

# CENTRAL ILLINOIS PARKINSON SUPPORT GROUP

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

Web site: [www.heartstohands.org](http://www.heartstohands.org)

They shall never cease to be entertained

**DATE: January 8, 2017**

**TIME: 1:30 – 3:30 PM**

**Program: Care and Share, Planning for next year.**

**WHERE: OSF PromtCare**

**5114 N. Glen Park Place**

**Peoria, IL 61614**

January 8<sup>th</sup>, will be our next meeting. We will have a Care and Share program, so please bring some of your questions and or concerns. We will also have some discussion on what you would like for programs during the upcoming year, so bring your ideas.

25 people attend our Christmas lunch, The Grinch payed us a visit and we played a little trivia from the Grinch cartoon. We had good food from Sonny's Steak and Pasta House a little time to sit back relax and enjoy some fellowship before the busy Holiday season.

We took a collection to make a donation to the Journal Star Christmas Fund and \$130.00 was collected. Thank you so much for making this a success. The Journal Star ran our donation listing on December 19<sup>th</sup>

Dues are \$7.00 per person and are now due. I have enclosed a self-addressed envelope or you may pay at the next meeting.

I would like to thank The Damien Foundation for a very generous donation of \$1,000.00 to our support group, this is the second year in a row that they have contributed to the Support Group.

The Damien Foundation 3235 W. St. Charles Place Peoria, Illinois 61615.

THE DAMIEN FOUNDATION  
3235 W. St. Charles Place  
Peoria, Illinois, 61615



On Sunday January 9<sup>th</sup>, the Fundracers will host a breakfast at the Pekin Moose Lodge, 2605 Broadway St. Pekin. The breakfast is from 8-11, the buffet includes scrambled eggs, toasts, biscuits, gravy, sausage, bacon, pancakes, tater tots, coffee, juice and milk. Omelets and special eggs can be made to order and are included in the \$8.00 adult and \$4.00 child price.

The Don Bohlander Parkinson's FUNDRacers next big event will be the Pulled Pork Dinner on March 4, 2017. Please mark this event on your calendars. You and your family will not want to miss it. The event is an evening packed full of activity with a live auction, raffles, and T-Shirt sales. We are however in need of auction items and volunteer help please contact Val Bohlander 309 241-5905 or Roger 309 219-210 for more information.



President Obama signs the 21st Century Cures Act into law.

On December 13, President Obama signed the 21st Century Cures Act into law. A number of key provisions in the bill, which will directly impact the Parkinson's community, are highlighted here.

Develop infrastructure to collect data on neurological diseases to better understand who is living with these conditions, facilitate research and plan for health care needs.

Summary: The Cures bill creates the National Neurological Conditions Surveillance System at the Centers for Disease Control and Prevention (CDC) to collect demographic information on people living with neurological diseases.

We do not currently have accurate information about how many people are living with Parkinson's disease, where they are located or who they are (their gender, ethnicity, etc.). Lack of this core data slows research and makes it difficult to ensure health care services are properly allocated. The database will provide a foundation for understanding many factors, such as clusters of diagnoses in certain geographic regions, variances in the number of men and women diagnosed with neurological diseases, and differences in health care practices among patients.

#### FIRST ASSESSMENT OF THE ANTI-ALPHA-SYNUCLEIN PRX002 FOR PARKINSON'S DISEASE

Alpha-synuclein can accumulate under certain conditions, primarily in Parkinson's Disease, dementia with Lewy bodies, and multiple system atrophy, but also in Alzheimer's Disease and neuroaxonal dystrophies. Small amounts of alpha-synuclein can also occur in individuals who do not have neurological disorders. The cytological effects of Parkinson's Disease can include the formation of hydrogen peroxide (because of the breakdown of superoxide anion), and also the accumulation of iron. Alpha-synuclein expression is regulated by iron, and hydrogen peroxide plays a dominant role in the aggregation of alpha-synuclein. It inhibits tyrosine 3-monooxygenase, which is the enzyme needed to form dopamine, whose deficiency causes Parkinson's Disease.

