



Parkinson's Companion

Voices of Parkinson's

I Love to See Him Smile! by Melinda Driscoll

Melinda Driscoll reports that her husband, Richard, did not have a booming voice to begin with. But as his Parkinson's disease (PD) progressed, his speech became more difficult to understand. He began to slur consonants, drop endings of words, and speak in a monotone. The commonly prescribed Parkinson's medication, carbidopa-levodopa, helped with most of Richard's PD symptoms, but did nothing for his speech problems.

Richard is not alone. Approximately 90% of people with PD develop speech, voice, and swallowing disorders due to increased rigidity of the vocal cords and slow, imprecise, and uncoordinated movements of the lips, tongue, and throat. In addition, the reduced movement of the diaphragm, rib cage, and abdomen result in shallow breathing and inadequate breath support needed for voice production. These changes may result in quiet speaking voice, monotone pitch, hoarse or breathy speech, slurring, and/or hesitant, rapid, festinated speaking.

Any of these altered vocal characteristics can limit one's ability to communicate. As the Driscolls discovered, the person with Parkinson's may repeatedly be told, "I can't hear you!" and "Can you repeat that, please?" Lee Silverman Voice Treatment (LSVT[®]-LOUD) was developed specifically for Parkinson's, and is the only therapy scientifically demonstrated to restore functional vocal communication to people with PD. According to Cheryl Lundgren, Speech Language Pathologist (SLP) at Dartmouth-Hitchcock Medical Center in Lebanon, NH, "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." Although LSVT[®]-LOUD focuses on just one objective, speaking loudly, Ms. Lundgren reports that this therapy helps people with PD to improve vocal loudness and clarity, articulation, resonance, swallowing, saliva control, and facial expression.

On a routine visit to his neurologist's office, Richard was referred for voice therapy with Lisa Sommers, SLP, at Northeast Rehabilitation Health Network in Salem, NH. Successful LSVT[®]-LOUD therapy requires that the patient make a commitment to a four week program comprising 16 one-hour SLP sessions in addition to daily practice at home. Although the Driscolls do not live near Northeast Rehab and treatments were scheduled during winter, Richard dedicated himself to this intense therapy with Ms. Sommers and did his homework daily. His exercises focused on using correct breath control to project his voice, shouting a range of high to low notes, and speaking scripted sentences and words as loud as possible. By the end of LSVT[®]-LOUD therapy, he had reached "loudness goals" set during an initial evaluation by Ms. Sommers. With continued daily practice, patients can maintain improvements for at least two years before requiring an LSVT[®]-LOUD "tune-up."

Ms. Sommers reports that LSVT[®]-LOUD helps her patients with functional communication, confidence, and self-worth. In an interview with Melinda Driscoll and in subsequent email contact, Ms. Sommers states, "The therapy is very exciting because it makes such a big difference in someone's quality of life. People can finally be

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Richard Driscoll and Lisa Sommers, SLP

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A Note from the Coordinator Diane L. Church, PhD

As I write this, the exciting 2010 Winter Olympics are wrapping up. I have included a list of exercise books, DVDs, and videotapes in this issue of Parkinson's Companion, and hope that you are all keeping as active as possible! Please also note that two sites in NH are now offering Parkinson's Wellness Programs (featured in Parkinson's Companion, Spring 2009;

see notice on page 4 of this issue). This newsletter features articles on speech therapy for people with Parkinson's and on the racial and geographic distribution of PD. I hope to see many of you at our upcoming April 17 symposium in honor of Parkinson's Awareness Month.

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heard by others and inflection and expression come back in their voices and faces. People improve so dramatically, and this makes me happy. I am energized, and could do this therapy all day."

Ms. Sommers also reflects on her role as a speech-language pathologist for the past 23 years. "I really have to learn how my patients learn. What their life experiences are and their education level. Even though the principles of LSVT are consistent, each patient is different, and I must gear the therapy to fit each one. This is the speech pathologist's role and responsibility.

"I learn a lot of other details about PD patients that help them. Problems and questions come up in therapy that may not come up when a patient visits their doctor....It is the mark of a good therapist to recognize this and suggest [that] patients see their doctors. I want to encourage patients to ask their doctors very early in the diagnostic process—even before they show many symptoms—if they can have a referral for speech, occupational, and/or physical therapy. This may help to prevent potential problems."

