CENTRAL ILLINOIS PARKINSON SUPPORT GROUP

Blessed are those who can laugh at themselves....

Web site: <u>www.heartstohands.org</u>

Volume I Issue II

Next: Meeting April 6, 2013 1:30pm – 3:30pm Methodist Hospital in the Morron Room. Our Program will be Robin Albright. Robin is certified Professional Life Coach and Motivational speaker.



24 people enjoyed a great bowl of chili at our March chili supper. The food and fellowship was outstanding. A special

thanks to Grace and Lloyd Burdett for providing the chili, and Marilyn and Ray Grimshaw for arranging the use of Second Baptist Church and our entertainment. We were also joined by new members Norman and Janet Diemer, Bob and Lisle Applegate and Walt and Joy Anderson.



Central Illinois Parkinson's Support Group Newsletter is changing. We will be using this format for a quarterly

Newsletter, coming to you in January, April, July and October. If you have an article or information that you would like included in the Newsletter please e-mail it to me at <u>peoriapdgroup@comcast.net</u> or give it to me at a meeting.

If you are interested in reading one of the Groups books that are available in the library please give us a call. We



will bring it to the next meeting. The list of books is available on our <u>web site</u> or call Barb at 309 699-7394.

We have the Parkinson's tulip awareness pin available. The cost is \$ 5.00. Please see Barb at the information



table at the meeting.



Coming May 18th at 6:30 pm Peoria Chief Baseball. Tickets will be about \$ 9.00 each. Please mark the date on your calendars and join your support group at the ball park.

More information later.

They shall never cease to be entertained April 2013

APDA Midwest Chapters Symposium Date: Saturday, April 13 Time:8:30 a.m. - 3 p.m. Place: Meadows Club, Rolling Meadows, IL

Cost: \$40 per person includes: continental breakfast, symposium, lunch, play, complimentary valet parking.

Tentative symposium presenters:

Leslie Chambers, new President/CEO of national APDA.

Chapter Medical Director Dr. Michael Rezak

Dr. Michael George Mercury, PhD, neuropsychologist, NorthShore University Health System, will discuss how PD may affect relationships.

A panel of experts will help you identify and



manage non-motor PD symptoms to maintain optimal quality of life.

Side Effects May Include, is one man comedy show -- written by former Seinfeld

writer Marc Jaffe -- chronicling his family's journey with early onset PD. Described as "a roller-coaster ride through an escalating mountain of pills, fidelity, secrets, questions of manhood and womanhood, age, and desire." It explores "how sometimes its not the disease that changes you, but the side effects..."



Eat at Chili's, for the month of April and May. You can help build Parkinson's Awareness and raise a



Dairy Queen in Washington will be holding a Parkinson's awareness night and donate 10% of the profit. Watch

little money for Parkinson's Action Network by eating at Chili's. A set coupons is attached Please see Roger for more details.



April is Parkinson's awareness month

April will be here before you know it. So let's not let April pass us by. Below is a list of several things that you can do to help build Parkinson's Awareness. For the most part this list is easy and really won't take a lot of time but will go a long way to building Parkinson's Awareness in the Central Illinois area. So let's take a look at what we can do.

- 1. Participate in the 30 day challenge and raise a little money to benefit a Parkinson's Organization. Please see the attached sheets for more information.
- 2. Wear something related to Parkinson's every day. T-Shirts would be great if you have several Parkinson's related shirts. You can just do laundry a little more often and have a shirt for every day. Or a Parkinson's pin is another option of something you can wear. We have some T-shirt's from a past Parkinson's event that you can purchase. We also have the tulip pins for \$ 5.00 and Parkinson's Action Network badges at no cost.
- 3. There is a group on Facebook that is doing Wear Grey for Parkinson's Disease. (<u>http://www.facebook.com/events/397872396964019/</u>) This will take place on Aril 13^{th.} If you do this, take a picture of you and your family or friends wearing gray and send it in and we will try to get as many included in their collage as possible.
- 4. Attend a Parkinson's event.
 - a.) Parkinson's Support Group Meeting Saturday April 6th
 - b.) Join us Saturday April 13 at the Peoria Speedway for the 6th annual Don Bohlander Tribute Race.

c.) APDA Midwest Chapter Parkinson's Symposium April 13th Meadows Club, Rolling Meadows, IL for more information Phone: 630-933-4392

d.) Eat. We will be working with several restaurants in the area on donating a portion of their profit from one night to a Parkinson's Organization.

- e.) There will be other events planned so please stay tuned.
- 5. Get your local Government to proclaim April as Parkinson's Awareness month.
 - Talk to Roger for more information.

6. Call your Senators and Representative and ask them to keep funding Bio-medical research. Even though the call-in day was on February 27th, we still need to be heard from. Please see attached sheet

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30 Day Parkinson's Challenge

This is very simple. Pick some form of exercise to do, something that you can do every day. You could make this as hard as saying, "I will walk 1 mile every day" or as simple as practicing getting up and down from a chair 8 times. You will use the form below to get sponsors that will sponsor you and encourage you to keep up with your challenge. The money raised will go to a Parkinson's organization of your choice. I have included a list of organization, and their addresses. Please keep this simple and make it easy. I want it to be somewhat challenging but still very doable.

