



Indy PD Update



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

Oct. 2018 - Dec. 2018

Upcoming PAACI Events:

Caregiver Conference - Saturday, November 10, 2018 (10 am-4 pm) MCL at Township Line Rd. - 2370 W. 86th St., Indpls., IN 46260

Our speakers will be Barbara Habermann, Ph.D., RN,FAAN and Julie Walker from Joy's House. Dr. Habermann is the Dean for Transitional Research and Director of the Ph.D. Program at the University of Delaware. Her expertise is in the area of research that focuses on decision making in advanced Parkinson's disease and end of life preferences. She has done extensive research with Parkinson's disease caregivers and how the family manages chronic neurologic disease and the associated illnesses. She has been funded by NINR, NIA and private foundations. She teaches in the PhD program in the areas of qualitative research and philosophy of science.

Julie Walker is a Speech-Language Pathologist with a certification in dementia care. Julie provides services through two home health care companies and a small private practice and she also works as the Caregiver Support Services Coordinator at Joy's House. Her passion for working with patients who have dementia as well as their caregivers comes from a deep respect for all life and the desire to increase the quality of life for all those she works with and treats.

We also plan to have a caregiver panel to have an open discussion about caregiving and Parkinson's disease. We will also have a separate room for your person with Parkinson's to hang out with a Care Buddy, play games, watch a movie or just visit. After the first speaker we will have an hour lunch break so you can reunite with your loved one, have lunch and then return to the rest of the conference. Your loved one will be in the very next room, so we can come get you if they need some help and you can relax and enjoy the conference, knowing they're in the very next room. Registration requested, but not required. Please contact Sheri at sheripaaci@yahoo.com or 317-255-1993.

PAACI Holiday Party—Saturday, December 1, 2018 (10 am-4 pm) MCL at Township Line Rd.—2370 W. 86th St., Indpls., IN 46260

Come join us for lunch, entertainment and a silent auction. Buy what you want to eat, enjoy the Burkhart Elementary Choir and bid on and buy something from the silent auction (you know all the money goes to a good cause). No registration required.

Princesses for Parkinson's Fundraiser—Saturday, December 8, 2018

(Benefits PAACI, IPF & some of CUMC's deserving Princesses)

Carmel United Methodist Church, 621 S. Rangeline Rd., Carmel, IN 46032

Bring your little Princesses (ages 3-12) and have a fun-filled morning! They can visit the "Hair Salon", "Nail Salon", "Make-up Station", "Jewelry Station", "Yum Station" and more. Parents & Grandparents please bring your camera since there will be some fun photo opportunities. \$50 per child and one parent/guardian. (Parent or guardian must stay with the child. No drop-offs.) Please have your little princess wear her favorite dress and come with clean nails, face and hair. Please also consider donating a Princess morning to a well-deserving princess. We will also have a silent auction with lots of Barbie's and other toys. Register early to have first selection on your arrival time (9:45 am, 11 am, & 12 pm). REGISTRATION REQUIRED! Registration on page 9 or call Sheri at 317-255-1993.

New Insights into Communication Difficulties Associated with Parkinson's Disease

Presented by Jessica Huber, Ph.D., Professor of Speech Pathology, Purdue University at the September 8, 2018 Symposium. Written by John Deck, Ph.D.

Dr. Huber shared that she has received grant funds from the National Institutes of Health for several years and has conducted research in the areas of speech, swallowing, communication, balance, and walking with Parkinson's disease. Their research lab focuses on how to treat Parkinson's disease.

Parkinson's is a progressive movement disorder which means over time it gets worse. It results from a deficit of dopamine which causes issues with movement and initiation of movement. PD affects one to one and a half million individuals in the U.S., and at least 4 million individuals in the world. There are many factors that may contribute to its cause. The incidence looks like it is increasing. It is one of the most common neurological degenerative diseases. PD has far reaching effects on the motor and cognitive (underlying memory and thought organization) systems resulting in speech and language problems.

