Indy PD Update

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

August — October, 2016

2016 PARKINSON'S SYMPOSIUM

SATURDAY

OCTOBER 22, 2016

$15 per person if 2016 dues and registration are paid by October 2, 2016.

$20 per person if 2016 dues and registration paid by October 10, 2016.

$25 per person after October 10, 2016 .

$25 for dues per household.

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.

Shaking Things Up:
Body & Mind

Current PD Treatments,
Motor Control, Exercise & Humor

12-1pm—Registration, Open House, Silent Auction & Lunch

1pm—Program Starts

Roger Elble, MD, Neurologist
Specializing in Tremor & PD
Southern Illinois University

Paul Flamme, MD, Neurologist
Specializing in Movement
Disorders at Joseph-Wallack-Munshower
Neurology

Peter Dunlap-Shohl
Author of "My Degeneration"
Blogger for Northwest
Parkinson's Foundation &
Former Editorial Cartoonist at the Anchorage
Daily News *will be Skyped in to talk at this year's Symposium.*

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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

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Newsletter

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

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Arranged & Edited by Sheri Kauffman

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.

Upcoming Events:

IPF—Choose to Move
Saturday, September 17, 2016

PAACI Symposium—
Saturday, October 22, 2016

IU PD Lecture on Staying connected: the benefits of art therapy and creativity.
November 18, 2016 @ 3pm.
For more information email pdtalks@iupui.edu.

Calling All Support Groups…

If we had a support group fair with lots of literature and handouts for you to use at your support groups, would you be interested in coming. Please call Sheri at 317-255-1993 and let me know if you'd be interested.

Helpful Phone Numbers

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

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 & 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 Cty PD Exercise & Support—317-398-7614 (Currently limited to Shelby County residents and Major Health Partners patients)

Westside Support Group—317-244-4463

Young Parkinsons of Indiana—317-203-3049

This Newsletter partially funded by the Dee Garrett Grant Fund.

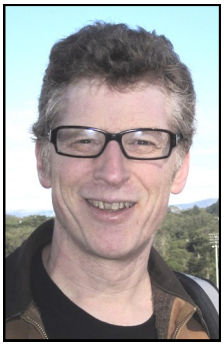
Meet this year's Symposium Speakers!

Dr. Roger Elble is board certified from the American Board of Psychiatry and Neurology since 1982. He is presently Professor of Neurology and Director of Parkinson's Disease and Movement Disorder's Center at Southern Illinois University School of Medicine, Springfield, IL. Dr. Elble is an internationally recognized expert in movement disorders, has published extensively and serves on various advisory boards, grant review committees, and editorial boards for professional journals. Dr. Elble sees patients in neurology and movement disorders clinics, teaches, conducts research, and lectures on movement disorders. His research interests include essential tremor, PD, motor control, gait initiation and gait disorders.

Recent Honors & Awards: Best Doctors in America (1996-present)
America's Top Physicians, Consumers' Research Council of America (2006-present)
Castle Connolly Top Doctor (2015)
Outstanding Scholar at SIU School of Medicine (2014)

