

CENTRAL ILLINOIS PARKINSON SUPPORT GROUP

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

Web site: www.heartstohands.org

They shall never cease to be entertained

DATE: May 2, 2020

TIME: 1:30?

Program: A Webinar on DBS

WHERE: From the comfort of your Own Home.

May 2, 2020 Support Group Right Now I am working with Abbott Infinity DBS on a Possible webinar to discuss General Parkinson's DBS Please stay tuned for more information.

Central Illinois Parkinson's Support Group



The Central Illinois Parkinson's Support Group is involved with and supports functions throughout the community that help improve the lives of people living with Parkinson's and Parkinson's-like diseases.

MEETINGS

Our meetings are held on the first Saturday of the month starting at 1:30pm at CSF PromptCare, 5114 N. Glen Park Place, Peoria. There are a few months where the location will change. Please call (309) 699-7394 or email pd@cipsupportgroup.org for location and program information.

THIRD FRIDAY DISCUSSION GROUP

2500 N. Main Street, East Peoria, IL 61611 (309) 634-6357

An open discussion group that will focus on a different Parkinson's related topic each month. Meets the third Friday of each month from 12 to 2pm.

ATYPICAL PARKINSON'S SUPPORT GROUP

2500 N. Main Street, East Peoria, IL 61611 (309) 634-6357

Provides support and information to people diagnosed with Atypical Parkinsonism, Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and others.

PARTNERSHIPS

The Central Illinois Parkinson's Support Group also partners with community organizations that serve people living with Parkinson's by providing information and resources to promote education and attendance.

- **Rock Steady Boxing Peoria**—5629 N. Galena Road, Peoria Heights, IL 61616, (309) 692-9948. Gives people with Parkinson's disease hope by improving their quality of life through a non-contact boxing-based fitness curriculum.
- **Parkinson's Exercise Class**—RiverFlex Recreation and Wellness Center, 600 NE Water Street, Peoria, IL 61603, (309) 282-1617. A group-based exercise program for Parkinson's patients led by an CSF physical therapist.
- **SPEAK OUT! and Loud Crowd**—CSF HealthCare Outpatient Rehabilitation, 6901 N. Sheridan Road, Peoria, IL 61614, (309) 621-4111. Parkinson Voice Project has developed an effective program that combines education, individual speech therapy (SPEAK OUT!) and ongoing group sessions (The LOUD Crowd).



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Facebook:
[@centralillinoisparkinsonsupportgroup](https://www.facebook.com/centralillinoisparkinsonsupportgroup)
Twitter: @PdPeoria
Instagram: @peoriaparkinsongroup

Roger Halson, roger@cipsupportgroup.org

Mission

To educate, coordinate and provide activities for persons diagnosed with Parkinson's disease, their care partners, and others working with Parkinson's and Parkinson's-like diseases.

Vision

An improved life for those living with Parkinson's and Parkinson's-like diseases.

Upcoming Events

PD Camp 2020
September 18 - 20, 2020
Eagle Crest Camp, Washburn

Pedal for Parkinson's 2020
November 7, 2020
River Flex Recreational Center, Peoria

Annual Educational Seminar
April 3, 2021
Jump Trading Simulation & Education Center, Peoria

For information on any of these events, email carp@cipsupportgroup.org.

How to Help

If you would like to help support our programs and events, please email pd@cipsupportgroup.org.

Well even during these times of COVID-19 we have been busy Take a look at the full page add that will come out with the May issue of the Peoria Magazine's Community Impact issue. I want to Thank Dee Dee and Ned and Barb and Dave for helping put this together. Thank you also to everyone that was at our March Meeting and volunteered to be in the photo. It is our hope that this will help build Awareness in our Community and Highlight some of the programing that is available.

So What if you had to go to the Hospital? The thought of that is bad enough but Parkinson's can complicate things. So Here is a quick list of things that you need to have put together.



Hospitals are often not fully aware or heedful of the medication schedule requirements for PD patients. In stressful times like now, it's particularly important to have this type of information at hand so you get the best care possible. If you have no advocate and are not communicating well, the "Emergency Hospital Kit" could be a lifesaver.

Here is what you need to do: to build a "Emergency Hospital Kit" In a small kit (bag) put the following:

1. Create an "Emergency Contact List for [Your Name]" listing your Health Care Proxy (identifying person who can make medical

decisions on your behalf in the event you can't communicate), your Primary Care Physician, Parkinson Care doctor, your Care Partner and close family members. ALL should have contact phone numbers, One should be highlighted and noted as EMERGENCY CONTACT - ALL HOURS: PHONE NUMBER IS: _____.

2. Make a "Medications List and Schedule for [Your Name]" and include that with a two-week supply of your PD medications, other medications and O-T-C in their original prescription containers. Put these in the bag.

3. Make a "Special Considerations for [Your Name]" Sheet. On it state the fact that you have Parkinson's, when you were diagnosed, your primary motor and non-motor symptoms (e.g. Tremors, swallowing, constipation, dizziness, balance, dementia, hallucinations, etc.), and advise if you have DBS or Duopa add-on equipment. Include your Parkinson's doctor's name and phone number.

Defining the symptoms helps medical staff understand symptoms that are related to Parkinson's. (Indeed, their appearance/exaggeration may be a wakeup call that your PD Meds are overdue). DBS and Duopa may influence use of diagnostic tests or require adjustments or other accommodations.

4. Include Living Will / Healthcare Directive / Five Wishes or other Advanced Directives about your personal wishes regarding end of life medical care are expressed in the event that you cannot communicate them yourself.

5. Have a "Financial and Insurance Information" sheet that has a copy of your Insurance and Credit Cards.

6. Put an AC Charger for your Cell Phone in the Bag, (you must remember to add your phone on your way out the door. (At least you'll be able to recharge phone).