Parkinson's Affects Speech Production

1. 89% of people with Parkinson's disease will develop voice problems.
2. 45% of people with Parkinson's disease will develop articulation problems where they do not accurately or precisely enunciate what they say.
3. People with Parkinson's disease sometimes don't recognize that they have speech problems.

Effect on Speech Production

1. Voice may have reduced loudness (hypophonia)
2. Voice quality may be breathy
3. Voice quality may be hoarse
4. Voice quality may lack pitch variations (monotone)
5. Speech rate may be fast, and you speak in short rushes
6. Some may have speech disfluencies (sounds like stuttering)



Reduced Loudness of voice and speech. Some people with Parkinson's disease have a lower sound pressure level (weak volume). This can impact communication if you have a partner that has a hearing loss, the reduced loudness further hinders the communication process. We need to be better in how we manage and treat communication. It is not just one sided.

Changes to Speech Rate with the Disease Progression. In a 2017 study (Huber and Darling), they showed over a span of 3-4 years PD patients used a faster speech rate. The impact of accelerated speech rate was that it was harder for listeners to understand what was said. When you talk faster it is harder for others to keep up.

Humans are not the best judges of their own behavior. Some PD patients do not think they have a speech problem. Parkinson's Disease results in self-perception impairments:

1. They do not perceive their speech and voice problems as being as severe as their communication partner does.
2. Individuals with PD have difficulty perceiving their own loudness of speaking (volume)
3. Individuals with PD may not perceive speech errors as accurately as those without PD
4. The impact of this is that therapy is more difficult as we must teach them to detect that their speech is impaired.

Therapy involves the individual recognizing and responding to cues to guide them to improve their performance. External cues are visual or auditory feedback provided by your environment or an individual to aid you in performing tasks. Internal cues are unconscious information or self-cueing guides that aid you with task performance. Improvement in walking (gait) patterns have been shown in response to both external and internal cues, however internal cues were not as effective as external ones. Studies have shown similar finding involving external and internal cues used in therapy for handwriting and speech, as well as gait.

Some patients may say that they failed speech therapy. You don't fail therapy. There is a treatment out there that will work for you. Therapy should take into consideration your ability to perceive your communication situation, and how to improve it.

Natural Cues Work for Increasing Loudness: some cues work better than others to achieve a specific goal. Most speech therapies for people with PD aim to improve loudness or rate. The cues used in therapy will affect the outcome.

Current PD medical treatments are usually through medications (pharmacological). L-dopa adds dopamine to the brain, but it does not remediate speech symptoms well. Deep Brain Stimulation will help tremor, but may diminish speech intelligibility, swallowing, and cognition.

Treatment for Speech

Behavioral management can be a speaker-oriented focus on changing the speaker's behavior and improving function or how you compensate. This may include counseling, support about speech changes, PD education including the course of the disease, and what the patient and family may do to maintain communication.

Treatment can be communication-oriented: focusing on changing the behavior of listeners or the environment.

Lee Silverman Treatment Program (LSVT LOUD)

This program is intensive with sessions one hour per day, 4 days per week, for 4 weeks. The clinician instructs the patient to talk more loudly, using greater effort. The clinician will work to help the patient with PD perceive their new, louder voice as normal for them. They practice 10 functional phrases the person uses in every day life which are used to cue the person to talk louder everyday outside therapy. Daily home practice is required. There is a large body of literature to support its use. Improvement in voice, articulation, and speech intelligibility are apparent when one speaks louder. The effects of therapy can last 6 months to a year without additional therapy for some patients. Some of the limitations of therapy are that generalization to everyday activities is difficult for some patients. Because PD affects cognitive function, it is difficult for individuals with PD to remember to talk more loudly. LSVT may not be appropriate for individuals who fatigue easily due to the intensive nature (effort) of the therapy. Another issue is that trained clinicians may not be available in your area.

