

Parkinson's

Companion

Climbing the Mendenhall Glacier

By Maureen M. Chamberlain

The diagnosis of Parkinson's disease came as a shock. It was threatening, intrusive, and incurable! I was young, in excellent health, and rarely took over-the-counter or prescribed medications. It wasn't in my character to accept anything without a protest, and this news hit me hard.

Denial was the first track I took. I read every piece of information available and tried to prove my doctors wrong. But the Parkinson's medication began to help me do things I had been struggling with, such as rolling over in bed, sliding across the car seat, and lifting my right leg with ease. Reality set in: I was in for the long haul with Parkinson's, and I was angry. This second track, anger, had its purpose but it didn't allow forward movement, and so my Parkinson's was a deep, well-kept secret for five years. Finally, however, I had my epiphany and awoke one morning on a new path, making a promise to myself that I would not let Parkinson's disease control my life. I had too many dreams to fulfill, passions to rediscover, and people to love and pick daisies with.

My young adult "children" engage in activities that would inspire fear in a movie stunt artist, and they continue to invite me to participate in some of their challenges. In August 2006, my husband and I went to Juneau, Alaska to visit our daughter. Kristen is an occupational therapist who also worked for a trekking company as a guide on the Mendenhall Glacier. She invited me to join her on a glacier climb.

Riding to the glacier in a helicopter with Kristen and four others on the tour was, in itself, an

amazing experience! Once aboard, I relaxed and was awed by the expanse of the glacier as we flew north over the Juneau Ice Fields. Miles inland, the chopper hovered over a flat section of ice marked by a brightly colored tent and an enormous X. We landed, and a second guide, Amanda, walked over to greet us as we unloaded mountaineering gear supplied by the trekking company. The helicopter then lifted off, circling above before leaving us alone on the ice.

Kristen and Amanda instructed us on how to wear crampons, walk horizontally across the steep ice, and use an ice axe, always keeping it strapped tightly around your wrist. Water on ice creates an extremely dangerous, slippery situation, and it was imperative that the guides' directions be followed so no one would slide into a stream and disappear down below the glacier's surface. While Kristen guided the rest of our group, Amanda was my personal guide. And climb that glacier I did, up and down, between the ridges and across the river of water that ran both above and below the ice, down into crevasses disappearing from view.

This adventure was exciting, unique and exhausting! I happily announced to my companions that I was willing to wager that I was the first Parkinsonian to have ever completed this feat!

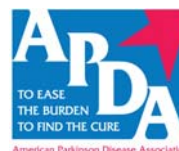
Maureen Chamberlain is an educator with an M.Ed. in Special Education and Learning Disabilities and 33 years of experience in New Hampshire schools. She retired in 2007, and now focuses on educating people about Parkinson's disease. Maureen is the President of the NH Chapter of the APDA. She lives with her husband, Fred, in Londonderry, NH, and enjoys spending time with her four grandchildren, writing, photography, kayaking, and hiking.



Climbing party on the Mendenhall Glacier: from left to right, front row - Fred Chamberlain (Maureen's husband); Amanda (NorthStar Expeditions Guide); Kristen Chamberlain (Maureen's daughter); and Maureen Chamberlain. Second row: Additional members of the climbing party.

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A NOTE FROM THE COORDINATOR

Diane Church, PhD

It's been a productive summer at the APDA Parkinson's Information & Referral (I&R) Center at DHMC, and I am happy to share the excitement with you. We welcome back our Peterborough Support Group, led by Suzanne Baker, PT, and Bernadette Stephens, exercise specialist. We also welcome Maureen Chamberlain, President, and Christine Robinson,

Vice-President, to the APDA-NH Chapter Board. Maureen and Christine are brimming with energy and ideas that will definitely keep the FUN in fundraising for the APDA! Maureen has contributed two pieces to this newsletter that illustrate her love of an active life. Also in the newsletter: Physical Therapy for people with Parkinson's, Q&A with Neurosurgeon David W. Roberts, and news from our April Parkinson's Awareness Symposium at DHMC. Please note the announcement for the Parkinson's event on November 13-14. I hope to see you there!

