

INDY PD UPDATE

January—March 2015

PRODUCED AND DISTRIBUTED BY: PAACI

April Parkinson's Mini-Symposium

April 25, 2015

6847 Hillsdale Ct., Indpls., IN 46250

11:30-1pm—Pizza buffet with Byrnes Pizza

****Sponsored by Maple Park Village****

\$5 per person, drinks may be purchased separately.



12-1pm—Noelle Gosling, Violinist

Enjoy your meal while listening to Ms. Gosling's beautiful music.

1-1:30pm—Rachel Glasser, Family Therapist

“Parkinson's Disease and Depression—A Family Affair”

Followed by a Question and Answer session

2pm—Rock Steady Boxing Presents:

“The Importance of Exercise to Quality of Life”

Parkinson's Jeopardy—a fun interactive game for the audience.

Please also come check out the fresh tulip sale by YPI and the Garden Center Fundraiser by PAACI.

In This Issue:	Page
Connie Carney Award Dietary Protein & PD	3
Symposium Question & Answer Panel	4
Grube Family Fellowship Speech Vibe	5
Memorials	6
Continued Memorials, Dues & Special Donations	7

This Newsletter partially funded by
the Dee Garrett Grant fund.

PAACI Board Members

Nancy Pressner—**President**
 Jeff Brodzeller—**Treasurer**
 Connie Beery—**VP of Publications &
 Communications**

Members at Large—Rebecca Parks, NP, Edward
 Daly, M.D., Ph.D., Ahmed ElAntably, Deborah
 Pardue, Rick & Carol Thorne, Caroline McNelley,
 Jeffrey Stinson, Attorney at law

Honorary Board Member—Julie Sanderson, Joe
 Carney

PAACI Executive Secretary—Sheri Kauffman

Newsletter

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

Funded by your donations and the Parkinson’s
 Awareness Association of Central Indiana

Arranged & Edited by Sheri Kauffman

PAACI Numbers:

PAACI Office—317-255-1993

**Parkinson’s Care Partner
 Support Group (For Caregivers only)**
 Meets 3rd Tuesday of each month at 7pm
 (317) 902-7373

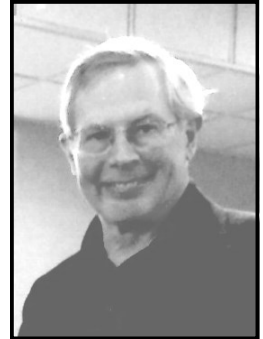
Helpful Phone Numbers

- American Parkinson’s Disease Assoc.-800-223-2732
- Aqua classes—317-547-8349
- Caregivers Spt Grp w/Catholic Charities—317-261-3378
- CICOA—317-254-5465
- Dr. Ruth Ann Baird—317-217-3000
- Dr. Joanne Wojcieszek & Dr. Liz Zauber—317-944-4000
- Chair exercise classes—317-872-4567
- Ft. Wayne exercise classes—260-486-4893
- Indiana Parkinson’s Foundation—317-630-0315
- 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
- Physical therapy—317-823-6841
- Rock Steady Boxing—317-205-9198
- Rx for Indiana—1-877-793-0765
- Shelby Cty PD Exercise & Support—317-398-7614
 (Currently limited to Shelby County residents and
 Major Health Partners patients)
- Southside Climb & Support Group—317-946-5340
- The Climb North—317-774-7252
- Westside Support Group—317-244-4463
- Young Parkinsons of Indiana—317-203-3049

Disclaimer: The contents or opinions expressed in
 this newsletter are those of the individual writers or
 presenters and do not constitute an endorsement or
 approval by PAACI Staff/Board. Please consult
 your personal physician, attorney or therapist re-
 garding your individual medical or legal issues.

Dr. Eric Siemers is awarded Connie Carney Award

On Saturday, December 13, 2014, Dr. Eric Siemers was presented the Connie Carney Memorial Award by the Parkinson's Awareness Association of Central Indiana, Inc, (PAACI) for more than 25 years of devoted service to the Indiana Parkinson's community. He was also recognized for his participation in the organization's Newsletter, and for his many years of contribution to their annual Indianapolis Symposium. The late Connie Carney was an active participant in the PAACI organization for more than two decades, and the award was created in her memory.



