



Parkinson Pathfinder

THE NEWSLETTER OF THE AMERICAN PARKINSON DISEASE ASSOCIATION
INFORMATION AND REFERRAL CENTER OF WASHINGTON

Fall 2005

One treatment approach to “Keeping your voice alive” with PD

The Lee Silverman Voice Treatment (LSVT) has been widely used as an effective approach to the speech disorders that can accompany Parkinson’s disease. It was developed at the urging of the family of a woman affected by Parkinson’s whose voice had become difficult to hear and understand. Researcher Dr. Lorraine Ramig, teamed up with speech therapist Carolyn Bonitati in 1987 to create a successful voice therapy program to help Mrs. Silverman, for whom the approach was subsequently named.

Through the work of the nonprofit LSVT Foundation an increasing number of Speech Therapists have chosen to become certified to provide the intensive 1 hour a day, 4-week course of therapy that teaches people with PD to develop the strength required to speak at normal vocal loudness.

Soft voice and monotone, together with lessened facial expression occur in nearly 90% of individuals with PD. These problems often progress, accompanied by swallowing disorders. Traditional neuropharmacological and neurosurgical treatments have been of limited help in improving these problems, with conventional wisdom being that speech disorders are resistant to medical treatments and efforts at traditional speech therapy have been considered ineffective. The PD process makes it difficult for those affected to perceive the loudness of their own voice, making it seem as though it is of normal tone whereas others hear it as diminished.

Research has demonstrated that a focused program of specialized speech therapy (LSVT®) has been shown to

provide benefits including improved speech intelligibility and generalized effects across motor symptoms (swallow, facial expression and respiration) and neural functioning. Speech treatment is an immediate, practical, and relatively inexpensive intervention for improving behavior with the locus of control with the patient, rather than the passive intervention of a drug or surgical procedure administered by a care provider.

The LSVT® approach is explained as one that “centers on a very specific therapeutic target: increased vocal loudness. This key target acts as a “trigger” to increase effort and coordination across the speech production system. Their research has shown that a treatment with a simple focus (e.g., “think loud” in speech production) may generalize to other systems (e.g., articulation, speaking rate, swallowing, respiratory mechanics).”

To get started with the LSVT method, people with PD are advised to obtain an evaluation by a certified speech language pathologist and enter into speech treatment based upon the recommendations of that evaluation. If you are having any difficulty with speech, voice, or swallowing - TELL YOUR DOCTOR - and request a referral to a speech therapist. The Foundation’s website lists 23 “LSVT Clinicians” currently in the state of Washington along with those in other states and 26 countries.

For additional information, including introductory videos, the scheduling of LSVT informational lectures across the US, and names of certified clinicians, contact the LSVT Foundation at 1-888-606-5788 or info@lsvt.org (email), or www.lsvt.org (website).



Anne Guthrie,
Suzanne Cameron,
& Ann Zylstra with
Vincent N. Gatullo,
National APDA
President at the
July APDA meeting
in New York
(See related article
on page 2)

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apda@u.washington.edu

For information packets, literature, or other Parkinson related issues, please contact the Information and Referral Center at the above address or visit our website at

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APDA Center Coordinator

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TBA

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1-800-223-2732

www.apdaparkinson.org

If you have any comments or suggestions regarding this Newsletter, please contact the I & R Center at (206) 543-5369.

The material in this Newsletter is solely for the information of the reader and should not be used for treatment purposes, but rather for discussion with the patient's own physician. It does not necessarily reflect the opinion of the Seattle APDA I&R Center or that of the Washington State Board.

Chapter News**WA APDA President Report***By Ann Zylstra*

How quickly the summer has come and gone. This summer began with the debut of "Managing Parkinson's Disease; Straight Talk and Honest Hope". What a huge success! The demand for copies of the DVD has been tremendous and has kept many people busy trying to keep up with the requests. We are proud to have provided such a professional informational tool.