The Driscolls are grateful to Paul Barlow, PA, for referring Richard for speech therapy and to Lisa Sommers, SLP, for working with Richard. Melinda Driscoll reports, "My hus-

band practices his routine religiously, and since he has strengthened his facial and vocal muscles, he smiles more, and I love to see him smile!...LSVT®LOUD has given him a renewed sense of himself and improved confidence as he goes forward dealing with PD for the balance of his life."

Portions of this piece, relating the Driscoll's experiences, are derived from an article by Melinda Driscoll that appeared in the Derry (NH) News on 12/17/2009. An interview with Cheryl Lundgren, CCC-SLP, appeared in Parkinson's Companion, Spring 2008. Please see the listing of NH and VT Speech Language Pathologists certified in LSVT®LOUD, below.

NH & VT Speech-Language Pathologists Trained in Lee Silverman Voice Therapy

NEW HAMPSHIRE

Dartmouth-Hitchcock Medical Center

Lebanon, NH
(603) 650-5978

- Cheryl Lundgren, MS, CCC-SLP
cheryl.m.lundgren@hitchcock.org
- Katrina Milo, CCC-SLP
katrina.l.milo@hitchcock.org

Northeast Rehabilitation Hospital

Salem, NH
(603) 893-2900

- Dale Goldstein, MS, CCC-SLP
Speech Pathology Team Leader
dgoldstein@northeastrehab.com
- Jessica Anderson, CCC-SLP
janderson@northeastrehab.com
- Lisa Sommers, MA, CCC-SLP
lsommers@northeastrehab.com

Portsmouth Regional Hospital

Newington, NH
(207) 332-6612

- Carolyn Marsh, CCC-SLP
whimsyhill@aol.com

VERMONT

Fletcher Allen Health Care

Colchester, VT
(802) 847-3970

- Lakshmi Joshi Boyle, MS, CCC-SLP
Supervisor, Center for Disorders of
Communication/Audiology Center
Lakshmi.Boyle@vtmednet.org
- Ashley Couture, MS, CCC-SLP
ashley.couture@vtmednet.org
- Karen McFeeters Leary, MEd, CCC-SLP
Karen.Leary@vtmednet.org

Rutland Regional Medical Center

Rutland, VT
(802) 747-1840

- Barbara C. Mallen, CCC-SLP
bmallen@rrmc.org
- Kelly Parker, CCC-SLP
kcparker@rrmc.org

Southwestern Vermont Health Care

Bennington, VT
(802) 447-5140

- Lisa Abbott Moore, MS,
CCC-SLP, CDAT
mool@phin.org



If you are trained in LSVT and would like to add your contact info to this list or to edit your current listing, please contact Diane L. Church at apda@hitchcock.org or (603) 650-5280.

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

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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.

201002-62

Racial and Geographic Variation in Parkinson Disease

by Allison Wright Willis, MD

This article first appeared in *Link*, Newsletter of the APDA St. Louis, MO Chapter, February 2010. Used with permission from Deborah D. Guyer, Editor, and Allison Wright Willis, MD.

Parkinson disease is a common neurodegenerative disease of the elderly with no known cause. My research seeks to identify demographic and environmental factors which may influence who develops PD and who does not. Previously, we did not know how common PD was in the United States, nor did we have extensive data on which people are more likely to develop the disease. Using Medicare data, which is utilized by 98% of Americans over the age of 65, we were able to determine Parkinson disease rates in the United States by race and region of residence. Below are the highlights from my recently published article in the journal *Neuroepidemiology* (A. W. Willis et al., *Neuroepidemiology* 2010; 34:143-151).

We found that Parkinson disease affects approximately 1.6% of the U.S. population over the age of 65, with about 480,000 people living with the disease at any time. Approximately 130,000 people are newly diagnosed each year. Men are slightly more likely to have the disease, with a male:female ratio of 1.55 (155 men have the disease for every 100 women). PD rates increase with age. White men have a much higher rate of Parkinson disease, up to double that is seen in Blacks or Asians. Asian women seem to have the lowest rate of PD in the United States. Geographically, Parkinson disease rates are highest in the Midwest and Northeast regions of our country, where the rates of new and existing cases of Parkinson disease are two to ten times greater than that in the West and South.

There are several interesting theories suggested by this recent study. The finding that Whites have substantially higher rates of Parkinson disease may mean that Blacks and Asians are somehow less susceptible to PD, perhaps due to a protective genetic factor or, to decreased exposure to key environmental factors. The finding that PD is more common in the Midwest and Northeast supports previous research which suggests that non-hereditary PD may be associated with environmental factors (some of which may be pesticides or metals). These areas of the country are hubs of agriculture and industry, and future studies may be able to identify specific environmental factors which raise or lower PD risk.