Clear Speech

Clear Speech is another speech therapy program. It involves hyperarticulation where you speak as if you are talking to someone with a hearing impairment. You speak very clearly. It has been shown to improve speech intelligibility and reduce speech rate.

Inspiratory and Expiratory Muscle Trainers

These training devices are where an individual breathes into a tube with nose clips on or into a mask. On the end of the tube or mask is a resistance device. Resistance makes it difficult to breathe in or out. The Expiratory device is "EMST 150," available from Aspire Products. The Inspiratory device is "PowerBreathe" (you can buy on Amazon).

The EMST Program (Sapienza and colleagues) consists of 5 sets of 5 breathes completed 5 days per week. You do training in the seated position at the same time of day. You wear nose clips with the trainer. You can follow a similar protocol with the inspirator trainer. Sapienza recommends training for 4 weeks, but this may not be long enough for people with motor disorders. Dr. Huber recommends 12 weeks of training. It should also improve the strength of your cough and breathing patterns.

Using these devices is like going to the gym for the respiratory system.

Treatment with the SpeechVive

The SpeechVive device is based on the principle of the Lombard effect or the Lombard reflex which is an involuntary tendency of speakers to increase their effort to speak more loudly in the presence of background noise to optimize them being understood.

Patients can be fitted with a SpeechVive device using the clinician software in about 15 minutes. The intensity of the device output is set to result in an increase of 3-5 decibels (increased speech loudness) from the patient

during the conversation. Patients are asked to wear the device in communication settings 2 to 8 hours per day, and to read aloud for 30 minutes per day, 5 days a week. The patient returns to the Speech Pathologist at 2-4-week intervals to check on the function of the device and the training. Research has shown (Huber et. al) that 68% of participants increased sound pressure level (loudness) in post treatment with the device off; and 76% increased sound pressure level in post-treatment with the device on. Sound pressure level (loudness) and length of utterance at the louder level changed for the majority of speakers. Patients and caregivers reported improvements in communication competence. Results showed that sound pressure levels and associated laryngeal and respiratory mechanism improved in participants with PD who wore the SpeechVive device. Participants will still display an automatic Lombard response after 8 weeks of wearing the device, and do not revert to speech of lesser volume. The SpeechVive device was an effective monaural (one ear) delivery device for automatically eliciting the Lombard effect in adults with PD.

Dr. Huber shared a disclosure that she is on the Board of Directors of SpeechVive, Inc, the company manufacturing and selling the SpeechVive device.

Rigid Rate Control Techniques

1. **Finger Tapping:** The individual taps a finger to their thumb as they say each word. There is a need for good fine motor control for this to work best.
2. **Pacing Boards:** A board with a series of colored slots on it, separate by ridges. The speaker points to one slot per word spoken. Individuals can speak at a rate of up to 70 words per minute with a pacing board. You need to take fine motor control into consideration when devising the board. If the patient tries to point faster to keep up with the speaking rate, rather than slowing down, you need to use a more ridged rate control technique like an alphabet board.
3. **Alphabet Board:** The speaker points to the first letter of each word as they say the word. Speakers may achieve a rate of up to 40 words per minute. This helps achieve a slower rate while providing the listener with additional information about the message (the alphabet letters are additional cues).

Advantages: This technique is often successful when other techniques are not. It results in increased intelligibility, it is not technical or expensive. It requires little user training and allows for continual practice of the slow rate.

Disadvantages: If the individual is not aware of the communication problem, they are less likely to use pacing techniques. Using the rigid rate control disrupts the naturalness of speech. Often speakers are self-conscious about using the board or may be overlearned with the alphabet board and cease to control their rate.

Alternatives to Behavioral Therapy include use of a voice/speech amplification system. Many are now portable, and Dr. Huber gave the Chattervox as an example, but other brands are available.

Everyday Strategies to Make Communication Better with your Family

Speaker-Managed Strategies

1. **Plan the timing of communication:** plan important communication for when they are least tired, and the listener is least distracted.
2. **Select a conducive environment:** choose quiet places to converse, choose places where the speaker and the listener can see each other.
3. **Use gestures:** encourage speakers to use natural gestures.