The National APDA meeting was held this year in New York City and was attended by Chapter presidents and I&R coordinators from all over the United States. We met many inspirational individuals and were inspired by the various personalities all gathered together to share the common goal of "Easing the Burden". We were educated about the disease, current treatments, research, and fundraising. The experience was wonderful.

This year we are repeating the "Build a Benefit" to try to raise money to support research for a cure for Parkinson's disease. We are doing this instead of the walkathon. Anyone interested is encouraged to host a benefit. For more information contact Anne Guthrie at the I&R Center.

Now that fall is here we are looking forward to the annual educational symposium. It will be held at the Shoreline Conference Center on Saturday October the 8th. Many wonderful professionals will share current information and treatment strategies with us. We hope to see you there.

Ann Zylstra and Suzanne Cameron, Co-presidents.



Washington State APDA is grateful for all the donations we have received over the decades the chapter has existed. These contributions are vital to support our continued work on behalf of the Parkinson's community. As a volunteer-based organization, the vast majority of our income is utilized to sustain our newsletter and website, support the network of PD support groups, produce educational materials and events and fund research on a local and national level. Occasionally donors share the reason they chose to donate to APDA. Following is a portion of one such eloquent letter.

Donna Dreessen died on July 14, 2005. When she was diagnosed with Parkinson's disease some thirty-four years ago, she had just graduated from college as a German teacher ready for a career in education. We had been married three years and she was three months pregnant. I remember that day clearly, we both held each other in our arms fearing the unknown with only L-dopa as a medicine. The pregnancy seemed to make the symptoms get worse faster than normal but she was determined to wait until our child was born to start the medication and delivered a healthy baby girl.



Donna and Marvin D. Dreessen

She started her meds almost immediately. Donna always wanted two children and Parkinson's was not to stop her dream, two years later our son was born.

Raising the children was a joy and a struggle. Fortunately I have a profession that allowed me to take a two-hour lunch. I would rush home at noon, feed the babies, fix Donna lunch, (unless her meds were "on" then lunch would be waiting

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Networking for Knowledge and Support

21st Annual Symposium of the Washington State Parkinson's Community
 American Parkinson Disease Association, Washington State

Saturday, October 8, 2005 Shoreline Conference Center, Shoreline, WA

Program

- 8: 30 - 9:00** Registration, coffee and exhibits
- 9:00 - 9:15** *Welcome and Opening Remarks* by the APDA
- 9:15 – 10:00** *“Update on PD Research: A ‘Local’ Perspective”* James Leverenz, MD
 (Break)
- 10:15-11:00** *“Parkinson’s Progression and Neuroprotection”* Jon Stoessl, MD
 (Break)
- 11:15 -11:45** *“Emerging treatments for PD”* Pat Hogan, MD
- 11:45 – 12:15** *“The Treatment of Parkinson’s disease by Brain-Cell Implantation: Up and Down Sides”* Professor Harry Bradford
- 12:15-1:15** Luncheon Program *APDA Presentation*
- 1:25- 2:05** *“Deep brain stimulation for Parkinson disease”* Ali Samii, MD
 (Break)
- 2:15 - 3:15** *Research and Health Provider Panel* The morning presenters will be joined by other area health providers in a discussion and to address audience questions and comments.
- 3:15- 3:30** *Closing Remarks by the APDA and organizers*

Registration Program Fee: \$22 per person before 10/1 or \$25 day at the door (See below)

Submission options *Online:* see www.waparkinsons.org
 Fax: 206-685-8100 Attn Anne
 Mail: APDA, Dept of Neurology UW Box 356465 Seattle, WA 98195-6465

SYMPOSIUM REGISTRATION

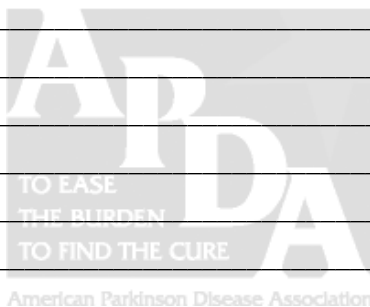
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Email _____



