two years, I would come to learn, I had been experiencing side effects from the DBS, not from the advancement of Parkinson's disease.

During those three days, I was evaluated by the clinic's physical therapist, occupational therapist, and speech-and-language pathologist. Members of the team consulted with one another throughout each day.

By the final day the team was in agreement that Dr. Adam O. Hebb, a respected neurosurgeon at the University of Washington, should see my records. If he felt there was an opportunity to improve my situation, he would let me know.

A new dance

Several weeks later we sat in Adam Hebb's office as he explained the DBS "revision" process. He said the electrode on the right side of my brain, which controlled the left side of my body, would be removed and a new one repositioned.

As he talked, it began to sink in that he believed my symptoms could be improved. And though I was agreeing to open-head surgery No. 4, I had absolutely no second thoughts.

Jennifer and I couldn't stop smiling as we drove home filled with hope.

During surgery the doctor replaced some of the existing wires, which were tangled, and attached them to a new battery implanted near my right collarbone. Then he turned on the stimulator to calm my ferocious leg tremors.

The changes in my body were obvious, and we were all optimistic. Improvement in my voice and swallowing was immediate, and the function in my left arm completely returned by the following week.

My brain needed to rest from the trauma of surgery so the programming resumed in a month.

It was a new experience for me to be greeted with excitement at a medical appointment, but a month later it was palpable as I walked back into the Booth Gardner Parkinson's Care Center.

Today, seven months later, I have no apparent tremor and my body is quiet. I can walk, talk, drive a car, and undertake many of the projects I never thought I'd be able to do again.

Each morning as I stroll through the woods near our home, resting on the walking stick I recently carved from a fallen branch, I reflect on my journey.

Simply put, the Booth Gardner team gave me back my life.

The respect Monique Giroux and Sierra Farris have for their work and each another translates into greater care for their patients. I leave each visit with better understanding and a greater feeling of control. Perhaps best of all was the realization that someone in the medical community saw me as a human being. I hadn't been listened to in such a long time that I'd forgotten what it was like to be heard.

The musical score that my body continues to compose will always be called Parkinson's disease—but these days I often enjoy the music. Today it may be a waltz, tomorrow a two-step. But whatever the dance, I do it with joy.



REMEMBER that there's strength in numbers! Why

not get involved in Parkinson's educational opportunities, support groups, and events in your area? It's a way to make friends and build your network. Go to www.nwpcf.org for a full listing of activities.

WHERE THERE IS WELLNESS, THERE IS HOPE
10 to 11 a.m. February 29 ♦ Evergreen Healthcare, Kirkland, WA ♦ Free of charge but registration is required ♦ This workshop will help you clarify what wellness means to you as well as help you to set and achieve goals ♦ Call 425.988.3000 to learn more

ANCHORAGE PARKINSON'S SUPPORT GROUP ♦ **1 to 3 p.m. third Saturday of the month ♦ Anchorage Senior Center ♦ To learn more, call Peter Dunlap-Shohl (Anchorage) at 907.346.3776 or Lory Jimenez-Betts (Mat-Su Valley) at 907.232.0187, 907.373.5679, or 888.652.5679 (toll-free)**

DEEP BRAIN STIMULATION SUPPORT GROUP ♦ **10 a.m. to noon April 24 ♦ Evergreen Healthcare, Kirkland, WA ♦ Free of charge but registration is required; refreshments provided ♦ Join other DBS patients and those who are curious about or considering the surgery ♦ Guest speakers will share the latest on DBS ♦ Hosted and moderated by DBS programming specialist Sierra Farris, MPAS, PA-C ♦ Call 425.988.3000 to learn more**

Submit calendar items to info@nwpcf.org.

Turn up the volume, kick up your heels

Q: I have heard that music can help movement for people with Parkinson's disease. What are the benefits and do they last?

A: Many people with Parkinson's have problems like slowness of movement and difficulty initiating movement or performing consecutive movements. Music can help by influencing brain function involved in motor control and emotional well being. In fact, some neuroscience studies have shown that certain types of music stimulate dopamine and serotonin, two brain chemicals that are diminished in people with Parkinson's.

Music therapist Concetta M. Tomaino describes how music can affect movement: "Music, particularly rhythm, can become a template for organizing a series of movements. The rhythm must stimulate the impulse or will to move in order for the impulse to transfer into real movement."

Music therapists are trained professionals who use music to help the physical, emotional, and social well being of people with medical conditions like Parkinson's.

The music therapist explores rhythmic patterns and musical styles with the patient to establish which help with walking, balance, motor freezing, and movement in general. Patients report that, by focusing on a rhythm and feeling its pulse, they can improve movement coordination and speed.

Music affects more than just movement. We've all experienced the way music can lift our spirits, soothe anxiety, and increase energy levels. Adding music to exercise can reduce stress and help the mood and anxiety problems that can occur with Parkinson's. The freedom of expression and creativity you may feel when



ASK THE EXPERT features questions from readers and responses from Monique Giroux, M.D., medical director of the Booth Gardner Parkinson's Care Center in Kirkland, WA. Got a question? Email it to questions@nwpf.org, mail it to 400 Mercer Street, Suite 401 | Seattle, WA 98109-4641, or call us toll-free at 877.980.7500.