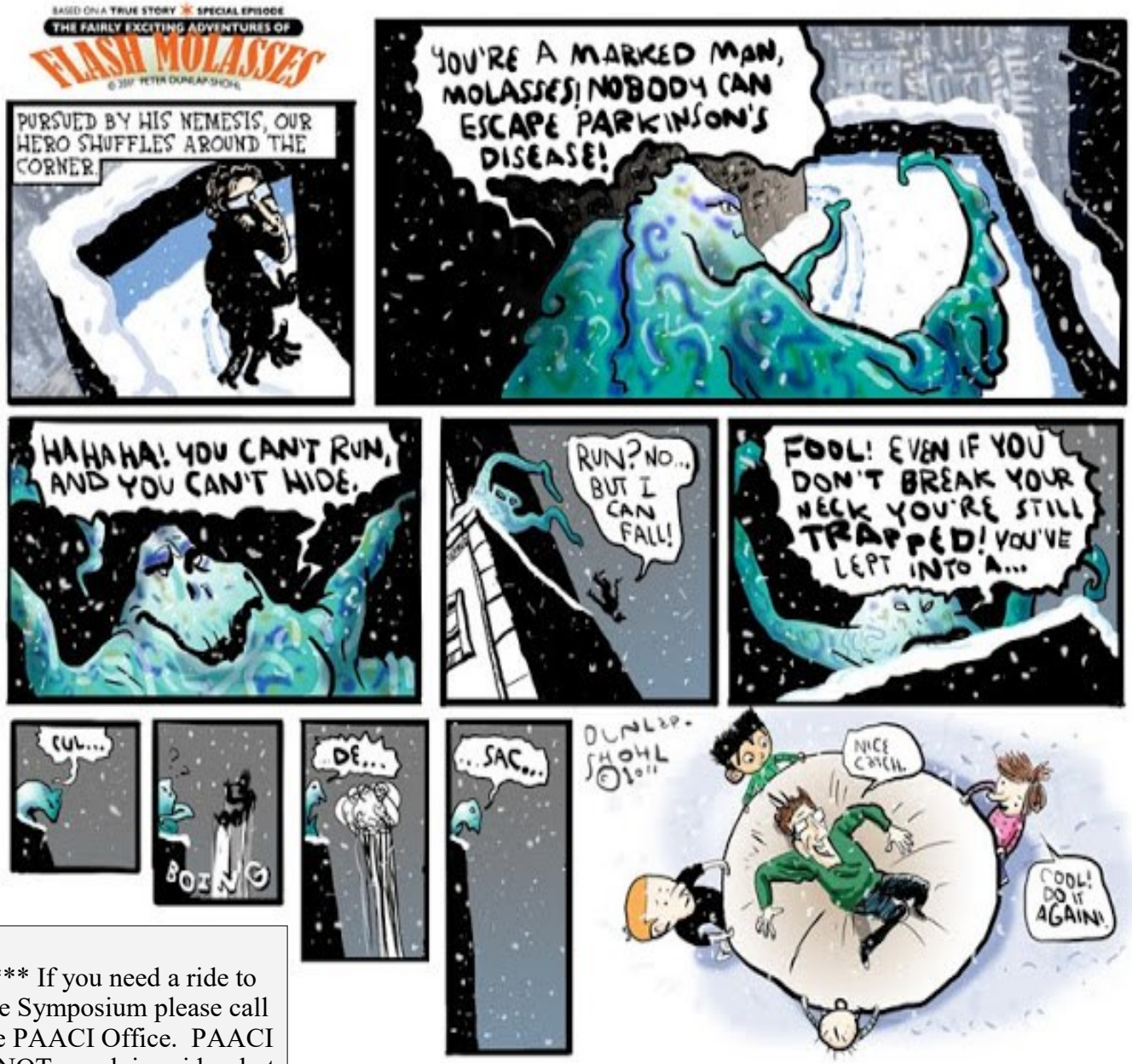
Member of: American Academy of Neurology, Association of University Professors of Neurology, Central Society for Neurological Research, Movement Disorder Society, Tremor Research Group, Parkinson's Study Group, Neuroprotection Exploratory Trials in Parkinson's Disease (National Institute of Neurological Disorders and Stroke), Tremor Task Force, European Recommendations on the diagnosis and management of essential tremor European Federation of Neurological Societies (external scientific advisor).

Paul A. Flamme, M.D. received his Medical Degree from Indiana University School of Medicine, Indianapolis in 2010. He completed his Neurology Residency at University of Iowa in 2014. He then completed a Movement Disorders Fellowship at IU School of Medicine in July of 2015. Dr. Flamme sees patients with all neurologic conditions. He specializes in Parkinson's Disease and other movement disorders as well as Deep Brain Stimulation and botulinum toxin for Dystonia and Spasticity. He's been a practicing physician for six years and lives in Indianapolis with his wife and daughter.