<i>FEE(S)</i>	
#1 \$ _____	
#2 \$ _____	
 <i>Donation</i>	
\$ _____	

<i>Total</i> \$ _____	

Optional donation to support this year’s Symposium \$ _____

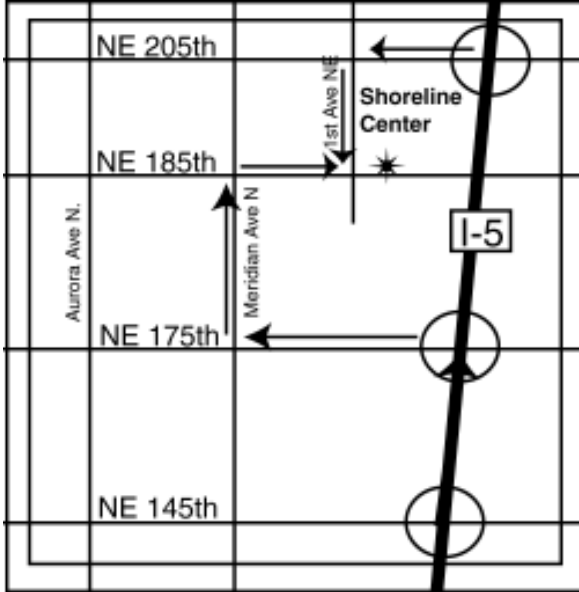
Payment options:

By Check: MAKE CHECK PAYABLE TO “ Washington APDA”
 Credit card Online: See www.waparkinsons.org
 Select “On behalf of Symposium”
PLEASE NO CREDIT CARD TRANSACTIONS AT THE DOOR

BE SURE TO COMPLETE REVERSE SIDE →

Shoreline Conference Center

18560 1st Ave NE
 Shoreline, WA 98155-2148
 206.361.4243 (for directions only)
 www.shorelinecenter.com



The Shoreline Conference Center is located in Shoreline WA, about a 20 minute drive north of Downtown Seattle and 30 minutes South of Everett. It is a short distance from the I-5 Freeway.

Northbound

- Interstate 5 North to NE 175th St. (exit #176 for Shoreline).
- Turn left onto NE 175th St. and go to Meridian Ave. N.
- Turn right onto Meridian Ave. N and go to N. 185th St.
- Turn right on N. 185th and go to 1st Ave. NE.
- Turn left on 1st Ave. NE. The Shoreline Center is on your right. (You are at the South end of the center.)

Southbound

- Interstate 5 South to NE 205th St. Lake Forest Park (exit #177). Exit Westbound (right).
- Turn right on to NE 205th and go to 1st Ave. NE.
- Turn left on 1st Ave. NE and continue South for .5 mile.
- The Shoreline Center will be on your left. (You are at the north end of the center.)

Parking Information:

Conference Center (North end of building) has a parking area entrance just south of the tennis courts. Enter the Conference Center at this north end. Handicapped parking will be designated by signs- please leave these for persons in most need.

SYMPOSIUM REGISTRATION (CONTINUED)

Luncheon selection: Your registration fee includes a luncheon. Menu and selection will be discussed with you by phone or email after your registration is received.

Special Requests

Please let us know of any requests you have to make your participation more comfortable. We will contact you to discuss your request.

___ Escort at drop off entrance. Details _____

___ Dietary/dining request. Details _____

___ Fee discount. Request _____

___ Other _____

Interests, Issues and Concerns Forums

The Washington Coalition of Citizens with disAbilities (WCCD) and the New Wings Advisory Council invite people with disabilities and their families living in King County to participate in one of a series of forums. Participants are asked to share their interests, issues and concerns related to living with disabilities in our area. APDA's Information and Referral Center, joins other area organizations in co-sponsoring this multi-site event.

