

PSGTC Newsletter

May / June 2011

Ann Milam, Editor annmilam@sbcglobal.net

Message from the President

Is it May already? The months sure fly by fast and another year for our support group is about over. May we have an important meeting because we elect three new Board of Director members and review the annual report. June is our Patriotic luncheon and the end of our fiscal year. I am looking forward to our time together.

Helen Robertson

Excerpts from Cathy Colliers talk in March.

Everyone really enjoyed it and asked that some of the message she shared be printed in the Newsletter:

1. Don't demand to understand. (Isaiah 55:8-9-His ways are not our ways. His thoughts are above our thoughts.)
2. Don't fail to be faithful. (He's a God Who can be trusted, even when we don't understand His plan.)
3. Don't bow to bitterness. (You can become bitter or better. The choice is yours. *No one knows what's in a vessel, mud or honey, until it's tipped over.*)
4. Don't be unwilling to wait. (Psalm 37:5-9-Rest and wait patiently on the Lord, cease from anger and wait on the Lord.)
5. Don't let your dreams dissolve. (Philippians 3:14-I press on toward the mark of the high calling of God in Christ Jesus.)

Philippians 4:13 "I can do ALL things THROUGH CHRIST Who gives me strength."

II Corinthians 12:9-10 "And He said to me, My grace is sufficient for thee; for my strength is made perfect in weakness. Most gladly therefore will I rather glory in my infirmities, that the power of Christ may rest upon me. Therefore I take pleasure in infirmities, in reproaches, in necessities, in persecutions, in distresses for Christ's sake; for when I am weak, then am I strong." God bless you and may HIS strength continue to be YOUR strength in weakness. I love you and am blessed by each and everyone of you in our Parkinson's Support Group!

Cathy Collier

Our Meetings are held at:

Broadway Baptist Church

305 W. Broadway, RM 302
Fort Worth, Texas 76104

May 23, 2011 @ 1:30pm—The meeting for May will be held at 1:30. We will have a speaker from "A Place For Mom" who will inform us of various options for independent living, assisted living and nursing home care. Refreshments will be provided. We will elect 3 new Board of Directors members. It is important that you participate in the election of the ones to represent you in the business of the Support Group.

June 27, 2011 @ 11:30am— Our June meeting is our Patriotic Luncheon and everyone is to bring a dish to share with the group. This Luncheon has been designated as a "Salads and Desserts" meal. So bring your favorite salad or dessert to share with everyone. My problem is, I have too many favorites!
BOD Meeting at 10:00!!



Exercise

*The exercise group meets at 10:30am every Monday, Wednesday and Friday in room 206 at Broadway Baptist Church. Remember the single most important thing you can do to help with your Parkinson's Disease, is to **exercise**. It is so true that if you don't use it, you will lose it.*

*This last month, Elsie Wilson arranged for Charles Morris to attend one of the exercise meetings and present a program on "**CHAIR TI CHI**" Mr. Morris has developed this method of exercise for Parkinson and MS patients. He sells DVD's teaching the steps involved in the Ti Chi exercise. If you are interested in acquiring a DVD, please call Elsie on the Help Line listed below. She can put you in touch with Mr. Morris.*

During bad weather, Exercise meetings may be cancelled. Call the help line (817/275-1909) if you are in question about a particular day's meeting. Be sure to check our Website at: www.psgtc.org.

The contents or opinions expressed in this Newsletter are those of individual writers and do not constitute an endorsement or approval by Parkinson's Support Group of Tarrant County.

Membership Annual Dues

Your dues must be paid no later than **June 15** to remain on the active member list.

Dues are as follows:

Individual & Family (patient and partner) annual dues.....	\$20.00
Professional Member annual dues.....	\$30.00
Life members: One time fee.....	\$200.00

Please mail your dues along with a membership application form, so the dues will be credited to the correct person/family. (Form is on last page of this Newsletter)

YOUR DUES PROVIDE THE FOLLOWING:

- Building usage – Annual donation to Broadway Baptist Church
- Parkinson Phone Help Line – Manned by Elsie Wilson
- Equipment – Exercise Classes
- Hospitality – Refreshment Supplies and Caregivers Luncheon
- Newsletters and Member Directory – Printing and Postage
- Sunshine Fund – Cards and postage
- Educational Programs – Speaker Honorarium
- Research – Annual donation to Parkinson Research Fund

Take this Barcode to Kroger's grocery store with you and have them scan it to your Rewards Card.