Peter Dunlap-Shohl was the cartoonist for the Anchorage Daily News from 1982 through 2008. He was diagnosed with Parkinson's Disease fifteen years ago at the age of 43. He's the author of "My Degeneration: A Journey Through Parkinson's" and cartoonist and author of the blog Frozengrin.blogspot.com and On and Off, The Alaska Parkinson's Rag (offandonakpdrag.blogspot.com). Peter has noted that his book "My Degeneration" examines the current state of Parkinson's care, including doctor/patient relations and the repercussions of PD and how it can impair daily living. He also discusses deep brain stimulation, changes that can occur in a life with PD and a realistic basis for hope of a decent quality of life.
*** ***Peter will be Skyped in to speak at the Symposium.***

A Sample of Peter Dunlap-Shohl's Talent



*** If you need a ride to the Symposium 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.

*** Symposium grants available to persons interested in coming, but unable to afford it.

Contact Sheri at 317-255-1993 or skauffman@paaci.org.

Monumental Marathon

On November 5, 2016 Dustin Arnheim will be running his first Monumental Marathon to raise funds for the Parkinson's Awareness Association (PAACI). Dustin is doing his run in honor of his dad and late uncle. If you'd like to support Dustin's run and PAACI at the same time please go to: https://99pledges.com/fund/monumental/dustin-arnheim and follow the directions. You can donate a set amount or make a per mile pledge. Any support you can give Dustin and PAACI would be most appreciated.

Parkinson's Awareness Association of Central Indiana, Inc.
317-255-1993

Parkinson's Symposium Registration Form

$15 per person if 2016 dues & registration are paid by 10-2-16.

$20 per person if 2016 dues & registration are paid by 10-10-16.

$ 25 per person if paid after October 10th.

Dues: $25 per household

Name of Attendee:	**Paying $25 Annual Household Dues :**	**Amount Paying:**
*** I would like to make an additional donation this year to help someone else, who can't afford it, come to Symposium this year.		
Total Attendees:	Total Dues:	Total Payment:

Method of Payment: Check_____ Cash_____

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

Credit Card Number:_____

Zip Code (where credit card statements are received):_____

Signature:_____

3 Digit code on the back of card:

___ ___ ___

Contact Information

Name:_____

Address:_____

City, State, Zip:_____

Phone:_____
(Please include phone number for questions)

E-mail:_____

Please make checks payable to PAACI. Registrations and payments can be mailed to the PAACI Office at:

PAACI
P.O. Box 19575
Indpls., IN 46219

Contact Sheri at 317-255-1993 or e-mail skauffman@paaci.org for questions or more information

***Most time sensitive information is sent out through e-mail. If you would like to receive messages from us that include information about new or updated PD info, local events, or webcasts please be sure to share your email with us in the contact information.

New Medical and Surgical Treatments for Parkinson's Disease

Presented August 12, 2016 by Leo Verhagen, M.D. & Jessica Karl, PA
from Rush University Medical Center
As written by John Deck, Ph.D.

Dr. Verhagan Discussed advanced Parkinson's Disease. The cardinal symptoms of Parkinson's disease are tremor, rigidity, bradykinesia (slowness of movement), and postural Instability. Among PD medications carbidopa-levodopa is the most effective medication. It improves how one functions with PD, but long term use of carbidopa-levodopa may be associated with motor problems. Individuals may also develop non-motor symptoms including neuro psychological problems, sleep disorder, and other autonomic dysfunctions, such as abdominal, bowel, and bladder issues.

Motor fluctuations can be related to levodopa medications that are taken. There can be fluctuations in involuntary movements occurring with on versus off times. As the disease progresses there are fewer cells to absorb the benefit of the medications, dose failures occur, and some of the proteins in the food we eat may interfere with carbidopa-levodopa absorption.

Involuntary movements increase often after being on levodopa for 10 years. During the off period there can be dystonia, and during the peak times there can be dyskinesia's. Dr. Verhagen showed slides demonstrating how the performance of on time may decline. These observations were based on diaries kept by patients noting occurrences of on/off periods.

Treatment options included the standard medical treatment such as adjusting medications to reduce motor fluctuations, and often increasing levodopa doses. Treatment may include the addition of dopamine agonists, COMT inhibitors, MAOB inhibitors, and amantadine, and liquid levodopa therapy. Strategies for new therapies may focus on continuous therapy with subcutaneous apomorphine. Levodopa infusions, that are needed several times daily, are currently used in Europe, but not available in the United States.