Exercise and Parkinson's Disease: A Necessary Combination

Adapted from an article written by Maureen M. Chamberlain for the Derry (NH) News

Exercise was always part of my pre-Parkinson's routine, but PD made it hard for me to move at all! With guidance from my neurologist, physical therapists, and staff at my local wellness center, I devised a workout plan that is manageable and appropriate for me. Some days I struggle to motivate myself to go to the gym, but know it is the best thing I can do for myself.

So, ask your doctor's permission, use caution and common sense, and get moving! Exercise will not cure PD but may slow its progression, and your quality of life will improve by keeping your body moving, flexible and toned. Perhaps these tips, based on my experiences, will help you to personalize a program of your own!

- Work out several times each week for greatest physical and mental benefit.
- Plan your medication cycle so you are "on" for your workout.
- Join a gym and attend classes led by instructors who provide warm-ups and cool-downs to prevent injury, music to help you move rhythmically, and vocal cues to keep you on track.
- With PD, movement doesn't come as naturally

as it once did, so consciously tell your individual body parts what to do. Talk to yourself and count aloud in the gym...it helps!

- Use the gym's full-length mirrors to correct "Parkinson's postures", such as a forward-bent body with arms that do not swing naturally. Avoid corners where mirrored walls meet; your double reflection may cause confusion and unsteadiness.
- Modify exercises to make them Parkinson's-appropriate. "Step aerobics" is excellent exercise, but omit dizzying turns, lower the step, and move behind the step (rather than across it) to reduce the danger of falling, tripping, or missing the step. Weight lifting builds strength and helps prevent osteoporosis, but use lighter weights and do more repetitions to avoid injuries such as "frozen shoulder."
- To learn a new movement or routine, watch several times, break it down into pieces, and perform it slowly and repeatedly. If distractions break your concentration, you may have to begin again. Be patient and persistent!



- Try new activities. Yoga gently stretches rigid muscles. Both yoga and golf twist your trunk. Boxing improves hand and foot movement. In "warm pool therapy" and aqua-aerobics, water supports your body and provides resistance to strengthen muscles.
- Accommodations, frequent breaks, snacks, and the company of friends will keep you safely involved in your favorite outdoor activities. Hiking, skiing, and kayaking provide excellent opportunities to move limbs and torso rhythmically and to get aerobic exercise. Adjustable-length hiking poles aid balance and stability, and fold down for easy packing. Cross-country ski poles likewise provide balance. Lightweight kayak, car-rack with rollers, contoured paddle with grips, seat with back-support, and towrope (just in case!) make outings easier.

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This newsletter is intended solely to provide you with information on Parkinson's disease. You should not make any changes in your treatment without first discussing them with your healthcare provider.

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Faces of PD Professionals



Dawna Pidgeon with her sons, Matthew and Tyler.

Dawna Pidgeon, PT

Which Parkinson's symptoms have you been able to ease with physical therapy?

Physical therapy (PT) helps people with PD to maintain strength, flexibility and balance. Because PD tends to make people stiff and to adopt a forward-flexing posture, it is important to do regular exercises to stretch muscles that become tight and to strengthen weakening muscles. Studies have shown that exercise can help protect the muscles from the effects of Parkinson's. Physical therapy can also help improve gait (or ability to walk) and balance.

When should a Parkinson's patient request that his doctor or neurologist refer him/her to a physical therapist?

Ideally, a person should be referred to physical therapy as soon as the diagnosis of PD is made. This allows the physical therapist to set up a home program aimed at keeping muscles strong and flexible and providing the protective benefit mentioned earlier. But PT is helpful regardless of how long a person has had Parkinson's, and we encourage all patients to seek physical therapy for strength, flexibility, gait, and balance issues.

Are there any special PT programs that benefit Parkinson's patients?

In addition to individualized PT sessions, a specific program of exercise and functional training developed by Boston University researchers provides benefit to individuals with Parkinson's. It is a 6-week program meeting 2 times/week for 1-1/2 hours each session. We are currently bringing that program to DHMC, and are very excited about the possibility of starting our first class this fall.

Dawna Pidgeon, PT, received her physical therapy degree from the University of Vermont in 1986. She has been at DHMC in the Department of Rehabilitation Medicine since 1992, working primarily in the Balance and Vestibular Program treating people for dizziness and problems with balance and mobility. She is a member of the NH Falls Risk Reduction Task Force and chairs the Dartmouth-Hitchcock Outpatient Falls Risk Reduction Task Force. She has given many presentations on balance within New Hampshire and nationally.

