

INDY PD UPDATE

May –July 2015

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

Symposium Save the Date

October 24, 2015

Please reserve October 24, 2015 on your 2015 calendar for this year's Symposium, "The Parkinson's Journey and Care Along the Way". Our keynote speakers will be Jane Malkoff, MSN, RN, NP speaking on "Empowering Yourself—Living with Long Term Illness" and Leo Rafail, BSW will be discussing "The Changing Concept of Hospice—How it Can Be Helpful." We will also have a segment on the new trend on acute rehab care for Parkinson's patients, an exercise break, open house, question and answer panel and silent auction. More information to follow in the next newsletter, eblasts, Facebook and website.

Monthly Education Meetings

PAACI and Rock Steady Boxing are co-sponsoring monthly educational meetings on the last Sunday of each month (except on holidays) from 2-3:30 pm at the PAACI Office/RSB Headquarters located at 6847 Hillsdale Ct., Indpls., IN 46250

June 28, 2015—Leo Rafail, BSW, Angelique Dahncke, and Susan Lowe—
3 H's that Help: Home care, home health & hospice

July 26, 2015—Larry Dykes, Financial Advisor
Golden Glove Techniques for Gracious Giving, Understanding Estate Planning

August 23, 2015 - Angela Ockerman Jones, Assistant Professor of Pharmacy
Understanding Your Parkinson's Medicines and How They Work

Parkinson's Disease Foundation Online Seminars

Did you know that you can view online seminars on many different topics pertaining to Parkinson's Disease? Go to www.pdf.org to view upcoming or past online seminars.

World Parkinson's Congress

The next upcoming World Parkinson's Congress will be held in Portland, Oregon from September 20, 2016 to September 23, 2016. The World Parkinson's Congress will also be holding a video competition starting November 9, 2015 through May 1, 2016. For more information please visit their website at www.wpc2016.org.

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Newsletter

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Arranged & Edited by Sheri Kauffman

PAACI Numbers:

PAACI Office—317-255-1993

**Parkinson’s Care Partner
Support Group (For Caregivers only)**

Call for more information

(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 regarding your individual medical or legal issues.

Depression and Parkinson's Disease

According to a report in the Neurology journal depression is associated with an increased risk for Parkinson's disease, and the more severe the depression, the higher the risk. Swedish researchers compared 140,688 people with depression with 421,943 people without the disorder. They followed the group for an average of seven years, and in some cases as long as 25 years, and found 3,260 cases of Parkinson's.

The study, in Neurology, found that the rate of Parkinson's disease among people with depression was almost three times that of people without it. Among people with depression, those who were hospitalized and those whose depression was recurrent were at higher risk, suggesting that the more severe the depression the greater the risk.

The lead author of the study, Peter Nordstrom, a professor of geriatrics at Umea University in Sweden, said the effect is small and detectable only in a large population, and that most people with depression will never get Parkinson's. Whether depression is a risk factor for Parkinson's or an early symptom of the illness is unknown.

"It could be that depression damages the brain, causing the increase in Parkinson's," Dr. Nordstrom said. "Or it could also be that very early in Parkinson's, we are more prone to depression. It's impossible to say."

*Excerpt taken from the Neurology journal.

Are you a Caregiver or a Care Partner?

Words matter. The words we choose to use each day can affect the feelings of those around us as well as our ability to successfully communicate with one another in all manner of relationships.

When we call someone a caregiver, we are saying that they care for someone who cannot fully care for themselves at the present time. This also implies that the relationship between the two people is of one person giving and one person taking or receiving. However, caring is—and in ideal circumstances—a two-way street of both parties giving and receiving being care partners.

The word caregiver is fairly new in the lexicon. Care+giver dates back only to the 1970s and is basically defined as "a person who cares for someone who is sick or disabled."

Caregiver has its origins in the word caretaker, which dates back to about 1860. One definition of caretaker is "a person who takes care of another." Both words imply the single flow of care from the person providing that care to the person needing care. For instance, someone living with ALS (Lou Gehrig's disease) who is in a wheelchair, his care partner can talk with him about his simple pleasures, his hobbies, the things that he has long derived joy from and learn that this man loves to go fishing. Even if the care partner has never been fishing, he or she can be part of a fishing day by assisting with the wheelchair and other support and they might also learn about fishing from this person living with ALS.

Such interdependent relationships emphasize the strengths and gifts or talents of each person and from this is the opportunity to learn and grow. To be a caregiver or to give care is worthwhile and beneficial.