Eric Siemers, M.D. is currently a Distinguished Medical Fellow of the Alzheimer's Disease Global Development Team at Eli Lilly and Company. He earned his MD with highest distinction from the Indiana University School of Medicine in 1982. After an internship in the Department of Internal Medicine at the Indiana University School of Medicine, he completed his residency in the Department of Neurology in 1986. He then joined the faculty of the Neurology Department and founded the Indiana University Movement Disorder Clinic. Dr. Siemers established the Movement Disorder Clinic as a leading site in North America for clinical trials in Parkinson's and Huntington's diseases, and he established one of the first centers for surgical PD treatments in the US. He played a leading role in establishing the PROGENI study, a large study of the genetics associated with Parkinson's disease funded by the NIH and performed as a collaboration between the IU Department of Medical Genetics and the Parkinson Study Group.

Dr. Siemers currently directs late stage clinical research efforts at Lilly concerning investigational treatments for Alzheimer's disease, and is more broadly involved with other neurological indications such as Parkinson's disease. Major research interests include the use of biomarkers in investigational drug research and the development of trial designs that broadly characterize the effects of investigational drugs on neurodegenerative and other chronic diseases. Dr. Siemers is a founding member of the Alzheimer's Association Research Roundtable and is currently serving as Chair. He is a member of the Steering Committee for the Alzheimer's Disease Neuroimaging Initiative (ADNI), which is funded by the National Institute on Aging and a consortium of pharmaceutical companies. He served as the chair of the Industry Scientific Advisory Board for ADNI in 2007. Dr. Siemers is a current member of the New York Academy of Sciences Alzheimer's Disease Leadership Counsel. He participated as a member of the National Institute on Aging working group that proposed criteria for preclinical Alzheimer's disease in 2011. He is a past member of the Board of Directors of the American Society of Experimental Neurotherapeutics.

Dietary Protein and Parkinson's Medication

Amino acids (from dietary protein) can interfere with the uptake of levodopa into the brain. If you find (not everyone experiences this) that eating high-protein food (such as meat, fish, poultry and dairy products) decreases the effectiveness of levodopa, keep the meat portion of your meal to about the size of a deck of cards and take your Sinemet half an hour prior to a protein-containing meal.

Do not use a restricted-protein diet. The problem, if you find you have one, is usually with the timing of the protein intake, not its total quantity over the course of the day. For more information please visit the PDF website at http://www.pdf.org/en/winter06_07_Nutrition_and_Parkinson.

Symposium Question and Answer Panel

1. **Does cinnamon help the treatment of Parkinson's Disease:?**
Dr. Houghton: There is mention of cinnamon bark for the treatment of PD, but I do not think this has been scientifically tested.
2. **Is it best to take Sinemet every 3 hours or extend the time between doses?**
Dr. Joanne: You should take Sinemet when you need it, because the medicine is not long lasting. If there are any side effects, you should take that into consideration
3. **Once you do the LSVT program do you need to re-enroll later?**
Ms. Washburn: This is dependent on how well you continue practicing and the carry-over of your success. Your care partner should participate and hold you accountable.
Ms. Cox: There will be a new LSVT BIG program coming out in the future.
4. **Generally will insurance cover the LSVT program?**
Mr. Campbell: The principles of treatment seem to be accepted by Medicare.
5. **Is there a video available of LSVT?**
Ms. Washburn: On the LSVT global website you can see the video or LSVT on You Tube.
Ms. Cox: LSVT BIG videos are available.
6. **Is IU considering group visits?**
Dr. Joann: We are not considering them yet.
Dr. Houghton: Group times are about 90 minutes, and then about 10 minutes of direct contact with the patient.
7. **What is the effect of skipping 2 doses of levodopa at night, and playing catch-up the next morning?**
Dr. Houghton: General practice dictates you use the regular dose during the day. Sometimes we will increase the levodopa in the morning, to get you going. Dopamine sparing drugs are designed for 24 hour action. The dopamine patch is for 24 hours.
8. **What is the duo dopa pump effectiveness? Who is it best for, and when will it be available?**
Dr. Houghton: It is available in Europe. There are studies in America, but the FDA has not approved it yet. It is on during waking hours. It will be for patients with moderate to more severe disease, and when a DBS is not an option.
9. **What do you know about wrist bracelets that keep track of activity?**
Dr. Houghton: This is a technology issue, with wearable monitors. It will be a promising thing to look at.
10. **Why do I have an issue with sliding out of chairs?**
Dr. Joanne: This is often related to dyskinesia. You have to determine why sliding out of chairs is occurring.
11. **How can we get the staff in hospitals to recognize the importance of timely administration of medications?**
Dr. Houghton: Hospitals now have patients sicker than they were in the past. So meeting the need is harder on the staff. The Aware in CARE package may help the staff or see if family can be given permission to give the Parkinson's medications.
12. **Why is Ritalin not used more often? For me it really helped me with apathy.**
Dr. Joanne: Ritalin moves out the dopamine you have in reserve and is not a good idea. It can be used for sleepiness secondary to medications but has to be considered carefully, and in low dosages.