Listener-Managed Strategies

1. **Main topic identity:** 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 since the breakdown will be easier to repair that way.

Try to pause occasionally to allow the listener to indicate comprehension or ask if the listener understands. The listener can periodically summarize their understanding thus far in the conversation.

2. Do not just repeat the message: rephrase the message or describe further the idea to be communicated.
3. It may be helpful to have a strategy for repairing communication that is agreed upon between the speaker and listener.
4. Use shadowing: where the listener repeats what the speaker says to demonstrate/check comprehension.

Support Groups

Attending support groups is important:

1. Allows for carry-over and natural practice
2. Provides an opportunity for the client to see techniques being employed
3. Let the client see they are not alone in this journey
4. Allows for peer feedback and advice
5. Provides an opportunity for informal and formal educational programs

Treatment Take Home Message

Several treatments have data to support their ability to improve speech or respiratory function for individuals with PD. These include:

1. LSVT LOUD
2. EMST
3. Clear Speech
4. SpeechVive
5. Rate Control Techniques
6. Voice Amplification
7. Strategies for Speaker and Listener to Improve Communication
8. Support Group/Group Therapy.



Speech treatments can be mixed together as needed to obtain the best benefit for the patient. Trial therapy is important to determine which treatment will best work for you.

Questions and Answers:

1. Q: If you have a hearing impairment, how do you know you are speaking loud enough?

Dr. Huber: Pay attention to your listeners. Ask family how they feel about your communication.

2. Can you comment on power breathing?

Dr. Huber: Power breathing did not originally start with PD treatments. It was used for people with breathing problems and was a way to improve their breathing.

3. Can you comment on swallowing treatments?

Dr. Huber: I look at swallowing from the ingestion part. You need to make sure your lungs are healthy, you need to have a strong cough, and make sure you are as active as you can be. Swallowing can also be improved with oral strengthening exercise, and compensatory strategies (the best way to chew, what size of bite, or food consistency). A speech pathologist can help you. Referral for speech pathology can be from a neurologist or physician. A neurologist is more likely to request a specific swallowing assessment.

4. How many people with PD get speech therapy?

Dr. Huber: Three to 4 percent. Way too few!

5. Does insurance cover speech therapy?

Dr. Huber: Medicare covers up to 30 outpatient therapy visits a year, but this is physical therapy and speech therapy visits combined. If you are on Medicaid, you should check to see if the system you are in covers this.

6. What about multiple system atrophy (MSA) and PD?

7. Dr. Huber: If you have MSA, you may need to consider an augmentative communication system such as an i-pad or eye-gaze system. There are augmentative communication evaluation services in Indianapolis.

The President's & Executive Secretary's Corner

John & Sheri wish to thank all of you who attended the Women's Conference on Saturday, July 28th. PAACI partnered with the planners of this event and a short synopsis of it is included in this Newsletter.

We are also very pleased to include in this issue of the Newsletter the presentation of Jessica Huber, PhD. From the 2018, Symposium, "New Insights into Communication Difficulties Associated with Parkinson's Disease." We wish to give thank all our sponsors: Medtronic, US World Meds, Abbvie, Adamas, Abbott, Acadia, Impax Labs, Lundberg, Stinson Law Firm, the State Health Insurance Assistance Program, American Senior Communities, Prestige Performance II and Equilibrium Yoga Therapy, and presenters Jessica Huber, Ph.D., Victoria Wessler, Dr. Brooke Wells, and Dr. Joanne Wojcieszek for their excellent, informative presentations. In the next issue of this Newsletter you can look forward to the write ups of Dr. Wells' and Dr. Wojcieszek's "Update on PD", and Victoria Wessler's presentation on Tai Chi. We also wish to thank the Knights of Columbus, 2100 E. 71st St., Indianapolis, for their kindness, hospitality and a very nice lunch. We would also like to thank all the board members who helped plan and assemble materials for the 2018 Symposi-um, and special thanks to Joann Whorwell for all her hard work in organizing the silent auction.