Yet partnering in care is a meaningful experience for all involved and lets everyone thrive.

***This article courtesy of www.homewatchcaregivers.com.

Want to win a \$25 gift card to Walmart of Brookstone?

If you'd like to win a \$25 gift card complete the following or send PAACI an email at skauffman@paaci.org with the following information.

Name _____ Phone _____

What has PAACI done to help you? _____

What does PAACI do that you like? _____

***Please note by completing this form (or sending an e-mail) and including your name and phone number you are consenting for PAACI to use your name and comments in any future editions of the Indy PD Update.

Speech Easy PD

SpeechEasy is a tool to help you regain control of your speech. It is proven technology which can be used to increase speech intelligibility in those with Parkinson's. Worn in one ear and similar in appearance to a hearing aid, SpeechEasy has been shown to help those with Parkinson's increase their ability to communicate more effectively and confidently. SpeechEasy delivers Delayed Auditory Feedback (a time delay) and Frequency Altered Feedback (a change in pitch) to help address speech intelligibility issues, specifically the repetitions of speech that many people with the disease exhibit. When using DAF and FAF, a person experiences what is called the "choral speech effect." Choral speech is simply people speaking together in unison and it has been shown that this effect can help lessen repetitions and hurried speech. Simply put, by using the device and hearing oneself speak at a light delay and change in pitch, the brain perceives that as someone speaking along with you. Therefore, the effects of choral speech are present.

The SpeechEasy PD offers four models costing between \$2,500-\$4,500. They are currently giving away 10 SpeechEasy devices through their National Outreach Program and/or you can get a \$250 evaluation rebate. Applications are being accepted through July 31, 2015. You can get information and apply online or call 1-866-551-9042. Veterans can often get help with the cost through the VA.

They also offer a free fluency app for Parkinson's patients called Parkinson's Speech Aid through the Apple Store.

Parkinson's Disease and Depression: A Family Affair

Presented by Rachel Glasser, Marriage and Family Therapist, MS, MA, LFT

Rachel began by quoting Peggy Penn who said, “bodies even while suffering within illness are deeply in relationship.” We cannot avoid the impact we have on each other when one suffers, we all suffer.

Symptoms of Depression

1. Feelings of hopelessness, helplessness, worthlessness
2. Guilty feelings
3. Loss of interest in daily activities
4. Sleep too much or too little
5. Eat too much or too little
6. Desire to hurt oneself or others
7. Fatigue
8. Difficulty with concentration
9. Irritability

Special Thanks to Maple Park Village and American Senior Communities for sponsoring the food truck buffet at the Mini Symposium in April.

Grief is a loss of anything and it comes and goes. Grief affects function, mobility, and the ability to get things done. Depression is persistent over time. Grief becomes depression when one is stuck in the grieving process. Depression is unaffected by external events or enjoyable interactions.

There is “ambiguous grief, where one feels guilty because things are not the same, and “anticipatory grief,” which is grief in the present for what is about to happen.

Facts about Depression and Parkinson’s Disease

1. Forty to fifty percent of patients develop depression
2. Forty percent develop anxiety
3. Depression and anxiety are more common in PD than other chronic illnesses
4. Depression in PD may not be a result of poor coping or lack of strength of character. PD may have an organic component; the lack of the same chemicals (neurotransmitters) that cause PD also affect mood, energy, motivation, appetite and sleep: dopamine, norepinephrine, and serotonin.
5. Depression can increase pain perception and make it harder to manage PD
6. Depression may worsen cognitive problems and vice versa
7. Persons with an emotion-focused coping style are more likely to become depressed than their solution-focused counterparts.
8. Depression can result in a poorer quality of life.

The Diagnosis of Depression in Parkinson's Disease

Parkinson's and depression have overlapping symptoms

1. Sleep problems
2. Feeling slowed down
3. Inability to concentrate
4. Decreased appetite
5. Social isolation
6. Parkinson's patients express less emotion due to changes in facial expression, making it harder to interpret feelings
7. Body language changes due to postural changes