Ask the Doc

David W. Roberts, MD
Chair, Section of
Neurosurgery,
Dartmouth-Hitchcock
Medical Center



Q Would you provide a snapshot of how Deep Brain Stimulation (DBS) works?

A DBS is a neurosurgical treatment for PD symptoms resulting from reduced production of the neurotransmitter dopamine. Dopamine acts like the brakes and gas pedals of a car to slow down/speed up activities in specific parts of the brain. DBS modulates an altered activity by means of soft electrodes, implanted into the brain and controlled by a pulse generator similar to a cardiac pacemaker.

Q How is DBS surgery done?

A The neurosurgeon uses a stereotactic frame placed on the sedated patient's head, MRI images, and computers to guide the accurate placement of the electrode. In addition, each type of brain cell produces a characteristic microelectrode recording, so the neurosurgeon knows precisely where the electrode is as it travels to its destination by listening to the language of the cells. No portion of the device is exposed after implantation, with wires from the electrodes passing under the skin from the head to the pulse generator placed via a separate incision in the chest.

Q What are the benefits & risks of DBS surgery?

A DBS benefits include

- reversibility, because brain tissue is not destroyed,
- flexibility, because the amount of stimulation can be turned up or down, and
- selectivity, because the neurosurgeon can target a tiny region of brain that best matches the symptoms

DBS risks are uncommon (occurring in 1-2% of DBS patients) but very serious, and include

- hemorrhage
- infection

Q Which Parkinson's patients are good candidates for DBS surgery?

A The best candidates for DBS surgery are those

- with medically intractable and disabling symptoms of PD,
- who are medically able to tolerate an operation, and
- who have PD symptoms that respond to DBS (particularly tremor, rigidity, bradykinesia, and dyskinesias).

DBS does not ease certain PD symptoms, including cognitive impairment; swallowing, speech, and visual difficulties; orthostatic blood pressure problems; and psychiatric symptoms, nor is it effective for other syndromes such as progressive supranuclear palsy. We do not wish to withhold a helpful treatment from a patient, but the last thing we want to do is put someone through an unnecessary surgery.

Because of the inherent risks of hemorrhage and infection, one should not undergo brain surgery unless it is necessary, so the tendency is to delay DBS surgery as long as symptoms are mild and medically manageable.

To submit a question to our Parkinson's medical team, please contact our Information & Referral Center Coordinator at apda@hitchcock.org or call (603) 650-5280.

April 19, 2008: The First Annual Parkinson's Awareness Symposium

On April 19, 2008, our community gathered in Lebanon, NH for a Parkinson's Awareness Symposium, "Improving Parkinson's Disease Treatment Through Innovation and Research." The meeting was well received by 205 attendees from New Hampshire, Vermont, and New York. We opened with a reading of Governor Lynch's proclamation of April 2008 as PD Awareness Month in New Hampshire, recognizing the Parkinson community and the assistance offered by the APDA Information & Referral Center at DHMC.

This symposium highlighted the partnership between neurosurgery and neurology in providing state-of-the-art care for patients with movement disorders and hope through research initiatives. Dr. David W. Roberts, Chief of Neurosurgery at DHMC, spoke about brain surgeries for Parkinson's patients, focusing on Deep Brain Stimulation (DBS) surgery. Dr. Roberts' honesty and warmth in addressing all aspects of neurosurgery for PD was appreciated by audience members. He treated us to stunning before-and-after videos of patients who had undergone DBS surgery for treatment of intractable tremors.

Our second speaker, Dr. Stephen L. Lee, MD, PhD, DHMC Neurologist and Movement Disorders Specialist, illustrated the complexities of PD research, which includes genetic, molecular, and epidemiological investigations into causes, treatments, and cures. Dr. Lee detailed his own research into the function of PD genes. By discovering biochemical pathways that may lead to PD, he hopes to identify new targets for drug or gene therapy.

