

Indy PD Update

PRODUCED AND DISTRIBUTED BY: PAACI
Parkinson's Awareness Association of Central Indiana, Inc.

Aug-Oct 2017

Fall Parkinson's Symposium & Health Fair "Debunking Myths"

Saturday, October 28, 2017 (1pm-5pm)

2017 Dues are \$25 per person / couple

Tickets are:
\$20 per person for 2017 dues paying members
\$25 per non-dues paying members

At the Knights of Columbus
2100 E. 71st St.
Indpls., IN 46220

For more information contact
Sheri at 317-255-1993 or
skauffman@paaci.org

12-1pm—Registration, Open House,
Silent Auction, Chair Massages and Lunch.

1pm—Program starts

**"Debunking Myths in the Treatment of
Parkinson's Disease"**

By Albert Espay, M.D.

**"Using Music & Music Therapy to
improve your health— Mind, Body &
Spirit"**

By Brenda Kenyon, LCSW & Bongo Boy

Genetics & Parkinson's Disease

Medtronic

By Alexe' Engel, BA,
BS

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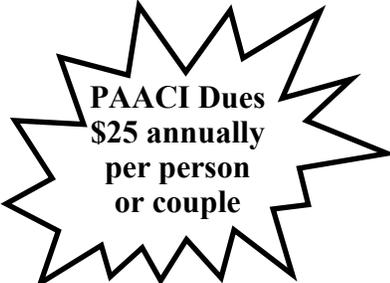


Prestige Performance II, Inc.



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PAY YOUR 2017 DUES!!!



**PAACI Dues
\$25 annually
per person
or couple**

You can pay your dues by mailing a check to PAACI, P.O. Box 19575, Indpls., IN 46219, call Sheri at 317-255-1993 or go to www.paaci.org and hit the donate now button.

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Sheri Kauffman

**Welcome to new board member
Terri Weymouth!**

Helpful Phone Numbers

Movement Disorder Specialists

Ruth Ann Baird, M.D.—317-217-3000
Joanne Wojcieszek, M.D.—317-944-4000
Liz Zauber, M.D.—317-944-4000

PAACI Office—317-255-1993

- American Parkinson’s Disease Assoc.-800-223-2732
- Aqua/Swim classes—317-547-8349
- Caregivers Spt Grp w/Catholic Charities—317-261-3378
- CICOA—317-254-5465
- Chair exercise classes—317-872-4567
- EquiLibrium Yoga Therapy (Bloomington) 812-331-7423
- Ft. Wayne exercise classes—260-486-4893
- Indiana Parkinson’s Foundation & The Climb—317-550-5648
- Indiana Reading & Information Services—317-715-2004
- National Parkinson’s Foundation-1-800-473-4636
- Parkinson’s Action Network- 800-850-4726
- Parkinson’s Disease Foundation- 212-923-4700
- Rock Steady Boxing—317-205-9198
- Rx for Indiana—1-877-793-0765
- Shelby County PD Exercise & Support—317-398-7614
(Currently limited to Shelby County residents and Major Health Partners patients)

Newsletter

Published by the Parkinson’s Awareness Association of Central Indiana, Inc. (PAACI)

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Arranged & Edited by Sheri Kauffman,
John Deck & Susan Szep

Treatment of Speech in Individuals with Parkinson's Disease

Jessica E. Huber, Ph. D., Professor in Speech Pathology, Purdue University, West Lafayette, Indiana

Background Information

Parkinson Disease (PD) is a common progressive disease. It is a progressive movement disorder in which there is a deficit in dopamine production in the substantia nigra of the basal ganglia part of the brain. It affects 1.5 million people a year in the U.S. It is one of the most common diseases of neurological origin. The cause of PD is unknown. It has far reaching effects on the motor and cognitive (thought organization) systems resulting in speech and language problems.

Parkinson's Disease Affects Speech Production

1. 89 percent of individuals with PD will develop voice problems.
2. 45 percent of people with PD will develop articulation (enunciation) problems.
3. People with PD sometimes don't recognize that they have speech problems.