- **Sept. 8, 1-3pm: Des Moines Library**
- **Sept. 24, 1-3pm: Woodinville Community Center**
- **Sept. 20, 1-3pm: WCCD, Seattle**
- **Sept. 28, 6-8 pm: disAbility Resources, Redmond**

For more information visit www.wccd.org or call (206) 545-7055. Everyone is welcome to join!

Information about the organizing team: *New Wings Advisory Council* is a team of people with disabilities and service providers who have been meeting for over two years to create a day center for adults with disabilities in King County. *WCCD* seeks to evaluate how their organization can reach out to more people in King County. They are joining forces to assess the service needs of persons impacted by disabling conditions in King County.

Continued from page 2 . . .

for me). We would play with the children and put them down for naps before I returned to work. As they grew, Donna helped them with their school homework until I got home when I helped them too.

Sewing was a hobby of hers. Donna made all kinds of clothes: dresses, blouses, coats, all with a special flare. It would take her longer than normal as she worked around the on/off times but she was persistent. This hobby was one of her favorites, with fleece blankets for newborns a special gift.

Computers were another tool for her. She was our at home office secretary paying bills and making sure supplies were ordered. However, the on/off symptom was always present from unable to move to extreme rhythyming as the sinament schedule round the clock dictated. Her work was always finished no matter how long it took.

She was fortunate to go to Sweden for bilateral pallidotomy, what a relief for her not to have the tremendous medical swings. We would always be grateful to Dr. Laitinen for his gifted hands.

At one period we were Parkinson's Support Group leaders. She was always available to talk openly about Parkinson's, with a positive attitude on what she could do and not what she could not do. Our marriage was full and strong, filled with love, going any place together that we desired. We didn't dwell on the Parkinson's but enjoyed the activities

New Resources You Can Use

• **ICE your cell phone**

ICE stands for In Case of Emergency. If you add an entry in the contacts list in your cell phone under ICE, with the name and phone number of the person that the emergency services should call on your behalf, you can save them a lot of time and have your loved ones contacted quickly. It only takes a few moments of your time. Paramedics know what ICE means and they look for it immediately.

• **Library E-book Service**

The King County Library System has started an e-book service that allows individuals to download audio e-books to home computers. The e-book can be downloaded from the library's Web site and either burned to a CD or transferred to an MP3 player. E-book titles include fiction and non-fiction. Log on to the e-book Web site for more information.

• **These resources were found on "Resource Talk,"** a free monthly e-newsletter published by the **Crisis Clinic** in King County. Postings provide critical resources, community events, and feature articles on important health and human service topics. As a King County organization, Crisis Clinic offers a variety of products and services to connect people with critical resources. Information services and subscription can be obtained by calling 206.461.3200 (or 800.621.4636) or at www.crisisclinic.org.

that were being attended. We were proud to be out and enjoyed each other's company no matter where we went. An electric scooter or wheelchair were just devices to get us there.

Donna enjoyed her life. We built a new home some twenty-two years ago in anticipation of the progression of Parkinson's. Our planning was superb with conveniences made for her. Her kitchen is not wanting for a special tool nor her sewing room for that needed item. The computer/office has time saving equipment.

The biggest joy was grandchildren, what a special spot in our home for all four of them. She had that special grandmother touch. To see her hold her new granddaughter with sparkling brown eyes is a joy to remember.

My true hope is that those just diagnosed or those who have had Parkinson's for a long time don't become a recluse. To spouses, your mate hasn't changed, he/she still loves you, return that love and reap its rewards. Give them time to accomplish what they can and take time to enjoy your life as well as enhance theirs. Our thirty-seven years of marriage was fulfilling, those of you that are married, I hope yours will also be filled with joy.