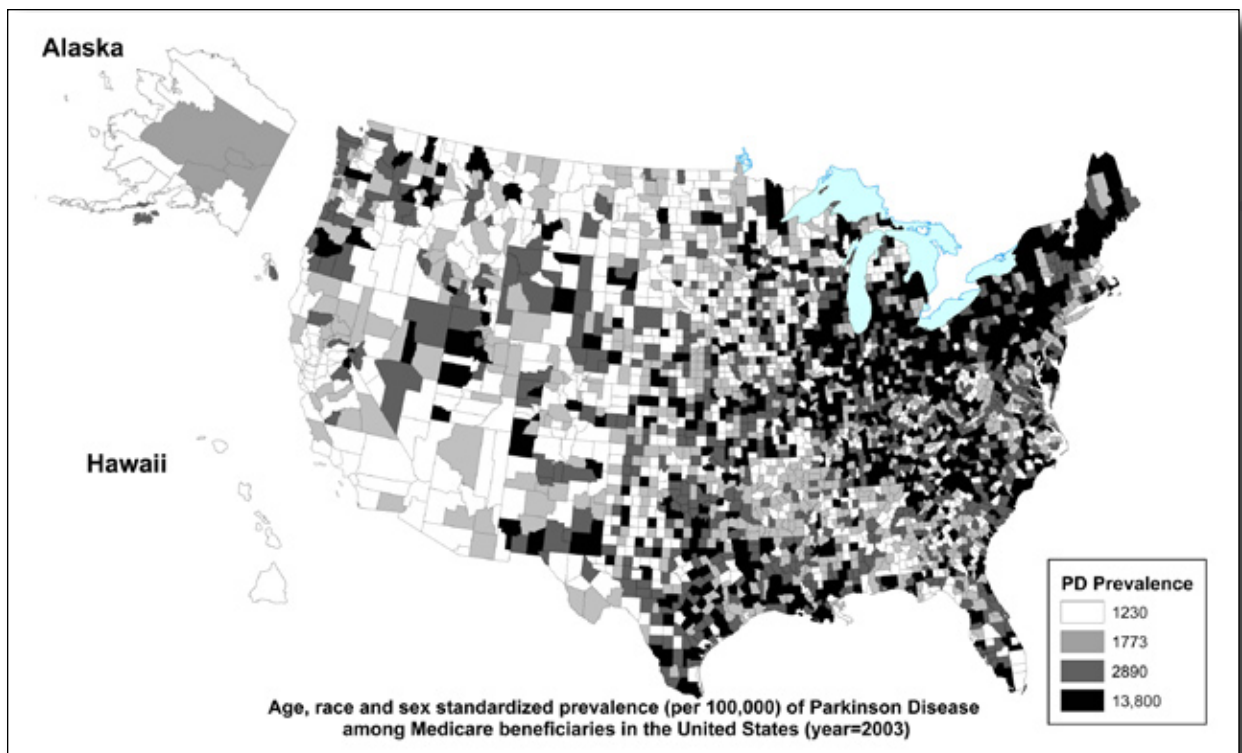
Allison Wright Willis, MD is an Assistant Professor of Neurology at Washington University School of Medicine. Her clinical areas of expertise include treatment of adults and children with movement disorders; such as Parkinson disease (PD), dystonia, and Tourette Syndrome/tics. Her main area of research is in the environmental epidemiology of PD.

Notes from Diane L. Church, Editor, *Parkinson's Companion*:

- Several PD patients have pointed out that they have lived in many different parts of the U.S. and the world, in both rural and urban settings. This will certainly confound making correlations between environmental risks and the incidence of PD based on geographical distribution.

Additional points from the discussion section of the original paper by Dr. Willis et al.:

- This study is particularly strong because it utilizes the enormous Medicare data set. Thus this analysis includes 98% of Americans over age 65, with more than 450,000 PD cases per year, and data available for 10 years. In contrast, previous studies analyzed data sets with fewer than 400 PD cases.
- With the aging of the American population and the increase in PD prevalence into very old age, we need to consider the implications for the allocation and delivery of public health care resources.
- "Our findings highlight the urgent need for neuroprotective & neuropreventive interventions."



Announcements & Events

From the APDA Parkinson's Information and Referral Center at DHMC.