Our upcoming events are the **Caregiver's Conference on Saturday, November 10th**, with Barbara Habermann, Ph.D. speaking on "Symptoms Management in Parkinson's Disease: Use of multiple strategies across the disease stages". Julie Walker from Joy's House will be our second speaker and then we will have a panel/open discussion with and for the caregivers. This event will be different from most PAACI events since it's for Caregiver's only, however we will have a separate area for our partners with Parkinson's to hang out and visit with other people with PD. This will allow the caregivers to relax and know that their partners are ok and in the very next room, while allowing them to speak and discuss caregiving in an open and honest way. More information about this event and how to register and attend are included in this issue.

On Saturday, December 1st we will be hosting the Holiday Party, at MCL (2370 W. 86th St., Indpls., IN 46224) at 11 am. So mark you schedule and please try to attend. We will also be having a silent auction with some terrific seasonal items.

On Saturday, December 8th, PAACI will be hosting our first ever joint event with the Indiana Parkinson Foundation to promote Parkinson's awareness while raising money for both organizations with our **"Princesses for Parkinson's" fundraiser**. Please bring your Princesses (ages 3-12) and enjoy a fun-filled morning at the "Hair Salon", "Nail Salon", "Make-up Station", "Jewelry Station" and "Yum Station" along with other fun things. This will be a great event to enjoy with your daughter, granddaughter, niece or neighbor to give as an early Christmas present or just a fun thing to do together. You can also purchase a "Princess day" for a princess who might not be able to attend otherwise. This should be a very fun day that will benefit three different local non-profits: the Parkinson's Awareness Association of Central Indiana (PAACI), Indiana Par-kinson Foundation and the Carmel United Methodist Church. Please see registration form on page 9 in this Newsletter for more details.

I, John Deck, and the PAACI board, wish to personally thank, Sheri Kauffman, Executive Secretary of PAACI, for all her diligent, hard work in planning the 2018 events.

PAACI also had information tables at recent health fairs at Marquette Manor, the IPF Walk/Run, and the Boone County Senior Expo. If you stopped by to speak with me (John Deck), it was a pleasure to chat with you.

***On a personal note: Sheri and the PAACI board would like to thank John Deck for the countless hours he's graciously given to PAACI over the years writing most of the Newsletter articles. His time and efforts are appreciated more than he knows.

Medical Disclaimer. The information in this Newsletter is not intended or implied to be a substitute for professional **medical** advice, diagnosis or treatment. All content and information contained herein are for general information purposes only.

Update on Women's Conference on Parkinson's Disease: Stronger Together

By: Stephanie Combs-Miller, PT, Ph.D.

On a beautiful day, Saturday, July 28th, 95 women with Parkinson's disease, women caregivers of those with Parkinson's disease and others gathered at the Northside Knights of Columbus for a full day of education, discussions and fellowship related to Parkinson's disease. This was the fifth time since 2010 that women in Indiana had the opportunity to come together for a conference specifically related to women's issues and caregiving. This year's conference was made possible by the help of our generous sponsor (Medtronic, US World Meds, Abbott, Abbvie, Acadia Pharmaceuticals, Adamas, Impax Laboratories and Lundbeck) and a new partnership with PAACI. The sponsors had representatives on site to provide conference participants important information about their products. We also had representatives from several local and national organizations available during the conference to educate conference attendees about the services provided by their organizations. The local organizations included PAACI, Rock Steady Boxing, Indiana Parkinson Foundation and American Parkinson's Disease Association. It is most important to recognize and thank the conference planning committee, including Linda Hinkle, Paula Tomlin, Terri Weymouth and Deb Williams. Without the dedication and persistence of these four women the conference would not have taken place.