13. Is there any therapy available for small motor skills?

Mr. Campbell: Occupational therapy.

14. Why don't they use Sinemet with Parkinsons plus?

Dr. Joanne: Dopamine will be tried, but with these other disorders it does not always work.

15. With genetic predisposition for PD, what causes the switch to come on?

Dr. Joanne: They have discovered the genetic link but this has been in the past 15 years. Perhaps in the future we will understand this better because in many individuals the tremor may not appear for many years after onset.

Dr. Houghon: Sometimes the genetic link starts the process, and then something else in the environment trips the trigger.

16. What's the next big thing?

Dr. Joanne: A vaccine. We have benefited from the research of other diseases which are helping guide us.

The Grube Family Fellowship in Movement Disorders

Dr. Joanne Wojcieszek, Director of the IU Movement Disorders Program and Director of the IU NPF Center for Care shared that Paul Flamme, M.D., has accepted the Grube Family Fellowship in Movement Disorders at IU. This a new fellowship that is privately funded. Dr. Flamme began his fellowship July 1st, 2014, and will be learning about PD with Dr. Joanne and then begin seeing patients with PD himself July 1, 2015. He received his bachelors degree in biology from IUPUI, graduated from IU Medical School in 2010, and spent 4 years in residency in Neurology at the University of Iowa.

Dr. Flamme is from the Greenwood, Indiana area, is here with his wife and family, and plans to remain in the Indianapolis area. He has been active in the Christian Medical Association and looks forward to a career of service to those with medical needs with neurological conditions.

Speech Vive

Speech Vive is a device worn behind the ear and is designed to elicit improved speech clarity without placing cognitive demand on the patient. Speech Vive does not require training or behavioral modifications and may immediately improve a patient's speech clarity by altering volume, articulation or speech rate.

Speech Vive detects when the patient is speaking using an accelerometer which is built into the earpiece. During speech, the device plays a background sound into the user's ear. The background sound, which resembles a room full of people talking during a party, is a natural cue that elicits louder and clearer speech through an involuntary reflex known as the Lombard Effect. When a patient is not speaking, the Speech Vive device turns off the background sound, which enhances the patient's ability to hear and communicate effectively.

Multi-site clinical trials over 4 years demonstrated that 90% of the people who participated in the clinical trial had a significant improvement in their speech. Long term data continues to demonstrate that people who use Speech Vive develop clearer and stronger speech over time. Data yet to be published shows a physiological change to the respiratory system demonstrating better lung volume in 70% of patients who used the Speech Vive device for over 12 weeks.

For more information please check out their website at www.speechvive.com or contact Steve Morgensen at 612-723-7200.

Memorial Donations

Husband, Father & Grandfather Ancel—Carol & Martin Zagarinsky

Husband, Father, Grandfather & Great Grandfather Klein—Carol & Martin Zagarinsky

Virginia Ballard—Bill & Mary Linhart, Lenora Leppert, Tom & Kathy Spencer

John Barber—Pat & Lou Loy

Merle (Kenneth) Boyd—Carolyn Boyd

Noah C. Cantrell—Bonita & Ed Armantrout Family, Linda & Noah Cantrell, Patricia Cantrell, Ella & Kenneth Jones Family