Also on hand were panels of PD patients and caregivers who had opted for DBS or participated in clinical trials. Attendees and panelists alike were dismayed that time considerations limited panel participation! As one panelist eloquently wrote, "I so looked forward to impressing on your audience the apparent success thus far of this gene therapy program...My point was to have been that there is new found hope on the horizon for many of us." The Parkinson's Center at DHMC is happy to put you in touch with those who have undergone DBS or are participating in clinical studies, and who are eager to provide their insights.

The Symposium can be viewed at www.dhmc.org/goto/Parkinson and is available upon request as a DVD by contacting the Parkinson's Center at DHMC.



Terry and Jo Ortwein were available on April 19 to answer questions about DBS surgery. The Ortweins also read a humorous one-act play at the Parkinson's Symposium in Concord, NH on October 4, 2008, to be covered in the next issue of Parkinson's Companion.

Announcements and Upcoming Events

Thursday and Friday, November 13-14, 2008, Parkinson's Perspectives: Focusing on Wellness, APDA New England Regional Parkinson's Conference Sturbridge Host Hotel, Sturbridge, MA

Fee: \$20 per person. Pre-registration must be received by November 3, 2009. For registration form, call (603) 650-5280 or send email to apda@hitchcock.org.

Save the Date! Saturday, April 25, 2009 Symposium in honor of Parkinson's Disease Awareness Month, DHMC, Lebanon, NH

Details in the next Parkinson's Companion newsletter.

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To request a title or to suggest materials that you have found interesting and helpful, please contact Diane Church at (603) 650-5280 or apda@hitchcock.org.

Starting a Support Group

Would you like to start a Parkinson's Support Group in your area? Please contact Diane Church at (603) 650-5280 or apda@hitchcock.org.

THANK YOU TO OUR DONORS!

Mary C. Murphy
And those who have contributed through:
New England Women's Network
BAE Employee Community Fund, Inc. (BECFI)
Community Health Charities of New England

New Hampshire Support Groups and Contacts

Concord

Lucy Crichton(603) 227-1346
Terri Goodsell(603) 229-1103

Greater Nashua

John Ghiorzi(603) 888-1944

Lakes Area Mutual (Wolfeboro)

Ray Lord(603) 569-1408
Ed & Joy Reed(603) 539-6520

Manchester

Mary Blevens(603) 663-3170

Monadnock Region (Keene)

Joe Nicholas(603) 352-1727

Kearsarge (New London)

Ellen Schauff(603) 526-6150

Peterborough

Suzanne Baker(603) 924-4635
Bernadette Stephens(603) 487-3228

Rochester

Jane Arlin(603) 332-8135

Upper Valley (Lebanon)

Bill Brawley(603) 643-7494

Northern New Hampshire (Newport, VT)

Sid & Estelle Burton(802) 626-3707

Does your corner of New Hampshire need a Parkinson's support group? The APDA Parkinson's Center at DHMC can help. Please contact Diane Church at (603) 650-5280 or apda@hitchcock.org.

Caregiver Support Groups

For caregivers and care partners of those with PD and other chronic illnesses. Please phone or email the noted contact person for meeting times and locations.

Bristol

Lisa Dunham(603) 744-2733, lisa@nanainc.org

Concord

Jean Fiske(603) 224-8171, FiskeTLC@aol.com

Keene

Beverly Lee-Packard(603) 355-8281
bleepackard@hcsservices.org

Laconia

Patricia Marceau . . .(603) 524-8444, (603) 528-6945
pmarceau@commhlth.org

Lebanon

ServiceLink(603) 448-1558, (800) 634-9412

Meredith

Patricia Marceau . . .(603) 524-8444, (603) 528-6945
pmarceau@commhlth.org

Nashua (Alzheimer's and Dementia)

Joan Marshall(603) 882-3999, x66453
jmarshall@sjh-nh.org

Northfield

Ginny Timmons(603) 286-7066
ginnytimmmons@yahoo.com

Portsmouth

Nancy Lamoureux(603) 430-0070

Wolfeboro (Alzheimer's and other memory disorders)

Linda Johnson(800) 499-4171
LJohnson@cchhc.org

Other

Caregivers Network (connects caregivers via phone or email)
Velma Harrison, ServiceLink/Rochester . . .(603) 332-7398
caregiveradvocate@straffordnetwork.org

Caregiver Teleconferencing

Beverly Lee-Packard (Keene)(603) 355-8281
bleepackard@hcsservices.org