Mr. Dreessen's letter concluded with a contribution to Washington APDA, saying "it is with great promise for finding the cure that we, her family and friends, make a donation in Donna's name."

Washington State Parkinson Support Groups

Eastern Washington

*Okanogin

Valley Care Nursing Home

Contact Sandra Johnson

509.826.0491

Meets 3rd Thursday, 1pm

Wenatchee

Wenatchee Senior Center

Contact Estella Lenhart

509.667.0844

Meets 3rd Monday, 1:00pm

Richland

Richland Lutheran Church

Contact: Neurological Center

509.943.8455

Meets 3rd Thursday, 1:15

Spokane

Riverview Retirement Center

Contact Carol Lewis

509.466.0188

Meets 1st Monday, 7pm

Spokane Parkinson's

Educational Group

St Luke's Rehab Institute

Contact Spokane Parkinson's

Regional Center

509.473.6740

3rd Monday, 2-4 pm

Walla Walla

Congregational Church

Contact Darlene Lambert

509.382.4012

Meets 4th Saturday, 6pm

509.473.6740

3rd Monday, 2-4 pm

Yakima

Wellness House

Contact Kristyan

509.248.8539 or

kristyan@senioravenues.com

Meets 2nd Saturday, 1-2pm

Western Washington

Puyallup

United Methodist Church

Contact Jennifer Wrye

253.752.7112

General Support Group

Meets 3rd Thursday, 1:30pm

Caregivers Support Group

Meets 2nd Thursday, 1pm

Tacoma

Tacoma Lutheran Home

Contact Sharon Jung

253.284.4488

Meets 3rd Friday, 11:30 am

Anacortes

Island Hospital

Contact Pat Grady

360.299.3150

Meets 2nd Friday, 2pm

Bainbridge Gardens

P.D. Young at H.E.A.R.T. Group

Contact Steve Bohannon

206.842-1385 sbohann@msn.com

Meets 1st Monday, 1 pm

Bellingham

Parkway Chateau

Contact Debra Ivanovich

360.724.3382

Meets 2nd Monday, 2pm

Bellingham Young Onset

Fourth Corner Community Church

Contact Susie Morrow

360.384.4634

yopdnw@hotmail.com

Meets 2nd and 4th Wednesday, 7 pm

Burlington

Homeplace Care Center

Contact Nancy Gentry

360.755.1493

Meets 2nd Tuesday, 2pm

Mill Creek

Merril Gardens

Contact: Bob Detmer

425-316-3958

Meets 2nd Tuesday, 7pm

*North Whidbey Island

Oak Harbor Senior Center

Contact J.C. King

360.675.7695

Meets 1st Tuesday, 1:30pm

Vashon Island

General Group

Contact Robin Stover, 206.463.5173

Young Onset Group

Contact Kate Lanigan, 206.463.3140

Port Angeles/Sequim

Sequim Library

Contact Gene Andrews, 360.582.9076

Meets 3rd Wednesday, 1pm

Bremerton

Green Mountain Rehab. Center

Contact Deb Carpenter, 360.373.9119

Meets 1st Tuesday, 1:30pm

Chehalis

Dayspring Baptist Church

Contact Parkinson's Resources/Oregon

800.426.6806

Meets 2nd Tuesday, 2 pm

Longview

Canterbury Park, Broadway and 7th

Contact Don Taylor, 360.636.1375

Meets 3rd Wednesday, 1:30 pm

Olympia

Evergreen Nursing and Rehab Ctr

Parkinson's Education Society

of Puget Sound, 360-491-9700

Meets 3rd Tuesday, 11:30

Vancouver

SW Washington Medical Center

Contact Jeanne Laviolette

360.403.8896

Meets 3rd Saturday, 2pm

*Everett

Providence General Medical Center

General Group

Contact: Leona Burges, 425.338.3136

Meets 4th Saturday, 2pm

Caregiver Group

Contact: Bill Coy, 425-338-3136

Meets 2nd Monday 2-4pm

Young Onset of Snohomish

Contact: Karen Painter, 425.327.9401

kpainter62@aol.com

Meets 3rd Saturday, 2 pm

Greater Seattle Area

*Bothell

North Shore Senior Center

Contact Suzie Favaro

425.486.4564

Meets 2nd Tuesday, 9:30am

Bellevue/Eastside

North Bellevue Senior Center