Kroger's will donate a percent of everything you spend to our Parkinson Support Group.

PARKINSON SUPPORT GROUP OF TARRANT COUNTY



Caregivers

Meetings are held next to the exercise room on the 2nd and 4th Friday of the month. At 10:30am. You will get great Caregiver support at these meetings. The meetings are very informal and we discuss a plethora of subjects. From medications to medical aids, to anything that will assist us in caring for our PWP. We welcome your participation in this group.

Estate planning lets you avoid guardianship

BY DEBORAH L. COCHELIN

Scenario No. 1. A longtime neighborhood resident is diagnosed with Parkinson's disease. He lives alone. He has no one to check on him regularly. Recently, he experienced some bad side effects from medications.

They included lightheadedness, cognitive problems, hallucinations and impulsivity control. These conditions mask Parkinson's disease, leading an uninformed bystander to assume that he might lack capacity.

Wrongly judging him to be incapacitated, concerned neighbors call Adult Protective Services to report his circumstances. Based on a case manager's assessment, the Attorney General's Office files a petition for guardianship. A guardian ad litem is appointed to represent his best interests. After conducting an investigation, the guardian ad litem files a report with the court recommending the nature and extent of the guardianship and who should be the guardian. A medical examination is required. If he contests the guardianship, he can select his own attorney or have one appointed for him from the court's registry of guardianship attorneys. The attorney's and guardian ad litem's fees are paid from his assets. If he cannot afford an attorney, the court will appoint one for him at county expense. If the matter is not re-

solved at the guardianship hearing, a trial date is set.

Scenario No. 2. The spouse managing the family finances is diagnosed with Parkinson's disease. The afflicted family member can no longer write checks or keep track of due dates and mismanages their finances. Refusing to acknowledge Parkinson's disease in a timely manner, it is too late for estate planning. Using the same process as Scenario No. 1, an expensive guardianship is started to preserve the couple's lifelong, and now endangered, assets.

UNFORTUNATELY, THESE SCENARIOS can happen to people as Parkinson's progresses. The lost ability to speak intelligibly, coupled with diminished ability to write legibly, can lead to communication breakdowns, affecting estate planning.

This provides you with the opportunity to plan to avoid having a court supervised guardianship imposed upon you. Durable powers of attorney for health care and financial decisions are alternatives to guardianships providing a roadmap with your instructions for someone who can be trusted to take over your personal and financial affairs. Having a power of attorney is far less expensive and private than a guardianship.

A durable power of attorney for healthcare decisions is a document expressly authorizing one or more family members, friends or a professional fiduciary as your agent (attorney-in-fact) to make healthcare and other personal decisions on your behalf if you become unable to do so.

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(cont from page 2) Estate Planning

This document allows you to maintain autonomy and privacy by handpicking a trusted friend or family member to act as your informed medical decision maker. A healthcare power of attorney avoids guardianship proceedings if emergency medical treatment is necessary when you have no family member to give consent by designating a single decision maker for you in an emergency situation.

The durable power of attorney for your finances operates in much the same way with many of the same advantages. The distinction is that you are appointing someone to handle all of your financial affairs. Your healthcare attorney-in-fact and your financial power of attorney-in-fact can be the same person.

A healthcare directive, or living will, insures your wishes are carried out so that you can be in charge of your life support decisions before you lose capacity. The Washington Natural Death Act permits you to direct whether life sustaining treatment should be withdrawn or withheld in the event you are in a terminal condition or permanent unconscious condition. This document can be revoked, regardless of your mental state or competency.

Even if you do not have a living will, healthcare providers are allowed by law to comply with your immediate family's agreement that life-sustaining treatment may be withheld without the appointment of a guardian. Loss of independence is a significant concern associated with Parkinson's disease. Planning gives you peace of mind. Play it safe and avoid the invasive, costly guardianship process by obtaining these key estate-planning documents. You'll avoid placing your family in a dilemma by making these significant healthcare and financial decisions in advance. *Deborah L. Cochelin is the principal of Law Office of Deborah L. Cochelin, PLLC, in Seattle. The purpose of this article is to provide information rather than professional advice or legal opinions. Examples are for illustrative purposes only. The author disclaims and shall not be held liable for any losses caused by reliance on the accuracy, reliability or timeliness of such information.*

(This article was copied from the North West Parkinson's Post., but it is the belief of the editor that Texas laws follow pretty closely to Washington in this regard.)