What can you do? *Dealing with PD 101*

1. Exercise, relaxation therapy or guided imagery may help
2. Seek therapy, which may include counseling for stress management and/or cognitive and behavioral therapy
3. Take prescribed medications
4. Increase your social network/support: don't withdraw
5. Communication is important; communicate about illness concerns
6. Identify what has "not" changed as a result of PD, such as one's sense of humor, the desire to help others, etc.
7. Set boundaries. Notice when PD should not be the primary focus, such as family gatherings. PD does not have to overshadow everything
8. Identify issues that are "not" the result of PD: stop blaming everything on PD
9. Notice what you can control. You can't change the physical factor, but can change the benefits of psychoactive medication
10. Stay abreast with research
11. Be flexible and expand your definition of normal
12. Be knowledgeable about insurance, disability programs, etc.
13. Develop realistic hopes and goals. Identify your strengths, utilize healthy coping and positive thinking skills. Rather than looking at before and after the diagnosis, look at PD as a journey that still allows opportunity for a meaningful life.

With PD there are mood swings and role changes. How do we handle this? Communicate: talk. Discuss who is involved in the decision making, and negotiate rights and privileges of those involved. Roles and routines change. Cognitive issues may change from day to day, and caregivers may differ in their assessment of cognitive abilities.

Issues that Impact How a Couple Copes

1. Age of onset
2. Areas affected: speech, mobility, and/or cognition
3. Societal attitude: how those around you perceive illness
4. Individual characteristics
5. Messages from one's family and life experience about dependency, loss, productivity, abandonment, vulnerability, etc.
6. Quality of the relationship and unresolved issues before the PD diagnosis

Thanks to Prestige Performance II for the donation of PAACI Cares bracelets.

Stress Points in PD progression include balancing changes with over protection, changes in patient's condition, and family conflict.

Family Techniques Leading to “Poor” Outcomes

1. Controlling directive statements
2. Criticizing
3. Using Guilt
4. Over protection
5. Family taking responsibility for patient behaviors and outcomes
6. Ignoring or minimizing patient symptoms
7. Anger, fear, guilt, blame
8. Substance abuse
9. Shame

Family Techniques Leading to “Better” Patient Outcomes

1. Empathy
2. Concern
3. Offering choices and alternative to the patient
4. Provide rationale for the advice given
5. Address conflicts about caregivers
6. Developing accurate perceptions of the patient's feeling and abilities
7. Focusing on successes. Plan positive things you may need to do in a different way.
8. Discuss anxieties, fears and losses.

Caregiving

Set boundaries between husband and wife and caregiver/patient. Negotiate in advance realistic expectations of caregivers.

Caregivers can become overwhelmed. As a caregiver, you have to be flexible and adaptable. You have to plan for care in advance, being aware that additional care will be needed. Family should know the patient's wishes, then the caregiver doesn't have to feel guilty or like they failed. Set boundaries, although challenging it is necessary to decide who makes decisions.

Patient Perspective vs. Caregiver Perspective.

The Parkinson's patient may *feel* angry and critical, feeling like a burden, having difficulty giving up responsibility.

The well spouse may *feel* resentment, guilt, loneliness, depression, shame and anger, being cheated of a “normal” life or what one had hoped life would be.

<u>Signs of Caregiver Burnout</u>	<u>Prevention of Caregiver Burnout</u>
<ol style="list-style-type: none"> 1. Depression 2. Grief/loss 3. Sleep problems 4. Sustained exhaustion 5. Irritability: depression 6. Loss of interest 7. Problems of daily living 8. Worsening of health 9. Isolation 10. Anxiety: especially about resources and future needs 11. Guilt 12. Hopelessness 13. Loneliness: especially as cognitive impairment and depression increase 	<ol style="list-style-type: none"> 1. Reduce stress by becoming familiar with care procedures 2. Set appropriate expectations: the patient my help but it takes longer and you may have to do things in a different way 3. Be flexible 4. Communicate: caregivers are allowed to complain also 5. Use respite care 6. Get treatment if psychological or emotional issues exist 7. Make financial plans in advance.

Above all communicate!

Convalescent Aids are Available...

PAACI & Carter Van Lines host a convalescent aids closet with many helpful items available to borrow for as long as you need them. If you are interested in borrowing any of the following items please call Sheri at the PAACI Office for more information at 317-255-1993.

3-in-1 toilet/shower seat

Arm braces

Aqua therapy chair

Bathtub safety rail

Bed rail—black

Canes

Crutches

Hoyer lift with parts

Medical lecture cassette tapes—1 box

Photo slide projector and carousel

Rollator walkers

Sequential circulator (compression machine for arms/legs)

Swivel seat for the car/chair

Toilet seat toppers (makes toilet seat higher)

Walkers

Walker basket

Walker extensions

Respite Care is Important and PAACI Can Help

Respite: a short interval of rest or relief. This definition of the word itself is brief and simple. What is not so simple is recognizing, as a caregiver, that it's time to seek respite. It is often also not easy to determine how to pay for it.