Contact Carin Mack, 206.230.0166

Meets 4th Tuesday, 2:30pm

*Federal Way

Federal Way Library

Contact Norma Kay Fetz, 253.833.8306

Meets 3rd Monday, 2pm

Edmonds

South County Senior Center

Contact: Merrie Kay Sharar

425.774.5555

Meets 4th Tuesday, 3pm

Young Onset-Seattle

Meets in members homes

Contact Suzanne Cameron, 206.286.8149

Meets 2nd Tuesday, 7pm

Young Onset

Parkinson's Eastside Network

Evergreen Medical Center, Kirkland

Contact Mitch Levy res06h12@gte.net

Anne Guthrie 206.543-5369

North Seattle/Shoreline

Shoreline Senior Center

Contact Scott Tieson

206. 365-1536

Meets 3rd Tuesday, 3pm

Mercer Island

Mercer View Community Center

Contact Carin Mack, 206.230.0166

Meets 1st and 3rd Tuesdays, 2-3:30 pm

*West Seattle

Admiral Congregational Church

Contact Anne Guthrie 206.543-5369

Meets 3rd Thursday, 1:30 pm

Seattle Well Spouse Group

Greenwood Activity Center

Contact: Carin Mack or

socialwkr@earthlink.net

Meets 1st Monday, 4 pm

*Seattle Carers Group

Hamilton House (University District)

Contact Carin Mack, 206.230.0166

Meets 2nd Tuesday, 1 pm

Seattle First Hill

VM Medical Center

Contact Laurel Beck

206.625.7373 ext.64553

Meets 1st Tuesday 1:30pm

Seattle VA Puget Sound

Restricted to Veterans

Contact Lois Osborn, 253.835.3144 or

Romay Franks, 206.277.4560

Meets monthly

Before joining a group,
please contact the Group
Leader to confirm
location and schedule

*Denotes APDA Affiliation

Parkinson's Notes: Updates and Upcoming Events

- **Ask the Experts about Parkinson's Disease** - A Panel Discussion is to be presented by the Booth Gardner Parkinson's Care Center on Monday, September 26 12:00 to 2:30 pm. It will be held at the Evergreen Hospital and Medical Center in the Education Classrooms (TAN Area) (NOT at the Booth Gardner Parkinson's Care Center) Registration required. Please call 425-899-3000 to register and for directions. Box lunches will be provided
- **Mature Workers Job Fair**- Mature Workers Alliance of Puget Sound holds a job and resource fair annually at Seattle Center. The fair includes workshops on how to start your own business, how to re-invent yourself, writing a good resume, interviewing skills, coping with career change, etc. 10am-2pm, Sept. 14, next to Seattle's Space Needle where the Monorail ends at the Seattle Center House (in the Food Court area). For information, call 206-838-8163.
- **Early-stage Memory Loss Seminars**- Three series of nine seminars are being held in 6 locations up and down the Puget Sound region. Topics covered include living with memory loss problems; self-esteem issues and Alzheimer's; improving quality of life; developing coping skills; managing changes in personal relationships; dementia; communication; preparing for the future; care partners; accessing programs and services. The seminars require registration and are sponsored by Alzheimer's Association. For registration and locations, contact Patricia Hunter at 800-848-7093 or visit www.alzwa.org.

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Is your address correct on this mailing?

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*Please take a minute to do so ~
 we will all Benefit!*

*Look inside for your registration form for
 APDA's 2005 Parkinson's Symposium
 "Networking for Knowledge and Support"*