The Women's Conference included local and national speakers with an exciting assortment of topics. Dr. Elizabeth Zauber from the Indiana University School of Medicine, Movement Disorders Clinic presented a review and update on Parkinson disease symptoms and treatments. Her presentation highlighted the motor and non-motor features of Parkinson's disease as well as current and upcoming treatments that can impact various aspects of the disease. Dr. Zauber's presentation was both a great resource for those new to understanding the disease and an excellent review for those with experience. We also busted the myths and misconceptions related to participating in clinical trials with a fabulous discussion by Andrea Hurt, Clinical Research Nurse at Indiana University School of Medicine, Movement Disorders Clinic. Andrea defined research related to clinical trials, explained how to find Parkinson's research trials near you, and how to get involved in research. We heard from Tina McIntosh from Joy's House, an adult day center in Indianapolis, with a top-ten list for essential know-how's for caregivers. Her list was rounded out with the number one recommendation to simply "embrace the imbalance" of life by doing the very best we can, wherever we are. The panel discussion with caregivers, Marcia Goller and Helen Schaefer, was heart-felt and applicable to everyday life of care for someone with Parkinson's. Marcia and Helen provided wonderful advice to caregivers on how to find time for yourself while managing caregiving and marriage.

The afternoon began with an interesting pair of stimulating presentations. First, we had the opportunity to learn about and practice mindfulness with Brenda Kenyon from St. Vincent's Hospice. Within a quiet and calm room, we practice being mindful of our bodily sensations (e.g. breathing) with the focus to observe ourselves from a place of compassion and kindness. We then switched gears entirely to a drum circle with Lisa Colleen and her Bongo "girls". She used the power of rhythm to liven up the room and wake our spirits.

Finally, the day was completed with our keynote speaker, Dr. Maria De Leon from Texas. Dr. De Leon is a Neurologist and Movement Disorder Specialist who also lives with Parkinson's disease. Through her first-hand accounts of her own experiences, both as doctor and patient, she described for the attendees how she has found ways to live an even better life with Parkinson's. She creatively illustrated how her "diva-like" attitude has helped her to be bold, take charge of her health, and not give up. It was clear that Dr. De Leon practices what she teaches, as she boldly stood in front of our crowd wearing a hot pink t-shirt that read, "I make Parkinson's look sexy!" We were very fortunate to have Dr. De Leon's knowledge and personal experiences as she spent time in open discussion with the conference attendees answering a wide array of questions from personal relations to medication and treatment for Parkinson's disease.

The Women's Conference for Parkinson's disease was a success! It was a true demonstration that we are "**stronger together**" in the fight against Parkinson's. If you would like to take part in future PAACI learning opportunities then consider joining us for the next PAACI event, our first Caregiver Conference on November 10th, 2018. We hope to see you there!

Princesses for Parkinson's Registration

Yes, I'd like to register my little Princess/es for Princesses for Parkinson's on Saturday, December 8, 2018.

<u>Name of Princess/es:</u>	<u>\$50 per Princess & Parent/Guardian</u>
<input type="checkbox"/> I'd like to donate a Princess day of fun for a deserving Princess for \$50.	

Please make checks payable to PAACI, at PO Box 19575, Indpls, IN 46219.

Contact Sheri at 317-255-1993 or sheripaaci@yahoo.com with questions or for more information.

Credit Card Payment (circle one): Mastercard Visa Exp. Date: _____

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Name: _____ Address: _____

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Connie Carney Award



The Connie Carney Memorial Award is in honor of an astounding woman who lived her life graciously with Parkinson's disease while donating a significant amount of her time to the Parkinson's Awareness Association of Central Indiana, Inc. (PAACI) and the local Parkinson's Community. In honor of all that Connie Carney did in PAACI's name we've established an annual award to honor and celebrate a person who has given of themselves to PAACI and the Parkinson's Community in a gracious and loving manner.

