

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: November 7, 2020

TIME: 1:30PM

Program: Brittany Heidemann, MS CCC-SLP on Swallowing issues

A Movement Disorder Doctor Sponsored by ACORDA.

Lora Mock, Ambassador, Parkinsons Foundation Aware in Care Initiative

This will Be On Zoom please follow this link.

Topic: Central Illinois Support Group

Time: November 7, 2020 1:30 PM Central Time (US and Canada)

Join Zoom Meeting

<https://us02web.zoom.us/j/84816636883?pwd=M0p1eHVyQVA4WEtUUWxQaCtWb1lFZz09>

Meeting ID: 848 1663 6883

Passcode: 596054

One tap mobile

+13126266799,,84816636883#,,,,,0#,,596054# US (Chicago)

Yes, this was to be our big "Pedal For Parkinson's" fundraiser and Educational Seminar, However COVID has had other plans. So, we will adapt and still have a very educational day and hopefully raise a little money for the Support Group.

Our Speakers for the day will be, Brittany Heidemann, MS CCC-SLP speaking on swallowing issues for people with Parkinson's. She will discuss the issues with swallowing and have tips on how to avoid choking and other problems.

Jim Mack from ACORDA will be lining up a Movement Disorder Doctor as our other speaker of the day. It is always great when we can get a Doctor from outside the area to speak and learn what they maybe doing different in the way of treating Parkinson's

I hope everyone will join us.

The second part is still the fundraising aspect and knowing how important exercise is for everyone and especially for People with Parkinson's lets get exercising! Like we have in the past set a goal for yourself, ask family, friends, co-workers, or anyone you can to sponsor you, then get exercising! If you can get out and ride your bike if you don't have a bike then walk, if the weather won't let you get outside find something to do inside JUST exercise!

Then send us a picture of you exercising to peoriapdgroup@comcast.net or upload at

<https://pedalforparkinsons.myevent.com/3/gallery.htm>

You and your sponsors can then go online and make a donation,

<https://pedalforparkinsons.myevent.com/3/donate.htm>

or mail a check to Pedal for Parkinson's 301 Baylor St East Peoria, 61611

We had two exceptionally good speakers at our October Zoom Support Group Meeting, the first segment was Jocelyn from the Michael J. Fox Foundation giving us an update on everything that was going with the Foundation. She told us that she would follow up with information on some of the questions we had, please find her reply in this Newsletter.

Our second presenter was, Dr Richard Trosche Speaking on. Your Journey with Parkinson's Disease provided by AMNEAL.

I hoped everyone learned something new from both speakers.

At the October Support Group Meeting Jocelyn from MJFF said she would follow up with some additional information Here is the Email that she sent.

I'm still waiting on an update about our wearable tech portfolio. But I wanted to send over the resource list below to be shared with the Peoria group. Would you mind sharing with everyone? If anyone has questions, they are welcome to reach out to me directly!

More information here on wearable technology as a solution for gait and balance (interview with MJFF scientist). Fox Insight: Join the 1,552 Illinoisans who are participating in this online clinical study as we work to understand the lived experience of Parkinson's patients and speed PD research forward. Fox Trial Finder: MJFF's online clinical study matching tool to assist PD patients in finding clinical trials they may be eligible for. We call it the match.com of clinical trials!

Parkinson's Progression Markers Initiative (PPMI):

<https://clinicaltrials.gov/ct2/show/NCT04477785> Webinars - On the third Thursday of every month join our free live webinars to learn about various aspects of living with Parkinson's disease and our work to speed medical breakthroughs. Log on, listen to the expert discussion, and submit your own questions to our panelists. Check out August's webinar Environment's Role in Parkinson's Disease. Ask the MD: To help you and your loved ones navigate life with Parkinson's, a movement disorder specialist discusses Parkinson's research and care through blogs and videos. Some of the latest topics include Ask the MD: Parkinson's Summertime Tips and Ask the MD: Six Tips for Your First Year with Parkinson's (and Beyond!). Team Fox: Team Fox members have raised nearly \$80 million for Parkinson's research since 2006. You too can be part of this passionate community of change-makers who are bringing us closer to a cure. Every penny donated by Team Fox members goes straight to our high-impact research programs to help speed a cure for Parkinson's disease. You can also check out our Virtual Events Hub where you can find ways to join with others virtually! Advocate: The annual cost to care for PWP in Illinois is \$2 billion. Your voice is powerful. By helping policymakers understand what is fundamentally important to those who know Parkinson's disease intimately, you can shape their decision-making. Contact your elected officials now and tell them how they can use their votes to support Parkinson's research and care. Donate: Support MJFF today to help us deploy as much research as possible in 2020. Our Board of Directors has generously stepped up and committed to a \$10 million board match, doubling each gift received before the end of this year. The impact of your gift will be doubled if you give today.

This year has been something else to say the least. It has also been challenging to present programming for the Support Group, so with the New Year approaching I would like your opinion on what the Support Group should do moving forward. I have created a survey and I would like your response to the following question. This survey will not collect Names or Email address. Please follow this link to take the survey. <https://forms.gle/y2z9R9WcjuZvMPcf7>

Or you may fill it out here and mail it to Parkinson's Support Group 301 Baylor St. East Peoria, IL 61611

Support Group Survey

Support Group Survey

1. In the Past we have done a Christmas Lunch if we would do a Christmas Lunch at a Restaurant and stay with in their current guidelines would you attend, a similar style event this year.

Mark only one oval.

Yes

No

2. What would you like to see as Topics for our Meeting

3. If we continue using Zoom for the foreseeable future how can we improve it?

4. When we do get back to meeting in person, is the current location and time good for you?

Check all that apply.

Yes

No

5. If your answer to question 4 above was no please provide additional suggestions for time and place.

6. PD Camp 2021 is currently scheduled for September 17 -19, 2021. If State and Local regulation allow this type of activity will you be willing to attend.

Mark only one oval.

Yes

No

Maybe

7. Our Educational Seminar is currently scheduled for April 3rd. (Note this is Easter Weekend). If State and Local regulation allow this type of activity will you be willing to attend?

Mark only one oval.

- Yes
 No
 Maybe

8. Do you have any other question and or comments?

9. Give the current COVID -19 situation would you be will to attend in person meetings? We would be limiting group size, social distancing and requiring mask be worn.

Mark only one oval.

- Yes
 No
 Maybe

10. The Support Group currently charges dues of \$10.00 for the Person with Parkinson's and their Care Partner how do you feel about this

Check all that apply.

- Dues are great keep it this way.
 They are a little high
 I would be willing to pay more



The APDA has some great webinars available on their website, with cooler temperatures coming you might want to take advantage of them. Here is the link.

<https://www.apdaparkinson.org/webinar/>

Celebrating 20 Years of Scientific Progress Closer to Cures

November 17, 2020

Join us on Tuesday, November 17 at 3 p.m. ET for a special Michael J. Fox Foundation (MJFF) Research Roundtable. Leading Parkinson's researchers and MJFF staff share highlights and impact from 20...



The Michael J Fox Foundation also has great webinars here is a link to their next one <https://www.michaeljfox.org/webinar/celebrating-20-years-scientific-progress-closer-cures>