Parkinson's Disease Results in Self-Perception Impairments

1. People with Parkinson's may not perceive their speech and voice problems are as severe as others do.
2. Individuals with PD have difficulty accurately perceiving the loudness of their own voice/speech.
3. They may not perceive the errors with their speech as accurately as others would.
4. The impact of these impairments of self-perception make therapy more difficult as you need to educate them how their speech is impaired.

We make judgements about our performance based on external and internal cues. External cues such as visual and auditory feedback are used when we communicate with others. Internal cues which can be unconscious information or self-cueing, guide our performance. It has been noted that improvement in gait patterns (walking), handwriting and speech have been shown with both external and internal cues, but that internal cues (one's ability to self-cue) is not as effective for most individuals with PD as are external cues (those cues from others or the environment).

Medical treatment for PD is usually with pharmaceuticals, and does not significantly improve speech symptoms. Deep brain stimulation, a neurosurgical treatment, which is often considered in later stages of the disease, diminishes tremor, and in some cases, is detrimental to speech, swallowing and cognition.

Speech treatments are considered a form of behavioral management. Therapy can be speaker oriented, where the patient strives to improve their communication performance. This may include counseling and support for speech changes, understanding the course of the disease, and what can be done by the patient and the family to maintain communication. This may include the use of wearable devices.

Behavioral management may include educating listeners in your environment so they may better understand the PD patient when they are communicating.

Treatment Programs

Lee Silverman Treatment Program

The Lee Silverman Treatment Program, Ramig et.al (LSVT Loud) is an intensive program of one hour per day, 4 days a week for 4 weeks. The clinician instructs the patient to talk more loudly: to use greater effort. The clinician will help train the patient to perceive their new louder voice as normal for them. They will practice 10 functional phrases the person uses in everyday life which are used to cue the person to talk louder

on a daily basis (outside of therapy). Daily home practice is a requirement. There is supporting literature for the success of this program. Improvements in voice, articulation, and intelligibility are noted when the patient speaks more loudly. The effects can last 6 months to a year without additional therapy for some patients. Reported limitations of the course of treatment have included generalization, which is the carry over to other spoken statements. Many patients find that generalization is difficult. Some individuals find it more difficult to remember to talk more loudly all the time. Patients who fatigue more easily, may find it difficult to keep talking more loudly for longer periods of time, and finding a certified trained clinician in your community may be difficult.

The Clear Speech Program

A program developed by Lam and Tjaden, uses a variety of cues, including hyper articulation (speaking, enunciating very clearly) and speaking louder. This program has been shown to improve speech intelligibility and to reduce rate of speech.

Inspiratory and Expiratory Muscle Trainers

These devices are used to increase breathing support for louder speech. An individual breathes into a tube with nose clips on and into a mask. Attached to the tube is a resistance device that makes it a little more difficult to breathe in and out, thus facilitating stronger breathing patterns. Two of these devices are Expiratory: EMST 150 from Aspire Products; and Inspiratory: Power Breathe, available through Amazon.

EMST Program (Sapierza and colleagues)

The program consists of doing 5 sets of 5 breaths 5 days per week. You are seated while doing these. A nose clip is worn. There is a similar protocol with inspiratory (inhaling) training. Sapierza recommends training for 4 weeks, but his may not be long enough for people with motor disorders like PD. Improvements have been noted for the strength of coughing and breathing patterns for speaking.

Treatment with the Speech Vive

This treatment is based on the Lombard effect which is the involuntary tendency of a speaker to increase their vocal effort when speaking in loud noise to improve their ability to be heard.

A patient can be fitted with a Speech Vive device using the software that come with the device. This takes about 15 minutes. The output of the device is set to elicit an increase of 3 to 5 dB in speech volume from the patient during conversation (an increase of this amount will be perceived by the listener as twice as loud). The patient is asked to wear the device in communication settings 2 to 8 hours a day, 7 days a week, and to read aloud for 30 minutes a day, 5 days a week. The patient will return to the speech pathologist in 2-4 week intervals to check on how they are doing with the training. The results of the training showed that 75% of patients improved vocal intensity by the end of treatment. Ninety to 95% of patients improved in some way either through vocal intensity, rate of speech, or speech clarity by the end of treatment.