Make a copy of all the documents (above) to be left at home to be used by your Care Partner or family communicating with the hospital. Keep this bag readily accessible by you and known to others.

Assume you will be alone in the hospital and that you may not be able to communicate with medical staff. It is important to try to keep the kit with you at all times.

Finally there is a way to totally supercharge your efforts to insure transfer of information regarding your Parkinson's. Call the Parkinson's Foundation 1-800-473-4636 and ask them to send you their "Aware in Care Hospital Safety Kit"). Included in the Kit is a Parkinson's Disease Alert Bracelet, List of PD Medications that may be Contraindicated for your PD Meds. Information that will help convince medical staff of critical importance of your getting PD Meds on time. Also included is a nylon carry bag. It's all FREE, It will arrive by mail in a couple of days.

The Third Friday Discussion Group spent about 8 months working on a Patient Education Brochure, Jennifer Rusk from OSF has sent us the Final draft Copy. While there are just a few minor changes that need to be made we are hopeful that this will be printed and made available to the Doctors and other on the Movement disorder team by the end of May.

PATIENT EDUCATION

What is Parkinson's Disease and Atypical Parkinsonism



This Brochure gives an overview of Parkinson's disease and other Atypical types of Parkinson's, a list of references and places to look for more information, highlights the programs available in the area, and gives great testimonials from those living with Parkinson's and their Care Partners.



If you go to Loud Crowd on Wednesday or Fridays, they are now holding the class online, at 1:00PM on Fridays. If you don't have internet access then you may call them and participate thru the phone. Please contact Amanda or Brittany for information on how to do this. If you need their email or phone number let me know.

Loud Crowd is live streaming a class every morning at 10:00am on their Facebook Page. It is about a 30-minute class and if you can't make it at 10:00am you can go to their page and find it any time. I cannot stress this enough. Use your Voice.

<https://www.facebook.com/ParkinsonVoiceProject/>

There are also some shorter videos on their main website

<https://www.parkinsonvoiceproject.org/ShowContent.aspx?i=2447>

Rock Steady Boxing Ned is going to do a live work out on ZOOM on Tuesday and Thursday. If you are a Rock steady Boxer and have not received an email, please contact Ned at neddeede@yahoo.com

The American Parkinson's Disease Association has some great resources to help fill just about any activity that you are looking for <https://www.apdaparkinson.org/article/online-parkinsons-disease-resources/?fbclid=IwAR0AvU6Z50FHNPoY7PVmtVdPW5FnC6BAjOZSHBfnDK0sT0yOpWg-0oF5mfs>

Educational Webinar Programs There is a lot to choose from at various Parkinson's organizations, these are all free to watch.

Michael Fox Foundation; <https://www.michaeljfox.org/webinars>

Davis Phinney Foundation; <https://www.davisphinneyfoundation.org/resources/webinars>

These suggestions come from Comfort Keepers They will be our Speakers at the June Meeting. I hope we can get back to regular meeting by then. Then there is Information from Right at Home one of our Speakers last year. Please Remember that the APDA Midwest has The Patient Aid Scholarship Program – Relief for People living with Parkinson’s in Midwest Illinois Please Call 630-933-4392 for more information.



Comfort Keepers can be reached at 309 685-7777

This isolation can take a toll a senior’s mental and physical health, and it’s important to remember that there are things we can all do to foster connection, hope, purpose, and support for seniors during this difficult time

- Connecting with others whenever possible. Spending time with loved ones doesn’t have to happen in-person to be meaningful. Video calls, Facetime, texts and emails can help seniors stay in touch with loved ones when they can’t be together. Get the whole family in on connecting with loved ones
- Get some exercise. It’s important for seniors to continue movement and motion through exercise, even during a period of isolation. Ensuring a senior’s range of motion is still intact through daily stretching or yoga is a great way to keep moving. Keep moving by getting steps in when you can or

turn up the tunes and have a dance party in the living room! Lifting light weights at home can help keep muscles strong when getting out of the house may not be an option.

- Maintain a healthy diet. When we spend a lot time at home it’s often easy to grab a bite anytime we pass the kitchen. It’s important to keep in mind healthy options when snacking – avoid too many salty or sweet snacks. And, when meal prepping remember the food pyramid – fruit, veggies, calcium, grain, and proteins.
- It’s a great time for spring cleaning! Not only is disinfecting surfaces in the home a recommended step to avoiding Coronavirus, it’s also a good time to consider a larger spring-cleaning project. And, a spring refresh doesn’t have to be a chore – seniors can make housework fun by playing upbeat music or using the time to look at photos and mementos with loved ones

The advertisement is a vertical rectangular graphic with a dark teal background. At the top, the text "HOME IS THE BEST PLACE TO BE" is written in large, bold, yellow capital letters. Below this, a paragraph of white text reads: "While social isolation is good, feeling isolated isn't. We are here for you and can help as you stay safe in your home." Three horizontal teal bars with white text list services: "Meals, errands, or light housekeeping", "Personal care including hygiene, dressing and ambulation", and "Schedules to match individual needs". At the bottom, there is a paragraph of white text: "Our office is open and ready to serve your individual needs during this time of uncertainty. A few hours a couple times a week for respite or 24/7 care...we can adjust to fit your needs. Call us today. Our caregivers are trained in COVID-19 safety protocols and practices. Let us know how we can help." To the right of this paragraph, contact information is listed: "309-327-0808", "info@inhomecarepeoria.com", and "www.rightathome.net/peoria". At the bottom left is the "Right at Home" logo, which consists of a stylized house icon and the text "Right at Home" in white, with "In Home Care & Assistance" in smaller white text below it. At the bottom right, the text "A global network where most offices are independently owned and operated." and "License #3001779" is written in white.