



# Parkinson's

*Companion*

## Voices of Parkinson's

### Timely Blessings

By David Bemelmans

It is more than ten years since I consulted a doctor about an occasional tremor in my right hand. My right arm also had a strange numbness to it—strange in that it was often numb and tingling at the same time.

After a series of x-rays failed to show anything unusual, I was referred to a neurologist. He scarcely took more than one look at me before pronouncing, "You have Parkinson's disease." My shock was brief, because it was so obviously true. How could I have missed it? I had earlier worked in medical publishing, editing articles for professional journals in neurology. But that I might have Parkinson's never really occurred to me, probably because, at 43, I thought myself too young for such a diagnosis. I was wrong.

Ten years later, my initial symptoms have been joined by others: slowness of movement, stiffness, gait and balance problems, etc., and let's not forget the side effects of drug therapy itself. Nevertheless, all things considered, I'm doing well at present. Maybe it's for that reason that occasionally someone tells me about a relative or friend with Parkinson's for whom PD has been a "blessing." This seems an odd word to use in this context, but I have come to have what I think is some sense of the experience it is meant to describe.

In "Regimen in Health", Hippocrates wrote that for the wise man health is the greatest of human blessings, yet he can learn to benefit from his illness as well. What sort of lessons might PD be well situated to teach us? What blessings to bestow? Only one possibility can be raised here. The characteristic slowness of Parkinson's advance, with all its daily challenges, grants us a deeper understanding of the relationship between health and illness: namely, that "health and disease" do not simplistically parallel "life and death." Note that Hippocrates did not say that health is the absence of illness; rather he can be read to have meant that, because it too has something to teach us, illness and health intermingle just as the joys of living intermingle with the ultimate mystery that is our dying.

Perhaps, then, Parkinson's often blesses us with the time and circumstances to ponder the progression of our health and illness, the felt reality of our living and dying, and the myriad ways these interrelate to weave the fabric of our mortality. With the patience afforded by time may come acceptance, prompted by the realization that our illnesses are not "outsiders" in relation to our healthy lives, but a part of that tapestry in which each of us may find life's meaning.

*David Bemelmans reviewed and edited scholarly, legal, and medical manuscripts for many years. He lives with his wife, Maureen Kaplan, in Rockingham, Vermont, where he is an avid gardener.*



David Bemelmans playing a Steinway grand piano donated in memory of longtime DHMC volunteer David Hall.

Photo by Tom McNeill, Image Quest Photography

### IN THIS ISSUE

- Voices of Parkinson's: David Bemelmans ..... 1
- Note from the Coordinator ..... 1
- News: On Balanced Nutrition ..... 2
- Faces of PD Professionals: Cheryl Lundgren .. 2
- Ask the Doc ..... 3
- Product Review: The Theracycle ..... 3
- NH Support Groups and Contacts ..... 4



National Office:  
135 Parkinson Avenue  
Staten Island, NY 10305  
www.apdaparkinson.org  
(800) 223-2732



### A note FROM THE COORDINATOR

Diane Church, PhD

Greetings from the New Hampshire Parkinson's Center at DHMC! Our APDA Information & Referral Center opened its doors in November 2006, and we are delighted with our progress in providing resources to patients, caregivers, and community members. We look forward to greater outreach and impact as awareness of the Parkinson's Center grows. I would

like to acknowledge DHMC's Kathleen Barrell, Marketing Manager, Ellen Reney, Web Developer, and freelance photographer Tom McNeill for sharing their talents and expertise in the production of this newsletter, our brochure, and our website. Please visit [www.dhmc.org/goto/parkinson](http://www.dhmc.org/goto/parkinson) to view all three!

# Balance Nutrition for Balanced Lives

Dieticians and neurologists agree: good nutrition is essential for good health, and nutritional awareness is especially important for people with Parkinson's disease (PD). Thanks go to our Parkinsonians and caregivers who submitted many of the following tips to help keep your life in balance!