In our daily activities we get busy and sometimes overwhelmed and forget to ask for help or respite. When we're overwhelmed is when respite is most important. Respite comes in different forms such as in home care, long term care facilities and adult day cares. It provides the caregiver a much needed break. Time can be used to run errands, sleep, go shopping or get drinks with a friend. There is something very freeing in having just a short period of time during which your loved one is in capable hands other than your own. We love them and give them all the best we have in attention, compassion, and act as their anchor through this long and challenging journey. We deserve the respite and they want what is best for us. Recharging our batteries makes us more patient and at times enables us to see things with a fresh perspective when we return home. It gives us back just a little piece of normalcy for a brief period of time. We can do the things that make us feel like us again. It doesn't make Parkinson's or the responsibilities of caregiving go away, but it does make us think about other things that are still out there in life. Consider respite care and actively seek it for the sake of your well being and the one you love and care for. You may find it a welcome and refreshing oasis in this difficult journey.

So, respite care is great, but how do you pay for it? There are many ways to pay for respite care. Your physician's office, hospital social worker or local Council on Aging offer resources to answer your questions on what insurances, veterans programs, or Medicaid/Medicare benefits are available for this type of care, and how you become eligible. Some care must be paid for out-of-pocket. This is where PAACI can be of assistance. PAACI Cares! is a PAACI program that can help fund the cost of care to qualifying families up to \$500 per year.

So how can you get these funds? First make sure your \$25 annual PAACI dues are paid and current then complete an application, have your doctor (or healthcare provider) complete their part of the application and send them both to the PAACI office at 6847 Hillside Ct., Indpls, IN 46250.

How do I know if I'm approved? Within just a few weeks of the PAACI Office receiving your completed application (including doctor statement and dues being paid) you will receive an email or phone call from the PAACI office notifying you if you've been approved. The funds will be paid directly to the caregiving agency.

Meet Donald McNelley...A Friend of PAACI

Donald writes: I have been married to my beautiful wife Lovelace for 59 years. We met through a friend. I saw her picture in a Montgomery Alabama newspaper, she had just won a beauty contest. I asked my friend if she knew how I could meet her. Turns out Lovelace was my friend's roommate...and the rest is history.

We have two daughters, a son and eight grandchildren. I practiced law in California and squeezed in some time for one of my favorite hobbies...tennis. Reading is also a favorite pastime. However, during the fall you will find my wife and I rooting for our favorite college football team...Roll Tide!...University of Alabama! Yes, I am wearing my Alabama sweatshirt in the picture, taken at the PAACI/Rock Steady Boxing Christmas Party.

My Parkinson's was discovered about 10 years ago by my physician, when he noticed I had a slight shuffle. Exercise, healthy food (tomatoes and fresh melon) and the love of friends and family have helped me cope with this inconvenient disease.



Memorials, Dues & Special Donations

Afterglow—I'd like the memory of me to be a happy one,
I'd like to leave an afterglow of smiles when day is gone.
I'd like to leave an echo whispering softly down the ways,
Of happy times, and laughing times. Author Unknown

Larry Chamberlain—Keith & Dee Eckler, Bill & Sue Loughmiller, Bill & Susan Vander Veen, Jim & Carol Anderson, David & Nancy Hand, Rick & Denise Tillman, Neighbors: Payton, Farmers, Young & Zurmanski, Rosemarie Zuranski

Floyd Chandler—Mary Skinner

Laurel DeSmet—Lee & Margaret Dolen, Rick, Dan, Theresa, Annett & Robin DeSmet, June Ann Roberts, James Howell Family, North Salem State Bank

Rosalie Hood—Jerry & Toby Gearries, MAC Corporation

Midge Lackey—William Froelich

Elizabeth Liston—Oakland Chapter No. 159, Order of the Eastern Star

Eleanor Katherine Muldoon—Waldron United Methodist Church

Diane F. Murray—Diane F. Murray c/o Emily M. Ward

Jade Sewell— Anonymous donor

James Skinner—Mary Skinner

Rickie Star—Carol & Martin Zagarinsky

William A. Stillman—Lyla Harold, Fall Creek Baptist Church, Donald Moeller, Alan & Vida Smith, Charles & Connie Stamm, Wilna Stillman, Dennis Huntington, Jim & Carol Gibson, Debbie & Rod Reel, Alice Kilgore