Dr. Verhagen discussed neurosurgical treatments done in the past: thalamotomy and pallidotomy. He then moved on to describe deep brain stimulation (DBS) of the sub thalamic nucleus in the brain. This is where electrodes in the brain connect to a pacemaker in the chest providing pulses of electricity, resulting in a regular firing to areas of the brain with abnormal patterns. Patients are considered for deep brain stimulation when medications are no longer succeeding. This includes individuals with advanced Parkinson's disease, a poor response to levodopa, motor fluctuations, dyskinesia's, and in general when medical management has become unsatisfactory. The candidates must not have psychosis, depression, severe cognitive (memory and thought organization) deficits, other medical problems, and unrealistic goals. The deep brain stimulation may not improve all motor performance. Speech is less likely to improve as much as motor performance for ambulation and upper body movements.

DBS is not a cure, but it can have positive impact on quality of life, motor symptoms, and may increase on time with about half the amount of medication In other words, DBS may improve your function and response to medicine because you often achieve greater benefit using less medication after the neurosurgery.

DBS has been used successfully for more than 20 years, with many in the PD community reaping the benefits. There have been several good research studies done on DBS, the first being a randomized controlled study in 2006. On February 17, 2016 the FDA approved neuro-stimulation for PD with early motor complications.

Dr. Verhagen is participating in a multi-site study call the INTREPID™ study funded by Boston Scientific. The goal of the study is to evaluate the safety and effectiveness of the Vercise™ DBS system (Boston Scientific's version of DBS) as a therapy for reducing some of the symptoms that are not adequately controlled with medications. The Boston Scientific device has leads with 8 different contacts, and will provide multiple ways to program the device for optimized therapy. The study is a double blind study and will look at immediate activation or delayed activation (after 12 weeks) of therapy. There are several inclusion criteria including being between the ages of 22 and 75 years of age, being diagnosed with PD for 5 or more years, prior use of carbidopa/levodopa, and additional eligibility requirements apply. If you desire more information about this study, please make an appointment with Leo Verhagen, MD, Ph.D. or Jessica Karl, PA at Rush Movement Disorder Group at 312-563-2900. Ask for their Medical Assistant Dayanna Ocegueda.

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.

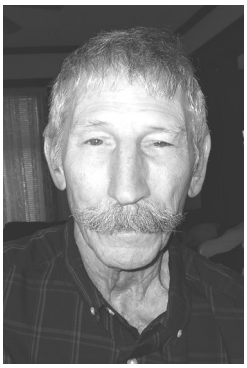
From downtown Greenwood, IN:
38 Minutes, 23.6 Miles

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.

The President's Corner...with John Deck



Hi Friends—
I'd like to share with you a story of a resident in my hometown of Lebanon, IN. His journey started with serving our country admirably through his military service and continued through to a life lived with Parkinson's disease.

Clarence "Terry" Bayles is a 71 year old veteran who served in the first infantry of the Army in Vietnam from February,1967 through June, 1968. He was 19 years old, and served in the field firing mortars. He was drafted in 1966 and discharged in June 1968. After his wartime experience, he worked on river boats navigating many rivers in the U.S. as a wheel house pilot/captain until 1986. Following this he worked at the Indianapolis, Marion County Building Authority, and earned an Associates Degree in heating and cooling from Ivy Tech. Later he worked for the Lebanon Public Schools.

Terry was diagnosed with Parkinson's disease in 2006, and is now rated 100% service connected disabled for his Parkinson's disease. He goes to the Richard L. Roudebush VA Medical Center for his Neurology appointments, has been seen at the IU Movement Disorders Clinic, and participates in the Rock Steady Boxing program at Witham Hospital in Lebanon. He shared with me that in the last few years he's lost some of his stamina and energy, his speech has become less distinct, he has swallowing problems and weight loss. He is part of a Parkinson's Support Group that meets the 3rd Thursday of each month at the Roudebush VA. It was a pleasure to interview Terry and we thank him and the many other men and women who have proudly served our country.

Yours Truly,
John Deck

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

PAACI Office Phone hours:

Monday-Friday
9am-5:00pm

Call for an appointment if you'd like to meet with us at anytime.

PAACI thanks Acadia Pharmaceuticals for partially funding this Newsletter.

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