PRX002 is an antibody that targets alpha-synuclein, which has been shown in preclinical animal studies to reduce alphasynuclein pathology and to protect against cognitive and motor deteriorations and progressive neurodegeneration. This first-in-human, phase 1 clinical trial assessed the impact of PRX002 administered to healthy participants in 5 doses (either 0.3, 1, 3, 10, or 30mg/kg) or a placebo. PRX002 demonstrated favourable safety, tolerability, and pharmacokinetic profiles at all doses tested, with no immunogenicity. No serious adverse events, discontinuations as a result of adverse events, or dose-limiting toxicities were reported. A significant dose-dependent reduction in free serum alpha-synuclein was apparent an hour after PRX002 administration.

Reference : Movement Disorders [2016] Nov 25 [Epub ahead of print] (D.B.Schenk, M.Koller, D.K.Ness, S.G.Griffith, M.Grundman, W.Zago, J.Soto, G.Atiee, S.Ostrowitzki, G.G.Kinney)



The Illinois Neurological Institute new Acute Care Nurse Practitioner.

The Illinois Neurological Institute is proud to announce the arrival of our new Movement and Parkinson's disease APN, Melissa Glass. She obtained her B.S.N from Illinois Wesleyan University and M.S.N., Acute Care Nurse Practitioner degree from the University of Illinois at Chicago. Much of Melissa's work experience has been with OSF Saint Francis Medical Center, plus several provider facilities all in the Peoria area. We look forward to the wealth of knowledge and experience Melissa brings to the INI's Parkinson's disease provider team and patients.



## Strategies for Special Holidays

By David Lowell, MD

The holidays can be a time of renewal - renewal of friendships through visits and cards, renewal of family relationships through gatherings and shared meals, and renewal of one's faith. But the holidays also are a time that can be particularly challenging for a caregiver. It is a time during which the changes in one's life are highlighted and there are additional demands placed upon an already stressed life.

The holidays are always a whirlwind and this is especially true for caregivers. During the holidays it is important for caregivers to seek a balance - between caring for someone else and caring for oneself; between celebrating good memories of past holidays while not dwelling on what might have been lost. Here are ideas to keep in mind for both the caregiver and the care receiver as the holiday season arrives:

### Ideas for the Caregiver:

1. Don't try to do it all. In the past you may have prepared Christmas dinner for 20 and created hand-made gifts for all of your relatives. Ask other members of the family to carry on specific family traditions. Dividing the responsibility will help you manage your stress level.
2. Don't attempt to travel long distances by car if your loved one is not used to it and tires easily. You will both be exhausted by the time you reach your destination, and you will have a difficult time enjoying yourself.
3. Ask family or friends to provide respite care. Make time to enjoy holiday decorations or window shopping. Just a few hours of time by yourself or with a friend can be renewing and help combat a sense of isolation.
4. Avoid comparisons with past holidays. It is often emotionally draining to look upon change as loss. "Life is change" can be a helpful concept to hold onto.
5. Create new traditions that can be carried on year to year, rather than dwelling on old traditions that your loved one can no longer participate in.

## Ideas for Your Loved One:

1. Find a way to have your loved one participate in the holidays, whether its making decorations or counting the days on an Advent calendar
2. Decorate your loved one's room or living area for the holidays. Incorporate symbols and decorations that are meaningful.
3. Stimulate all of your loved one's senses with the sounds, sights, smells and tastes of the holidays. Ideas include holiday music and decorations, a favorite dessert and familiar scents.
4. Familiar holiday foods are a nice way to evoke positive memories.
5. If your loved one is in a care facility, extend traditions to other people in the facility. For example, pass out holiday cards or make a traditional dessert to share.

If you are interested in reading one of the books that are available in the library. Please give us a call we will bring it to the next meeting. A complete list of books can be found at <http://www.heartstohands.org/support.html> click on Book List.

Barb and I would like to thank you for your continued support over the past year and we look forward to having a great 2017 with you. Should you have questions or concerns please feel free to contact us at; Home 309 699-7394 Roger 309 219-1210 Barb 309 309 712-3770.