Grant Carey—Lynn & Mary K. Antrim

Constance Carney—Joe Carney

Ronald P. Caster—Terri Mauthe, Edna Lou Seebach, Thomas & Laura Ann Chandler

Floyd Chandler—Mary Skinner

Lloyd “Buzz” Craig—Ralph & Eunice Wiseman, Michael & Jennifer Aspy, Velma Hopper, Don & Wanda Phillips, Clyde Maar, Wayne Maar, Janet & Tim Butler, Gary & Kandi Maar, George & Cassie Iverson, Floyd & Sue Brunson

Robert S. Craig Jr.—Marlene Wullenweber, Anita Stevenson, Colette Brown, Roger & Janice Paul, Phillip & Phyllis Brown, Mark & Barb Smith, Charlie & Marilyn Lea, S.G. Bodony, Inc., Community First Bank

Cheryl Crapo—Becky Rhodes, Debra S. Nackenhorst, Joel & Kristina O’Neil & Boys

Paul E. Dyer—Dolores McFarland, E. Hope Rider, Melissa Young, Marylen Vail & Family, Michael & Jane Gorman

Ralph V. Earle, Jr.—Frances (Mrs. Ralph Earle) Family

Dr. Charles Echt—Carol & Martin Zagarinsky

David Eubank—Darcie Lang

Betty Fields—Michael Annn McIlwrath, Gary & Ronna Bohlander

Deloris Garrett—David Garrett

Rob Gearhart—Carol & Martin Zagarinsky

Jerry “Mike” Haston—Steve & Christi Norman, Foundation 212 LLC, Victor & Michelle Brouillette, Sandy Dale, Pam Flanders, Donald & kay Illingworth, John & Susan McCallister, Dale & Dana Randall, Anonymous, Hulecki Family, Alan & Carol White, Robert & Denise Atkinson, Ken & Dee Ely, James & Leann Hancock, James Martin

Ron Hastings—Paul & Nina Langley, Tony & Jayne Moore, Rick & Cindy Breedlove, Elaine Kissel & Bill Pearson, Lisa & Thomas Chilcote, The Forslund (Toni & T.K.)

Arthur Hirsch—Elizabeth Goldsmith, Elizabeth Goldsmith

Charlie Holbrook—Patricia Saschse, Jan-Phil Weck

Jim McGuire—James & Katharine McGuire

Franklin Miracle—Paul & Deb Graham

Jim Pressner—Brenda Murray

Wilford Ray Roseberry—Martha & Paul Thayer, Diana & Jim Stevens, Marcela Egan

Opal Mae Rowe—Bloomfield State Bank

Ruth Sandbrick—Don & Marge Stoll

Barry Sanderson—Rochester Class of 1964

Julie Anne Sanderson—John Deck, Rebecca Parks, Douglas Dobson, Jemele Sanderson, Doris Sanderson, Terry Sanderson, J. Ken Sanderson

Mary Lu Schwab—Jeff & Louise Golightly, Wendy & Paul Aglietti, Kay Taylor, Peter & Julie Sylvester, Jane Ames, The Feather Cove Neighbors, Michael & Holly Schwab, Nick Willey, Carlene Sensenbrenner, John & Marla Seneff, Brian & Jill Schuman

Edward A. Schulz—Mary & Paul Fleener

Jack Eagle Sewell—Randal & Nadine Turner

James Skinner—Mary Skinner

Memorials Continued

Sheryl Stowers—Bethel Baptist Church Family

Robert Tharp—Carol & Gary Foltz, Rick & Sue Russ, Linda & Glen Eaton

Helen Tomon—Helen & Paul Woodward

Dean Wacasser—Roseann Moss & Beth Mon

Sandra Warner—Chuck & Julie Fox, Geneva

Warner, John & Melody McCorkhill, The Tom Martin Family

Mother of Gerald Waterman—Charlene & Leonard Gringlas, Brenda & Charlie Tarzian, Carol & Martin Zagarinsky

Jack Lee Webber—Dr. James & Judith Wessar, Madge Castor, Tom & Debbie Warner, Martha Kettron, Dick & Sharon Webber, Thomas & Judy Delph

Donald Wilson—Mrs. Donald Wilson

Dues & Special Donations

Thank you so much to all our dues paying members. Every donation makes a difference!