**Avoid weight loss and malnutrition. For a variety of reasons, Parkinson's patients may need to put extra effort into ensuring adequate nutrition.**

- Has diminished sense of smell or taste reduced your appetite? Treat yourself to frequent small portions of colorful foods with textures that you enjoy.
- Are you less hungry due to nausea or because your digestive tract is emptying slowly? Eat smaller meals and snack throughout the day to feel more comfortable. Exercise also helps stimulate the intestine.
- Is constipation a problem? Drink plenty of fluids and eat foods rich in fiber, such as vegetables, fruits, cooked dried beans, seeds, nuts, and whole grain breads and cereals. Or, try the "anti-constipation recipe": mix together and refrigerate for up to one week 1/2 cup applesauce, 2-4 Tbsp miller's bran (or wheat germ or bran cereal), and 4-6 oz prune juice; take 1 Tbsp per day, adding more gradually until you find the right amount for you.
- Are you eating less because you need more time for your meal? Set aside plenty of time for

relaxed and re-energizing meals and snacks. Dishes with raised edges and utensils with built-up handles make it easier to maneuver food on the plate. Raising your plate to mouth-level by placing it atop a box on the dinner table can reduce the amount of effort needed to eat your meal. Ask your doctor to refer you to an occupational therapist for more tips.

- Do you have swallowing or choking difficulties? Softer foods and those of a single consistency may be easier to swallow. For further help, ask your doctor to refer you to a speech-language pathologist (and please see the interview below).

**Eat enough protein, but don't let protein interfere with your medications.**

- According to Registered Dietician Kathrynne Holden\*, people with PD need a daily intake of about 1/2 gram of protein per pound of body weight. To calculate this, divide your weight in pounds by two to get the grams of protein you need each day. Foods rich in protein include milk, yogurt, cheese, eggs, meats, cooked dried beans, nuts, and seeds.
- Unfortunately, protein interferes with the body's absorption of levodopa, the dopamine-replacement drug found in Sinemet®, Parcopa®,



and Stalevo®. Holden\* recommends dividing your protein intake equally between breakfast, lunch, and dinner, and taking levodopa 30-60 minutes before these meals.

- Low-protein snacks (bread, crackers, fruits, and vegetables) eaten between meals allow your body to absorb levodopa and may reduce nausea, a side effect of many PD medications.

\* Reference: Kathrynne Holden, MS RD, is a dietician specializing in Parkinson's. Her books are available at our lending library and at [www.nutritioncanlivewith.com](http://www.nutritioncanlivewith.com). For answers to specific questions, register at [forum.parkinson.org/forum](http://forum.parkinson.org/forum) and click on "Ask the Parkinson Dietician."

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The Parkinson's Center at Dartmouth-Hitchcock Medical Center, Section of Neurology, an Information & Referral Center of the American Parkinson Disease Association, Inc.

One Medical Center Drive, Lebanon, NH 03756

Diane Church, PhD  
Coordinator & Editor

(603) 650-5280

[apda@hitchcock.org](mailto:apda@hitchcock.org)

## Medical Directors

David Coffey, MD

Stephen Lee, MD, PhD

## National Affiliation

American Parkinson Disease Association, Inc.

135 Parkinson Avenue  
Staten Island, NY 10305  
(800) 223-2732

[www.apdaparkinson.org](http://www.apdaparkinson.org)

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.

# Faces of PD Professionals



Cheryl Lundgren with her husband, Alvaro Hernandez

**Cheryl M. Lundgren, MS, CCC-SLP**

Speech-Language Pathologist

Dartmouth-Hitchcock Medical Center, Lebanon, NH

**Which Parkinson's conditions have you treated as a speech-language pathologist?**

Low volume voice and hoarseness (dysphonia), slurred speech (dysarthria) and swallowing difficulty (dysphagia) are common reasons Parkinson's patients are referred to a speech-language pathologist. No matter the condition, my goal is always to improve or maintain a Parkinsonian's function and independence.

Impaired vocal loudness and poor articulation affect a person's communication with family, friends, and co-workers. Differences in facial

expression and monotone speech are common in PD, and affect how people communicate subtle aspects of emotion. Swallowing problems can lead to malnutrition, choking, and possibly pneumonia if food materials are aspirated into the lungs.