Iwill	for each of the	

30 days in the month of April. Will you please sponsor me in this Parkinson's Awareness Challenge? The Money I raise will go to ______ and in finding a cure and providing awareness for Parkinson's.

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Parkinson's Organizations list

Local

Don Bohlander Parkinson's FundRACERS 2213 September Ln. Pekin, IL 61554 Ph 309 347-6929 Web Site <u>http://www.heartstohands.org/</u> All money donated stay local by going to Dr. Cady at Bradley University, or other local projects.

Dr. Craig Cady

Bradley University 1501 W Bradley Ave Peoria, IL 61625 Dr. Cady ph (309) 677-3021 Web Site <u>http://lydia.bradley.edu/bradleyworks/2009/feature1/</u> Money is used for cord blood stem cell research on Parkinson's disease, Cancer and Heart issues.

State Wide

American Parkinson's disease Foundation Midwest Chapter 1800 N. Main Street, Suite 215, Wheaton, IL 60187. Ph 630-933-4392 Web site <u>http://www.apdamidwest.org</u> Donates to Research, works with Support Groups and provides respite care to Caregivers.

<u>National</u>

Parkinson's Action Network 1025 Vermont Ave. NW, Suite 1120 Washington, D.C. 20005 Phone: 800-850-4726 Web Site <u>http://www.parkinsonsaction.org/</u> Unified voice of the Parkinson's community though

advocacy. Donates to research.

National (cont.)

The Michael J. Fox Foundation for Parkinson's Research Grand Central Station PO Box 4777, NY 10163-4777 Ph <u>800-708-7644</u> Web site <u>https://www.michaeljfox.org/</u> Focus is on Clinical trials and donating to research.

Parkinson's Disease Foundation

1359 Broadway, Suite 1509 New York, NY 10018 Phone: (212) 923-4700 Web site <u>http://www.pdf.org/</u> Supports people living with Parkinson's through educational programs and services. Donates to research.

National Parkinson Foundation

Gift Processing Center PO Box 5018 Hagerstown, MD 21741-5018 Ph (305) 243-6666 Web site <u>http://www.parkinson.org/</u>

Focus on meeting the needs in the care and treatment of people with Parkinson's disease. Donates to research.

The Parkinson Alliance Post Office Box 308 Kingston, NJ 08528-0308 Ph 800-579-8440 Web site <u>http://www.parkinsonalliance.org/</u> Donates to research by Putting on the Parkinson's Unity Walk.



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April 2013

SURVEY OF THE CAUSES OF PARKINSON'S DISEASE Parkinson's Database Coalition

P.D.C.

Volume I Issue II

Our mission is fairly simple. We want to accumulate as much pertinent data on Parkinson's and related diseases as possible. We believe that this data and information needs to come from the patients themselves to paint a much clearer picture of this disease for researchers.

Our approach is unique in a couple of ways:

We do not want your personal information. We believe that we will receive a much wider and more honest responses by providing you anonymity.

We DO NOT send mailers (either electronic or physical), solicit funds or donations or engage in any type of 'Public Fundraising' activities. Research money should be spent on research, not propaganda and massive overhead costs.

The data accumulated will used to create more specific surveys questions based on the responses received. In addition to this, new questions will be generated by Researcher and Physician request as well as by Patient suggestions. We are not afraid to ask any question at least once to either include it as a possible cause or exclude it and move on. Every suggested question gets included. No one understands this illness like the Patients themselves. Research money should not be wasted on dead end studies. Research should be based on solid evidence accumulated through large scale data collection, not a study of 20 people. This has proven quite successful in Countries outside the United States. The margin of error is actually quite low.

We believe that Physicians and Researchers as a community should be the ones to make the decision on what research is funded based on the data accumulated. We have a plan for this.

For more information please contact the following info@parkinsonsdatabase.com http://www.parkinsonsdatabase.com

Your support group is not promoting this we are only providing this information for you.



Join us for the Don Bohlander Tribute Race Saturday April 13th at the Peoria Speedway. Gates open at 4:00 pm. hot laps start at 5:00 pm. and the racing starts at 6:00 pm. We will be selling Bolander Race Shirts and 50/50 tickets. We will also have a supply of Peoria Speedway Souvenirs for sale.



If you have question about this Newsletter or anything Parkinson's related please feel free to call Barb or Roger at 309 699-7394 or e-mail us at <u>peoriapdgroup@comcast.net</u>



Pepper Partner Program

Bring this voucher when you visit (Dine In or To Go) the **Chili's** location identified below and 10% of your purchase (excluding taxes) will benefit:

PARKINSON'S ACTION NETWORK

Group/Charity

APRIL - MAY

Event/Exp. Date

One coupon per person, per visit at participating Chili's restaurants only. Cannot be combined with any other offer. Offer ends per expiration date above.

4825 N. University St Peoria 309-692-0468

Chili's Location/Telephone #99999000003722



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