Mary Lou & John Adams, Katherine Autin, Calvin & Linda Bayles, Dave & Connie Beery, Debbie Bentz, Jeanne Bohannon, Mary Bowman, Jeff Brodzeller, Eugene & Barbara Busche, Jim & Lois Campbell, Joe Carney, Kathie Chudyk, Margaret Corya, Dick & Dorothy Crane, Ahmed ElAntably, David Garrett, Ann Grosh, Elaine Gust, Paul Henderson, Josephine Henn, Dixie Irwin, Linda Hinkle, Michael Jeffries, Mridula Jarial, Mary Johnantgen, Kay Johns, Bernice Jones, Martha Klemm, Kathleen Krueger, Martha Ladd, Lucinda Laughlin, Al & Dianna Laughner, Donald Leisure, Pat & Harry Kluempers, Barbara Mathauer, Charles & Mary Matsumoto, Joina McKinney, Caroline McNelley, Donald & Lovelace McNelley, Maxine Meach, Murray & Sylvia Mills, Hettie Mowang, Debi Nackenhorst, Sharon Need, Lynn & Christopher Newett, Deborah Pardue, Laura Parks, Rebecca Parks, Terry & Kathy Piket, Nancy Pressner, Glenda Ockerman, Randy & Jayne Rains, Tom & Marilyn Ransom, Daniel Reed, Peter & Elaine Rhetts, Martha Ridoux, Cece & Al Rodger, Robert Rose, Dave & Susan Schultz, Peg Sharples, Marilee Siefers, Paula Slinger, Rik Spier, Richard & Susan Szep, Rick & Carol Thorne, Rosemary Ward, Henry & Mary Weaver, Charles & Joann Whorwell, Clara Wyrick, Mary & David Yeaman, Carol & Martin Zagarinsky.

Special Donations from: Mary Neffner, Old National Bank, Doreen Fuery, Donita Bentley, Christina Johnson, Kam Wilma Lucero, Ranee Salkeld, Geraldine Simpson, Jeff Stinson, Alleyn & Sheila Lynes, Charles & Mary Matsumoto, M.L. Thurman, Vera & James Casper, Anonymous Donor, Kimberly Kessel Witchger, Ed Daly, Richard & Carol Thorne, Jeff & Tammy Brodzeller, Deborah Pardue, Dick & Dorothy Crane, Murray & Sylvia Mills, Tom & Marilyn Ransom, Carol & Martin Zagarinsky, Al & Chris Holden, Denise Dickson, Dawn Hatch, William & Sharon Marshall, Ray & Carol Andrejasich Blessing Fund, Linda Graham

In Honor of: Kay Johns, Mike McConnell, Bob Hatch, Dave Beery

Get Well Wishes to: Mike Hinkle

Anonymous Memorial Donations: Sterling W. Smith

PAACI Cares! Donations made by: Carolyn Boyd

**Parkinson's Awareness Association of
Central Indiana, Inc. (PAACI)**

6847 Hillsdale Ct., Indpls., IN 46250

317-255-1993

www.paaci.org

Facebook: Indianapolis Parkinsons

*****New Email: skauffman@paaci.org**

Could you???

Could you make a recurring nominal donation of \$5 or \$10 each month? That amounts to 17 - 33 cents a day or \$60—\$120 a year. We would be happy to set you up on an automatic deduction each month. If you itemize your taxes this would be a nice deductible. For more information or to set up a monthly donation, please contact Sheri at the PAACI Office at either 317-255-1993 or skauffman@paaci.org.



(317) 622-8181

1980 E. 116th St., Ste. 125, Carmel, IN

[Www.stinsonelderlaw.com](http://www.stinsonelderlaw.com)

Funny Corner:

When everything's coming your way, you're in the wrong lane. Courtesy of Parkinsonian People



Respite Care, Companionship,
Transportation, and more

317-204-2522 Licensed/bonded/insured



(317) 252-4472

**Dancing for
Parkinson's Group**

Windfall Dance Studio
Bloomington, IN
Tuesday's—3:15-4:15p
\$5 Donation requested
per session

812-334-2892

Want to see your business here?

If you'd like to see your ad here please contact Sheri at (317)-255-1993 or skauffman@paaci.org.
Ad prices starting at \$25.