Rigid Rate Control Techniques

1. **Finger tapping**: This is where the individual taps a finger to their thumb as they say each word. This requires that the patient has decent fine motor control.
2. **Pacing Boards**: A Pacing board is a board with a series of colored slots on it, separated by ridges. The speaker points to one slot per word spoken. One can speak at a rate of up to 70 words per minute with a pacing board. Fine motor control should be taken into consideration when choosing a board. Some individuals try to point faster to keep up with their normal speaking rate. Training in accepting a slower rate of speaking can be a challenge.
3. **Alphabet board**: The speaker points to the first letter of each word from a display of alphabet letters as they say the word. A speaking rate of up to 40 words a minute is often what is achieved with this technique. Alphabet boards have their advantages and disadvantages. The listener seeing the first letter of the word may find this helpful in understanding. The disadvantage is that an alphabet board may be bigger than most would wish to carry, and sometimes the listener will look at the board rather than making eye contact with the speaker.

4. Rigid rate control can be successful when other techniques are not, and can result in improved communication. The technique is not expensive, and requires just a little user training. The disadvantages are that if the patient is not aware of their communication problem they will not be acceptant of using the pacing techniques. Some individuals are self-conscious about using an assistive device or technique.

Alternatives to Behavioral Therapy

These may include:

1. A voice amplification system.
2. A portable microphone/speaker system used to amplify the speaker's voice. (An example is the Chattervox).

Speaker-Managed Strategies

1. Plan the timing of communication. Important communication might be scheduled when you are least tired and the listener is least distracted.
2. Choose a quiet place to converse, and choose a place where the speaker and listener can face each other.
3. Use natural gestures to aid communication.

Listener-Managed Strategies

1. Stay on topic: Periodically check that the speaker and listener are still on the same topic.
2. Pay attention to the speaker: concentrate on listening to and looking at the speaker.
3. Piece together clues: take the pieces you understand and try to put them together to understand the entire message.

Manage Communication Breakdowns

1. The speaker should encourage the listener to indicate right away if they do not understand as the breakdown in communication is easier to repair. Pause occasionally to allow the listener to indicate comprehension, or ask if the listener understands.
2. Do not just repeat the message. You may want to rephrase the message, or say a few key words.
3. It may be helpful to have an agreement on how to repair communication breakdowns when they occur. Sometimes taking a break, or "can we try again later," can be agreed.
4. Shadowing: Shadowing is when the listener repeats what the speaker says reaffirming they understand.
5. Let those involved in the communication be supportive. Allow practice times, attend support groups, and reaffirm the patient they are not alone in communicating. Provide feedback and advice, and attend educational programs through your support group/network to learn of new advances.

Treatment Take Home Message.

Several treatments have data supporting positive outcome and the ability to improve speech and breath support with PD: LSVT-Loud, EMST, Clear Speech, Speech Vive, rate control techniques, voice amplification, strategies for speaker and listeners to improve communication, support group, and group therapy. Speech treatment may be mixed together as need to achieve the best benefit. Trial therapy is important to determine which treatment choice works best for you.

Directions to Symposium: 2100 E. 71st St., Indpls., IN 46220

From downtown Kokomo, IN:

53 Minutes, 42.5 Miles

1. Go West on W. Sycamore towards N. Buckeye St.
2. Take 2nd left onto S. Washington/IN-22.
3. Turn slight right onto S. Lafountain St./IN-931.
4. Turn slight right onto US Hwy 31 South.
5. Take Keystone Pkwy/exit 129B toward Rangeline Rd. /Clay Terrace Blvd.
6. Keep left to Keystone Pkwy ramp. Turns into Keystone Ave.
7. Turn right onto east 71st St.

From downtown Avon, IN:

35 Minutes, 22.8 Miles

1. Go east on US Hwy 36 toward Park Place Blvd.
2. Go straight onto Rockville Rd. then merge onto I-465 North/USS Indianapolis Memorial Hwy North.
3. Take the 56th St. exit/Exit 19.
4. Turn slight right onto W. 56th St./Kessler Blvd. West Dr.
5. Kessler Blvd. West Dr. becomes Kessler Blvd East Dr.
6. Turn left onto E. Westfield Blvd./Broad Ripple Ave.
7. Left onto N. Evanston Ave.
8. Turn right onto E. 71st St.