In responding, Dr. Giroux seeks advice from a variety of specialists. For this month's response, Dr. Giroux sought input from Concetta M. Tomaino, D.A., MT-BC, LCAT, executive director and cofounder of the Institute for Music and Neurologic Function in New York City, and Ann Hatley-Settles, COTA, of the Booth Gardner Parkinson's Care Center.

moving to music can boost your self-confidence and reinforce your motivation to exercise by making it more enjoyable.

Occupational therapy assistant Ann Hatley-Settles leads movement-to-music exercise classes for people with Parkinson's and other neurologic conditions. She sees first hand the positive affects of music on movement.

"I see people surprised by what they can do, which reinforces a desire to continue," she says. "People who can't be heard in conversation can join in and be heard when the voice is a maraca or rhythm sticks."

According to Hatley-Settles, her class enables people to focus on what they *can* do, rather than on their limitations. In addition, they benefit from the social support of one another.

Here are some ideas on how *you* can get the most out of music:

- ♦ Find the right music for you. Explore various styles—salsa, reggae, rock, marches—to discover pieces that make you feel good *and* want to move.
- ♦ Create a library of "music to move by" and use a portable player to

enjoy this music while you're walking. (Be sure to talk to your doctor or therapist before adding music to your walking routine: It can be a distraction for those who need to focus their attention. And for safety, take caution when using headphones outdoors.)

- ♦ Participate in group music programs such as a local chorus (to keep your voice strong) or dance class. Start by contacting your local community or senior center. No classes? Consider starting one!

- ♦ Involve family and friends—dance at home with your loved ones. And you don't need to stand if balancing is hard—try dancing in a chair!

- ♦ Look for a music therapy program in your area. If none exists, take your favorite music to your next physical therapy visit and explore the benefits of music on your movement.

- ♦ Use rhythm makers—such as maracas, rhythm sticks, drums, or bells—to find and keep a beat.

- ♦ Create "musical sketches" by drawing to music. Sketches can be soft and flowing, loud and strident—visually reflecting what you are hearing.



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Gifts to the Northwest Parkinson's Foundation support educational programs including our website, email updates, caregiver booklet, newsletter, patient-education programs, and conference. Donations also fuel outreach and advocacy efforts on behalf of patients and families.

We are privileged so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year in honor or memory of special friends and loved ones. Thank you, all, for your support.

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Ms. Jennifer L. Woods

Chester Zobrist
Mrs. Margaret Zobrist

Charles Zwiers
Mr. Don Zwiers

TEAM PARKINSON'S : 200 MILES TOWARD HOPE

TEAM PARKINSON'S comprises people with Parkinson's and their family, friends, neighbors, coworkers, and caregivers. Team members participate in biking, running, jogging, walking, mountain climbing, hiking, swimming—and just about any other challenging endeavor or activity that can be used to get in shape and raise awareness for the Parkinson's community.

Team members collect donations and sponsorships, knowing that the proceeds support Northwest Parkinson's Foundation programs and services.

A lot of Team Parkinson's members favor biking events, most of which are best known by their catchy acronyms: the STP (Group Health Seattle-to-Portland Bicycle Classic), the RSVP (Ride Seattle to Vancouver & Party), RAGBRAI (Register's Annual Great Bicycle Ride Across Iowa), and

RAMROD (Ride Around Mount Rainier in One Day).

In recent years, we've also had bikers participate in the Johnny Ray Century (Opelika, AL) and Volcanoes to Valleys (Crater Lake, OR).

Others favor running events like the Amica Insurance Seattle Marathon, which includes a full marathon, a half marathon, a 5K run, and a kids run.

You can turn virtually any event or activity into your personal Team Parkinson's effort by registering for the team at www.nwpf.org/GettingStarted.aspx. Our site lets you create a personal web page you can use to share your effort with family and friends. Go online today or call us toll-free at 877.980.7500 to learn more.

**Team
Parkinson's**



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The Northwest Parkinson's Foundation is a cofounder and partner of the **Booth Gardner Parkinson's Care Center** (13030 121st Way NE, Kirkland, WA 98034). This comprehensive care facility is home to physicians, neuropsychologists, physical and occupational therapists, and speech pathologists, all specialists in working with Parkinson's patients. To make an appointment, call **425.899.3123**.

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Thank you for the gift of hope

With the help of many generous *Parkinson's Post* readers, the Northwest Parkinson's Foundation has raised more than \$33,000 to support the production of this publication in 2009.

If you would like to help us reach our *Parkinson's Post* goal of \$50,000, please consider making a gift today.

You may use the enclosed envelope to make your gift, visit our website at www.nwpcf.org to give a secure gift online, or call us toll-free at 877.980.7500 to make your gift by phone.

Nearly 20,000 households benefit from a free subscription to the *Parkinson's Post*, and countless people read it online. The publication, printed every other month, has domestic readers in almost every state and a growing international readership.

With your generous support, we can continue to offer the *Parkinson's Post* free of charge to anyone in need, helping thousands of people in the Northwest and far beyond discover hope and wellness.

Thank you for your generosity!