In 2018, the PAACI Board elected as the honoree of the Connie Carney Award, Edward Daly, M.D., Ph.D. Dr. Daly was born in New York City, grew up in Connecticut, and went to college in Pennsylvania. He came to Indiana over 40 years ago for IU Graduate School in Neurochemistry. He attended IU School of Medicine and completed Internal Medicine and Neurology training at IU Medical Center. Dr. Daly is board-certified in Neurology and has been a member of the Neurology faculty at the IU Medical Center and a staff Neurologist at the Roudebush VA Medical Center for more than 30 years. Dr. Daly's special interests include the treatment of headaches, multiple sclerosis, and neurochemical disorders including Parkinson's disease. His outside interests include genealogy and stamp collecting. Dr. Daly has served on the PAACI board for over 12 years and was one of the first neurologists to address a PAACI meeting in 1982. We are truly grateful that we've had the devoted service and support of Dr. Daly all these years. We are pleased to honor Dr. Daly with the 2018 Connie Carney Award.

Special thanks to our Platinum Symposium



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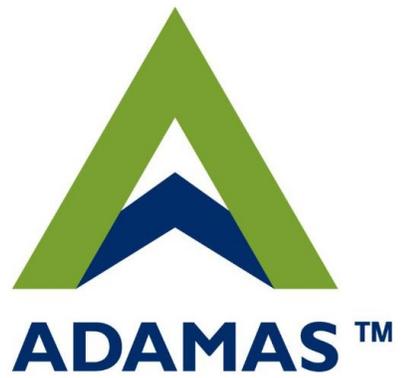
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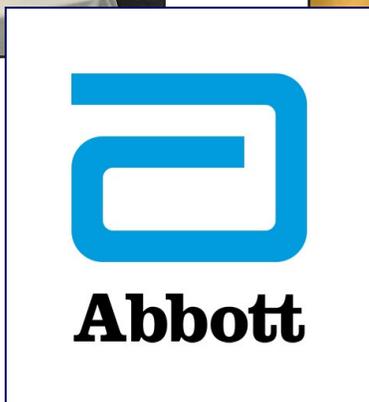
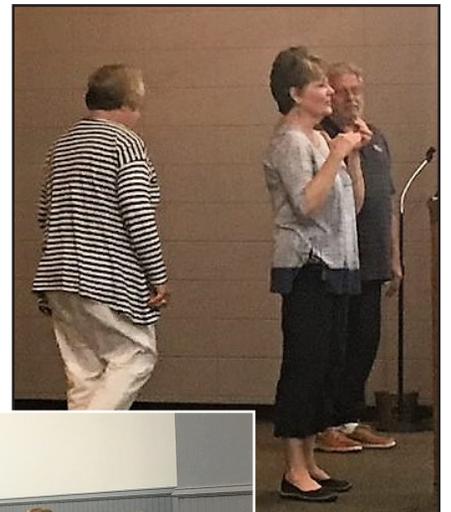
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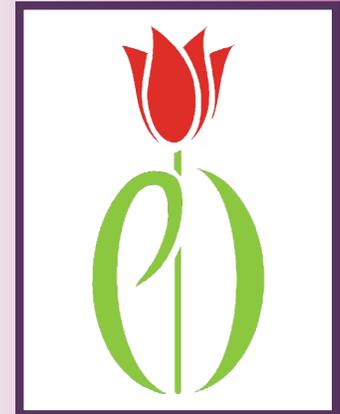
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Memorials & Special Donations

_____ Today I would like to make a special tax-deductible donation of \$ _____.

_____ Today I would like to make a donation in honor/memory (circle one) of a loved one.

Name of honoree: _____ Amount of donation: _____

Please mail acknowledgement of the donation to the family at: (Include name and address)

From: _____

Payments can be made by check to PAACI at P.O. Box 19575, Indpls., IN 46219 or by credit card on this form, by phone at 317-255-1993, or by the PAACI website at www.paaci.org and click on "Make a donation".

Name on card: _____ Phone: _____

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