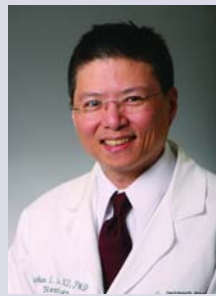
**I understand that you are trained to provide "Lee-Silverman Voice Treatment" (LSVT®). What is special about this particular therapy?**

LSVT was developed specifically for people with PD. It is also called "LSVT®/LOUD" because it focuses on one objective: speaking loudly. Because speech production and oral movements are so highly integrated, triggering "loudness" improves vocal volume, vocal clarity, articulation, resonance, and swallowing. I have also seen this treatment help improve saliva control.

LSVT is about awareness training and returning control to those with PD so they can correct their own vocal output. Patients learn to increase vocal effort and "recalibrate" their perception of appropriate vocal loudness. Treatment is intensive and works toward functional communication in a variety of contexts. It is a joint effort between patient and therapist with a success rate that is scientifically documented.

# Ask the Doc

**Stephen Lee, MD, PhD**  
Medical Co-Director  
Parkinson's Center  
Dartmouth-Hitchcock  
Medical Center



**Q** Is there an established sequence of treatments used for Parkinson's disease?

**A** There really isn't a single path to follow in treating Parkinson's disease. A variety of drugs and surgeries have gone through clinical trials and been approved for patient use, so we have many treatment options. Thus, three neurologists might recommend three different treatments, all of which might be effective! When you participate in clinical trials, you help to provide the information that is used to create the treatment guidelines used by your doctors.

Remember also that each Parkinson's patient is unique, so treatment must be tailored to the individual. It is important to consider how long you have had PD, your age at onset, other medical conditions you may have, and how your body responds to a given treatment. Regular communication and visits with your neurologist and primary care physician will ensure that your treatments are monitored and adjusted as needed.

**Q** Are there any non-traditional, alternative, or homeopathic treatments for Parkinson's disease?

**A** Unfortunately, few alternative treatments have been rigorously tested for effectiveness and safety in treating PD or other medical conditions. The National Center for Complementary and Alternative Medicine (one of the National Institutes of Health; see [nccam.nih.gov](http://nccam.nih.gov)) was established in 1998 to address this. Clinical trials are our "gold-standard" for weighing a treatment's benefits and risks, and are being used to test coenzyme Q10, magnetic stimulation, tai chi, other exercises, and more in the treatment of PD.

**Q** What is happening regarding gene therapy and stem cell research for Parkinson's patients?

**A** This is a very active area of research involving many different and innovative strategies. For example, one approach has been directed at altering the properties of nerve cells. DNA transferred into cells might enable the cells to produce an enzyme or growth factor that promotes nerve cell development, health, and survival. Another strategy is to drive the differentiation of human stem cells into neurons that produce dopamine. Current challenges include finding ways to implant the dopamine-producing nerve cells into the appropriate location in the brain and to increase their long-term survival. In my lab at DHMC, we are investigating the function of Parkinson's disease genes. By discovering the biochemical pathways that may lead to Parkinson's disease, we may identify new targets for drug or gene therapy.

To submit a question to our Parkinson's medical team, please contact our Information & Referral Center Coordinator at [apda@hitchcock.org](mailto:apda@hitchcock.org).

## The Theracycle

Rich Blumenthal, Vice President of the Exercycle Company, visited the Upper Valley Parkinson's Support Group to demonstrate the Theracycle and to answer questions. Here is a summary of the points he covered during his visit.

The Theracycle is a stationary bicycle that provides exercise for those with physical limitations. The current machine has its roots in a 1932 prototype built by a mechanical engineer for his wife, who had a neuromuscular disorder. This early motor-driven exerciser gradually morphed from a simple therapeutic device to a much loved exercise machine known as the Exercycle and used by fitness devotees in all walks of life!

The company returned to its initial goal of providing therapeutic exercise with the redesigned Theracycle. It is specifically built for people with Parkinson's, multiple sclerosis, and other conditions that limit one's ability to get a full range-of-motion workout.

The Theracycle is adjustable to all body sizes and physical abilities, and many support group members gave it a try. You can get a gentle stretch (if you let the motor do the work at low settings) on up to an intense aerobic workout (if you push/pull and pedal on your own). The Theracycle would benefit both the person with Parkinson's and family members.