For information, please contact Diane L. Church at (603) 650-5280 or send email to apda@hitchcock.org

Parkinson's Wellness Program

Six-week program, Tuesdays and Fridays, May 4 – June 11, 11:30 am-1:00 pm with pre- and post-assessments the weeks before and after. Exercise, balance, gait training, and education program to help those with PD achieve a better quality of life. "Medical Eligibility Form" is required to ensure that the program is appropriate and safe for you. Fee of \$250 per person; partial scholarships are available. **NOTE:** This program is also offered at Northeast Rehabilitation Hospital in Salem, NH. For information, please contact (603) 893-2900.

From the Dartmouth-Hitchcock Aging Resource Center

Pre-registration required—all sessions are free, but space is limited.

For information, please call Caroline Moore at (603) 653-3460, or email AgingCenter@hitchcock.org

Powerful Tools for Caregivers

Six-week workshop series: Fridays, April 2 – May 7, 2:30-4:00 pm or Wednesdays, April 28 – June 2, 2:30-4:00 pm. The focus is on caring for the caregiver. Topics include reducing stress, bringing balance to your life, communicating effectively with loved ones, and tackling tough decisions with confidence.

Spirit Boosters for Family Caregiver

Register for all sessions or select dates, Tuesdays, 1:30-3:00 pm. March 16: Breathing: Nature's Tranquilizer; April 20: Mandalas: Balance, Harmony and Spiritual Well-Being; May 18: Caregiving: Grit and Grace.

From the Parkinson's Center Lending Library: Exercise Resources

- APDA: "Be Active! An Exercise Program for People with PD" (free booklet)
- John Argue: "Parkinson's Disease & The Art of Moving" (book/DVD)
- Kevin Lockette: "Move It! An Exercise and Movement Guide for PD" (book/DVD)
- David Zid: "Delay the Disease" (book/DVD)
- Janet Hamburg: "Motivating Moves for People with Parkinson's" (DVD)
- "Tai Chi for Energy and Renewal" (DVD)
- "Smart Moves with Pam Quinn" (DVD)
- "PLUS...There's Exercise" (DVD)

To request a title, suggest materials that you have found interesting, update your mailing address or request an electronic version of this newsletter, please contact Diane L. Church at (603) 650-5280 or apda@hitchcock.org.

Saturday, April 17, 2010

9:30 am-2:30 pm

A Parkinson's Sampler: Symposium in honor of Parkinson's Disease Awareness Month, DHMC, Lebanon, NH. Presentations by Penelope J. Hallett, PhD; Dennis McCullough, MD; and Jenny Gelfan, MA, Ed. Fee of \$15 per person includes continental breakfast and box lunch. Space is limited. Pre-registration must be received by April 9.

Save the date!

Saturday September 25, 2010

Symposium for People with Parkinson's, Caregivers, and the Community. Lake Opechee Inn, Laconia, NH. Details in the next *Parkinson's Companion*.

Healthier Living Workshops

Six-week workshop series: Tuesdays, April 6 – May 11, 1:15-3:45 pm or Thursdays, April 29 – June 3, 2:00-4:30 pm. For older adults who are living with long-term health conditions. Topics include: improving strength, flexibility, and endurance; managing medications; improving communication; healthier eating; and making decisions about medical treatments.

Basic Training for Family

Caregivers Four-week workshop series: Wednesdays, April 28 – May 19, 12:30-2:00 pm. For family caregivers who find themselves thrust into a health care provider role for which they were not trained. Topics include: physical problems, mobility problems and exercise, dying at home, using medicines safely.

NH Support Groups & Contacts

Concord

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

Conway

Sue Nickerson (603) 356-2426

Greater Nashua

John Ghorzi (603) 888-1944

Lakes Area Mutual (Wolfeboro)

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

Manchester

Mary Blevens (603) 663-3170

Meredith (Meredith Bay Colony Club)

Kathie Thorndike (603) 707-7598

Meredith (Forestview Manor)

Amanda Cook (603) 279-3121

Monadnock Region (Keene)

Joe Nicholas (603) 352-1727

Peterborough

Bernadette Stephens (603) 487-3228

Rochester

Inge Valentine (603) 332-8132

Seacoast Parkinsonians (Brentwood)

Bob Hantman (603) 773-9901

Upper Valley (Lebanon)

Bill Brawley (603) 643-7494
Diane L. Church (603) 650-5280

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 L. 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

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