The Science and Practice of "Speaking LOUD" and "Moving BIG"

(Taken from APDA Midwest Chapter March 2011)

**"If you don't talk loud enough – people stop listening."
"If I have no voice, I have no life."**

These are direct quotes from two individuals who live with Parkinson disease (PD).

They reflect the devastating impact that a speech and voice disorder can inflict on the quality of a person's life.

These two are not alone. Research shows that 89 percent of people with PD experience speech and voice disorders, including soft voice, monotone, breathiness, hoarse voice quality and imprecise articulation. As a result, people with Parkinson's report that they are less likely to participate in conversations, or to have confidence in social settings, than healthy individuals in their age group. For years, speech and voice disorders in people with PD were resistant to treatment.

The effects of conventional treatments – whether medical or surgical – were neither significant nor lasting. The recognition that speech therapy could be tailored to the specific problems of the Parkinson's patient led to the development of a method aimed at improving vocal loudness: the Lee Silverman Voice Treatment ("LSVT® LOUD") method. This technique has helped many individuals with Parkinson's and speech problems, giving them new hope for improved communication for work, family and social activities.

Speech and voice disorders in PD

There are several reasons why people with PD have reduced loudness, monotone and hoarse, breathy voices. One is directly related to the disordered motor system that accompanies PD, including rigidity, slow, small movements and tremor. For example

the inadequate muscle activation that leads to bradykinesia (slow movement) and hypokinesia (small movements) in the limbs can also trigger a speech disorder. For speaking, the problem with muscle activation can result in reduced movements of the respiratory system (reduced breath support), larynx (reduced vocal loudness), and articulation (reduced clarity of speech).

Another cause of speech and voice impairment in PD is a deficit in the sensory processing that is related to speech. Clinical observations suggest that people with PD may simply not be *aware* that their speech is getting softer and more difficult to understand. When "soft speaking" people are told of this, they will often reply "No! My spouse complains all the time, but he/she needs a hearing aid!" Furthermore, if people in this situation are asked to bring their voice to normal loudness, they will often complain that they feel as though they were shouting, even though they are perceived by listeners to be speaking normally.

A third cause of this condition is that people with Parkinson's may have a problem with "cueing" themselves to produce speech with adequate loudness. Individuals with PD can respond to an *external* cue (e.g., an instruction from someone else to "speak loudly!"), but their ability to cue themselves *internally* to use a louder voice is impaired. These problems can be frustrating both for the person and for their families. Patients feel that they are speaking loudly enough and do not understand why people keep asking them to repeat. And because the speech loudness responds to external cueing – sometimes soft, sometimes normal – the family may feel that the patient can be louder and clearer if they would only try harder.

These motor, sensory and cueing problems have made people with PD particularly resistant to speech treatment. The conventional wisdom for years has been that people with PD can improve their speech during the speech therapy session, but the improvement "disappears on the way to the parking lot." (cont page 4.)

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As a result, conventional speech therapy has not led to sustained benefit, and has not been considered a valuable addition to the treatment of Parkinson's.

Speech therapy: LSVT® LOUD

“My voice is alive again!” Over the past 15 years, studies supported by the National Institute for Deafness and other Communication Disorders (NIDCD) of the National Institutes of Health have demonstrated that LSVT LOUD is an effective speech treatment for people who live with PD. Those who have used it have improved their vocal loudness, intonation and voice quality, and maintained these improvements for up to two years after treatment. Recent research studies have also documented the effectiveness of this therapy in meeting the common problems of disordered articulation, diminished facial expression and impaired swallowing. In addition, two brain imaging studies have documented evidence of positive changes in the brain following the administration of the therapy.

LSVT LOUD improves vocal loudness by stimulating the muscles of the voice box (larynx) and speech mechanism through a systematic hierarchy of exercises.

Focused on a single goal - “speak LOUD!” – the treatment improves respiratory, laryngeal and articulatory function to maximize speech intelligibility. The treatment uses loudness training to bring the voice to an improved, healthy vocal loudness level with no strain.

The program is administered in 16 sessions over a single month (four individual 60 minute sessions per week). This mode of administration – much more intensive than is the case with conventional programs – is consistent with theories of motor learning and skill acquisition, as well as with principles of neural plasticity and it is critical to attaining optimal results. In addition to stimulating the motor speech system, the treatment incorporates sensory awareness training to help individuals with PD recognize that their voice is too soft, convincing them that the louder voice is within normal limits, and making them comfortable with their new louder voice.

