

CENTRAL ILLINOIS PARKINSON SUPPORT GROUP

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

Web site: <u>www.heartstohands.org</u> They shall never cease to be entertained

DATE: September 6, 2014 TIME: 1:30 pm - 3:30 pm

Program: Tonya Welch, BSW WHERE: OSF PromtCare

5114 N. Glen Park Place

Peoria, IL 61614

Our Program this month will be Tonya Welch, BSW Social worker for Dr. Pratt and others at Illinois Neurological Institute. She will bring her "black binder" that she is known for. It is packed full of resources for patients

We had 25 in attendance at our August meeting. Paulette Hartmann gave us some very helpful information on programs that Lutheran Social Services offers should you need more information please feel free to give her a call 671-0308 x 236.

We also viewed the movie the "The Astronaut's Secret" about Michael 'Rich' Clifford and that spacewalk that he performed. Fifteen years later Rich Clifford reveals that he had Parkinson's disease while performing that spacewalk

Chili's Bar and Grill is once again supporting the Parkinson's Action Network by donation 15% of your pe-tax dinning checks. Please see the attached flier. Please pass this flier out to as many people as you can, Schools, churches and other organizations. If you would like, I would be willing to mail copies to them just provide me with the name and address of the organization.

Please consider becoming a member of the APDA Midwest Chapter. Membership benefits include being eligible to qualify for the Chapter's respite program for care partners who need "time out" from providing full time in-home care for a family member with Parkinson's disease. Each qualified member family may receive up to \$500 per 12-month period to pay for a substitute caregiver. Talk to Roger at the meeting or visit http://www.apdamidwest.org

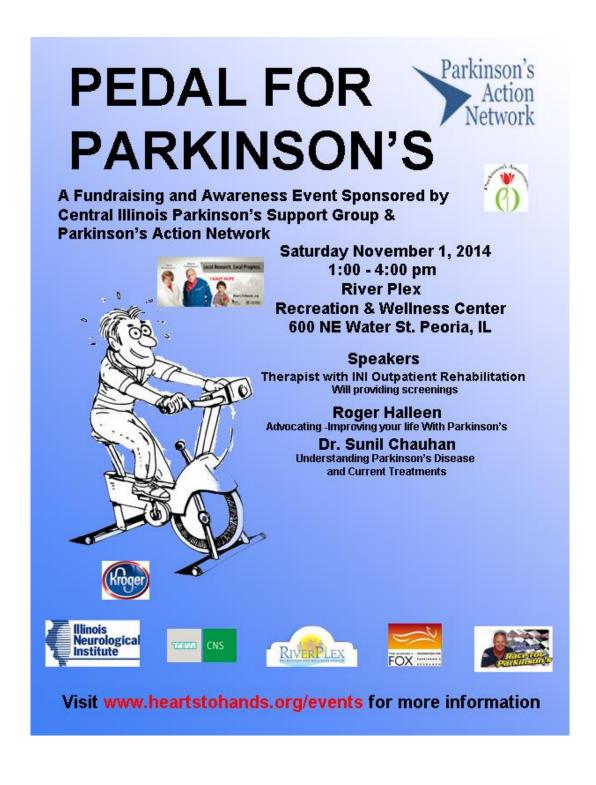
If you are a member of a church or civic group, is your club or group looking for a speaker? I would enjoy being able to give them a Parkinson's Awareness program. Please feel free to give them my name and phone number, Roger Halleen 309 219-1210

Join the Don Bohlander Parkinson's Disease Fundracers at the Pekin Marigold Festival September 6 and 7 at Mineral Springs Park in Pekin. Call Val for more information 241-5905. The Don Bohlander Parkinson's FundRACERS will be serving breakfast at the Pekin Moose Lodge 916 2605 Broadway Rd. Pekin, IL On Sunday the 7th from 8-11. Buffet includes, scrambled eggs, bacon, sausage, biscuits, gravy, hash browns, toast and made to order eggs. All proceeds benefit Dr. Craig Cady at Bradley University who is doing Parkinson's research.

Join the Parkinistas for coffee on10:00 am. September 17th at the Panera's in East Peoria Call Barb at 699-7394 for more information.

Upcoming meetings October 4, Amy Becker and other Therapists from Illinois Neurological Institute, will be giving a presentation on the Lee Silverman Voice Training/LSVT (BIG and LOUD).

Save the Date, November 1, Pedal For Parkinson's. This is an afternoon of awareness and education with a fundraising event will take place on the day of our regular support group meeting, but will be held at the River Plex Recreational and Wellness Center. Start getting your sponsor's today.



Here's What I Would Have Told Robin Williams About Living With Parkinson's

This was written by Karl Robb Virginia Assistant State Director with Parkinson's Action Network and the writer of several books. It was originally published August 15, 2014 in the New Republic

The world lost not only a comic genius and great actor with the death Robin Williams, but the Parkinson's community lost one of our own—before even knowing he was a member of our community, as his widow only revealed after his suicide that he was in the early stages of the disease.

I wish I could have helped Williams. Here is what I would have told him.

When I was in my late teens, I noticed a tremor in my left foot. My feet dragged when I walked, my body became stiff, and my speech became broken. By my early twenties, I noticed my handwriting was much smaller and illegible, and my coordination was greatly diminished. When I walked, my upper body propelled forward so badly that I would run rather than walk. The tremor that began in my foot had had moved to my hands, and my arms would not swing when I walked.

At age 23—after seeing several neurologists, and six years since I first identified a problem—I was diagnosed with Parkinson's disease (PD). It was devastating to be told I had an incurable, degenerative disorder, but I was thankful and relieved: I could have been battling an even worse condition, and knowing exactly what I was suffering from allowed me to accept it.

The brain remains a largely mysterious organ. In spite of years of good research and medical dedication we still don't know exactly what causes Parkinson's. (It's believed that to show symptoms of the illness, one must lose 80 percent of their dopamine receptors.) There's also no definitive test for it, only a battery of reactionary movements performed by the patient in the neurologist's examination room. Parkinson's afflicts roughly six million people worldwide, each of us differently. Some of the most common symptoms, though, are a resting tremor, depression, balance issues, stiffness, gait problems, and possible cognitive impairment. Among the first common symptoms can be a loss of a sense of smell, constipation, or depression.

I am almost 48 now. I have heard neurologists and researchers speak about Parkinson's disease being a "livable disease." It has been for me, but it took nearly 30 years with Parkinson's disease to fully accept the alterations and challenges that come with this disease. I now write and speak to support groups all over the country to tell them that Parkinson's doesn't mean the end. It may make you alter your life and make you re-prioritize your goals, but it doesn't have to demolish you.

Patients aren't the only ones who need to be informed, though.



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PARKINSONS ACTION NETWORK

Group/Charity

6/20/14 - 9/20/14

Event/Exp. Date

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