Key features of the Theracycle include:

- Step-thru design: easy to get on and off, even if you use a walker or wheelchair
- Cushioned seat: comfortable and safe
- Computerized time and speed settings: large buttons, easy to use, so you control your workout
- Smart motor: quiet and powerful, pedal and push/pull on your own or engage the smart motor to do the work for you
- Adjustable handlebars that work arms, chest, back, and shoulders; or, hold the bars alongside the seat if you do not want an upper body workout
- Secure pedals with adjustable pedal straps
- Safety shut off via button or pull cord
- Rugged and stable construction: steel frame, wide legs, low center of gravity

Theracycle users and healthcare professionals report increased circulation, flexibility, endurance, and strength. Resulting benefits include improvements in balance control, posture, speech, sleep, digestive function, effectiveness of PD medications, energy levels, and an overall sense of fitness and well-being.



**The Theracycle ([www.theracycle.com](http://www.theracycle.com))**

Contact Rich Blumenthal at (800) 367-6712 or [richb@exercycle.com](mailto:richb@exercycle.com) for more information.

Courtesy: Exercycle Company

# Announcements and Upcoming Events

## **Saturday, April 19, 2008, Improving Parkinson's Disease Treatment Through Innovation and Research**

Symposium in honor of Parkinson's Disease Awareness Month  
Free, space is limited. Please pre-register by April 10, 2008.

9:30am - 2:00pm

Dartmouth-Hitchcock Medical Center, Auditorium A-D, Lebanon, NH

For more info or to register, call (603) 650-5288 or send email to [apda@hitchcock.org](mailto:apda@hitchcock.org)

## **Friday, July 11, 2008, Golf Scramble**

To benefit "Can Do Can Cure", a private fundraiser for Parkinson's research  
Looking for corporate sponsors at \$200 per hole.

Plausawa Valley Country Club, Pembroke, NH

For more info, contact Christine Robinson at (603) 340-1479 or send email to [divot5@aol.com](mailto:divot5@aol.com)

## **How to Change Your Newsletter Subscription**

If you prefer to access the Parkinson's Companion newsletter online and would rather not receive a printed copy, please contact Diane Church at (603) 650-5280 or [apda@hitchcock.org](mailto:apda@hitchcock.org).

## **Lending Library**

We have many new books and DVDs in our lending library. Please contact Diane Church at (603) 650-5280 or [apda@hitchcock.org](mailto:apda@hitchcock.org) to request a title, receive an up-to-date library listing, or to suggest materials that you have found interesting and helpful.

## **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](mailto:apda@hitchcock.org) for information and resources.

## **Using GoodSearch.com to Raise Money for Parkinson's**

Raise money for the New Hampshire APDA Chapter each time you search the internet! GoodSearch.com, a new search engine powered by Yahoo!, donates half of its revenue (about one cent per search) to the charity that you designate. Just go to [www.goodsearch.com](http://www.goodsearch.com), enter "parkinson" in the search box, and select "American Parkinson Disease Association-APDA-New Hampshire" as your charity. Add GoodSearch to your toolbar so it is easy to use for all of your searches. GoodSearch estimates that 100 people doing two searches per day for the same charity will generate \$730 in a year. This is a grassroots effort, so please help us raise money by telling your family, friends, and colleagues about GoodSearch!

## **THANK YOU TO OUR DONORS!**

The New Hampshire APDA Chapter gratefully acknowledges donations received in memory of:

Charles Hanson, Meredith, NH

Pat Young, Laconia, NH

We thank you for your generosity!

## **New Hampshire Support Groups and Contacts**

### **Concord**

Lucy Crichton . . . . .(603) 227-1346

### **Greater Nashua**

George McHugh . . . . .(603) 889-3251

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**

Diane Church . . . . .(603) 650-5280

### **Portsmouth**

Compass Care . . . . .(603) 430-0070

### **Rochester**

Jane Arlin . . . . .(603) 332-8135

### **Upper Valley (Lebanon)**

Bill Brawley . . . . .(603) 643-7494

### **Northern New Hampshire (St. Johnsbury, VT)**

Sid & Estelle Burton . . . . .(802) 626-3707