Patients are trained to self-generate (that is, internally cue) the adequate amount of loudness to make their speech understood. While LSVT LOUD has been successfully administered to individuals in all stages of PD, it has been most effective among those who are in the early or middle stages of the condition.

Physical/Occupational Therapy: LSVT® BIG

Recently principles of LSVT LOUD were applied to limb movement in people with PD (LSVT BIG) and have been documented to be effective in the short term.

Specifically, training increased amplitude of limb and body movement (Bigness) in people with PD has documented improvements in amplitude (trunk rotation/gait), that generalized to improved speed (upper/lower limbs), balance, and quality of life. In addition, people were able to maintain these improvements when challenged with a dual task. LSVT BIG can be delivered by a physical or occupational therapist.

Therapy is delivered 4 days a week for 4 weeks; treatment sessions are one hour, individual 1:1 therapy. This protocol was developed specifically to address the unique movement impairments for people with Parkinson disease. The protocol is both intensive and complex, with many repetitions of core movements that are used in daily living. This type of practice is necessary to optimize learning and carryover of your better movement into everyday life!

The extension of this work to a novel integrated treatment program that *simultaneously* targets speech and limb motor disorders in people with PD (LSVT® BIG and LOUD) has recently been developed. Results from pilot work revealed all pilot subjects with PD increased vocal loudness and improved gait. This whole body, amplitude-based treatment program (LSVT® BIG and LOUD), may allow for essential simplification of rehabilitation approaches for people with PD.

How to get LSVT LOUD

Ideally, you should see a speech therapist face-to-face for a complete voice and speech evaluation and treatment. However, if a speech therapist is not available in your area, LSVT LOUD is now being offered in select states via internet and webcam technology. The speech therapist interacts with you in your home or office “live” through your computer screen.

Speech disorders can progressively diminish quality of life for a person with PD.

LSVT LOUD empowers people with PD to participate in their treatment in fundamental ways and to gain control over one important and burdensome aspect of their PD – the ability to communicate. The earlier a person with PD receives a baseline speech evaluation and speech therapy, the more likely he or she will be able to maintain communication skills as the disease progresses. Communication is a key element in quality of life and can help people with PD maintain confidence and a positive self-concept as they deal with the challenges of the disease.

How to get LSVT BIG

Start exercising NOW – as soon as possible. Physicians rarely refer their patients to health and fitness programs at diagnosis because medications are very effective early on at alleviating most of the symptoms and patients experience little change in function. Yet, according to a recent survey, it is at the time of diagnosis that patients often begin to consider lifestyle changes and seek education about conventional and complementary/alternative treatment options. Thus referrals to exercise, wellness programs as well as physical/occupational therapy would be best initiated at diagnosis, when it may have the most impact on quality of life.



May 2011

Sun	Mon	Tue	Wed	Thu	Fri	Sat
1	2	3	4	5	6	7
8 	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30 	31				

June 2011

Sun	Mon	Tue	Wed	Thu	Fri	Sat
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19 	20	21	22	23	24	25
26	27 	28	29	30		

The trouble with life is, you're halfway through it before you realize it's a "do it yourself."

May

Schedule of Events

- Monday, Wednesday and Friday Exercise at 10:30, Room 206 of Broadway Baptist Church. (*Monday May 30, there will be no Exercise class held due to Memorial Day Holiday*)
- Second and Forth Friday– Caregivers Meeting at 10:30 in the room adjoining Room 206 .
- Sunday May 8, is Mothers Day
- May 23, PSGTC meeting at 1:30 in the Third Floor Meeting Room



We do not have Membership Meetings, or Newsletters in July or August. We will return in September rested and ready for our new fiscal year. Enjoy your summer and be safe.

The Exercise classes and Caregivers Meetings continue throughout the summer months. There is an exception, **July 4th** falls on a Monday this year, and there will not be an Exercise Class held that day.

June

Schedule of Events

- Monday, Wednesday and Friday Exercise at 10:30, Room 206 of Broadway Baptist Church.
- Second and Forth Friday– Caregivers Meeting at 10:30 in the room adjoining Room 206 .
- Sunday, June 19 is Fathers Day
- June 27 at 11:30—Luncheon in the third floor meeting room. Bring a Salad or Dessert to share.

BOD Meeting at 10:00am on 3rd floor June 27, 2011.