William Taylor—Janet Johnson, Sally & Bob LaBoon, Retired Teachers & Staff of Decatur Central High School

Barbara Reeder Vandersall—David Vandersall

Barbara Waltz—Dan & Connie Waltz, Toy & Vivian Smith, The Tobey's, James & Nancy Bailey, Tom & Dorothy Moore, Norma Waltz

Charles Whorwell—Joann Whorwell, Curtis Trainer, Joe & Joellen Striebel, Ruth Fay, Rigel Family Trust, Engelstad Wealth Advisors, Inc., Tom & Marian Peters, Amy & Brad Kalas, The Lenhardt's, Jan & Patricia Yarosz, Darrell & Jule Rider, Richard & Sandra Lemke, John Alexander Frazier Inc., Daniel & Cheryl Norris (Kendall), Monica Orban, Kristine Hare, Paul Lipps, Carol Goodyear, Sarah McGuire, Michael & Nancy Rees

Bequests... are donations made at the request of the deceased by their families or estate.

PAACI wants to show special appreciation to
Diane F. Murray and Charles Whorwell.

Thank you so much to all our dues paying members.

Every donation makes a difference!

Carol & Raymond Andrejasich, Jerry & Phyllis Brown, Mridula Jarial, Roger Jenkins, Janet Johnson, Charles Keller, Patricia & Harry Kluempers, Barbara Roy, Sandra Sluss, Twyla Stech, Patsy & Clayton Wilson,

Special Donations from: The Barb & Tom Stayton Charitable Fund and Jack & Judy Young, Benevity Com Impact Fund, CVS Giving Campaign, State Employees Community Campaign and the United Way of Central Indiana, Inc.

Have You Paid Your 2015 Dues Yet?

If you haven't paid your 2015 dues please get them sent in as soon as possible. We need your dues to help pay for the Indy PD Update that you're currently reading, postage, rent, office staff, informational packets, Symposium and so much more.

Your PAACI dues are only \$25 per year per household. Not only do your dues cover newsletter and office expenses, but they also offer you a \$5 discount on each Symposium ticket you purchase along with helping to ensure PAACI continues to offer support and education to the Parkinson's Community.

Please take a few minutes to make your \$25 tax deductible donation either by check or through the PAACI website at www.paaci.org. or call Sheri at the PAACI Office and she'll help you make a credit card payment over the phone.

Dues payment for (name) _____

Address, City, State, Zip _____

Phone _____ Email _____

RESEARCH STUDY

Butler University (Indiana) is seeking volunteers with Parkinson's disease to participate in a research study. This study only takes 30-45 minutes and can be done in the comfort of your own home or at Butler. The study involves completing a few tasks of emotion recognition of facial expressions and tones of voice. Volunteers will be paid \$10 (or a gift of equivalent value) for their time.

To participate, call Dr. Tara Lineweaver at Butler Research Lab 317.940.9848 or email Colleen Frank, ccfrank@butler.edu

Did you know?

There are books, videos and informational literature available to borrow in the Cornerman's Lounge at the PAACI Office/RSB Headquarters. There is also a large selection of literature available in the PAACI Office that you can come look through at your convenience.

A Caregiver's Litany

By Camilla Hewson Flintermann,
"Voices from the Parking Lot"

For the day that starts and ends well,
We are thankful.
For medications that work—most of the time,
We are thankful.
For the hand that is steady, the food that can step,
We are thankful.
For the struggle that ends in success,
We are thankful.
For the smile that cracks the mask,
We are thankful.
For nights of healing rest,
We are thankful.
For shared communication,
We are thankful.
For those who understand,
We are thankful.
For memory of days past and hope for tomorrow,
For love that sustains us both,
We are, most of all, thankful.

**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**

New Office Hours:

Starting August 1, 2015 PAACI's Office hours will be Monday-Thursday from 8:30am-2:30pm. Phone hours will remain Monday – Friday from 9am-5pm.

This Newsletter partially funded by the Dee Garrett Grant fund.

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.

Funny Corner:

Some mistakes are too much fun to only make once.
Courtesy of Parkinsonian People

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.


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1980 E. 116th St., Ste. 125, Carmel, IN
[Www.stinsonelderlaw.com](http://www.stinsonelderlaw.com)