From downtown Greenwood, IN:

38 Minutes, 23.6 Miles

1. Go east on W. Main St. toward Hwy 31
2. Merge onto 465 N toward Indianapolis.
3. Keep right to take I-70 East/exit 112A toward Columbus.
4. Take exit 85B toward Keystone Ave. N./Keystone Way.
5. Continue going straight to N. Keystone Ave.
6. Turn left onto E. 71st St.

From downtown Greenfield, IN:

36 Minutes, 26.9 Miles

1. Go north on N. State St./ IN 9 toward E. North St.
2. Turn slight left onto I-70 W ramp toward Indianapolis.
3. Merge onto I-465/US-31 N/US-52/US-421 via exit 90.
4. Take Shadeland Ave/56th St./exit 40.
5. Keep left to take Shadeland Ave ramp.
6. Merge onto N. Shadeland Ave.
7. Turn left onto E. 71st St.

President's Corner with John Deck

I wish to thank Sheri Kauffman and the PAACI Board for all their time and effort in planning our exceptional 2017 Symposium Program and events. I hope the Parkinson's community, your families, caregivers, and friends will come and join us on Saturday, October 8th.

Want to come to the Symposium, but need help?

If you'd like to come to this year's Parkinson's Symposium, but need a ride please call the PAACI Office. PAACI is NOT supplying rides, but will post on our weekly e-blasts that you're looking for a rideshare.

Also, Symposium grants are available to persons interested in coming to the Symposium, but unable to afford it. Also, if you would be interested in sponsoring someone else's Symposium ticket please include the additional donation with your Symposium and or dues payment and please mark it "Sym Tix Donation".

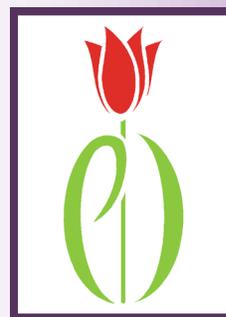
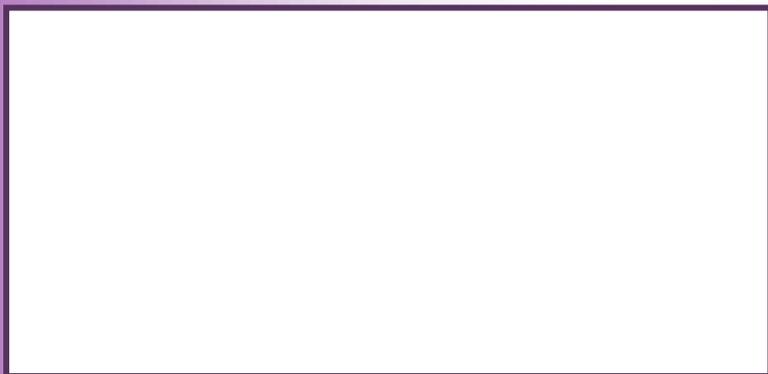
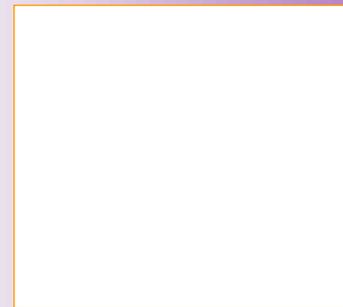
If you have any questions or need help with anything just contact Sheri at 317-255-1993 or skauffman@paaci.org.

COME TO OUR HOLIDAY PARTY

DECEMBER 9, 2017 AT 11 AM
MCL AT 2370 W. 86TH ST.,
INDPLS., IN 46260

There is no charge for the Holiday Party, just pay for your own meal, plan to bid on some silent auction items and enjoy the entertainment.

**Parkinson's Awareness Association of
Central Indiana, Inc. (PAACI)**
P.O. Box 19575, Indpls., IN 46219
317-255-1993 www.paaci.org
Facebook: Indianapolis Parkinson
Email: skauffman@paaci.org



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Special thanks to our *Tulip society members* who've paid their annual dues and made an additional donation to assist PAACI's mission

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