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: The Educational Seminar on April 4, 2020 Has been Postponed TIME: A New Date will be set soon. Program: WHERE:

The Care and Share discussion with Tammy Lott from INI and Sarah Neuhaus provided some very interesting conversations and hopefully gave some of us answers to our questions. I want to Thank Tammy and Sarah for hosting this Care and Share Program and we look forward to the next time we have this Program.

Due to the COVID-19 Many events and Programs have been postponed or Cancelled Please check and make sure the event you are planning on attending is still being held before heading out to the event.

2020 Midwest Educational Symposium, Friday June 26th 9:00AM NIU Conference Center 1120 E Diehl Rd, Naperville, IL 60563 Speakers will include Dr. Xie is a physician in the University of Chicago Center for Parkinson's Disease and Movement Disorders. Dedicated as an Information and Referral Center by the American Parkinson Disease Association Rebecca Gilbert, MD, PhD Vice President, Chief Scientific Officer for the American Parkinson Disease Association To Register and For more information; https://www.apdaparkinson.org/community/midwest/

Third Friday Discussion Group Friday March 20th cancelled

Atypical Parkinson's Support Group Friday March 27th cancelled for upcoming meetings Contact Larry 309 634-6357

City Of Peoria Proclamation, March 24th Postponed

Community Days Northwoods Mall

April 25th 10:00Am Is on Hold for right now Central Illinois Parkinson's Support Group will have a display.

May 2, 2020 Support Group Meeting Is on Hold for right now

April is Parkinson's Awareness Month, and while we may have to limit our activity, I think there is still a lot we can do to raise awareness. Let's be a little creative here and see how much awareness we can raise even with the COVID-19 reducing our ability to be visible.

Write a letter to the Editor of your local Newspaper, write it stating that you have Parkinson's and you want to thank the people that provide service for the Parkinson's community

Wear something Parkinson's related, take a picture of it and post it on your social media. You can also send it to me, and I'll post it on the Support Groups Facebook page. <u>@centralillinoisparkinsonssuppourtgroup</u>

Exercise Pick an exercise an do it every day, Tell you friends what you doing and ask them to support you. Post about it on your social media

Call a Friend with Parkinson's it just might brighten someone's day. Call one of you friends that has Parkinson's and check on them, see how they are doing and let them know your thinking about them.

Saturday, 11th World Parkinson's Disease Day 2020

This is your Day if you don't do anything for the Parkinson's Awareness Month take a Stand on this day and help build Awareness.



Basic Information About Coronavirus Disease 2019 (COVID-19) & the Parkinson's Disease Community:

Coronavirus Disease 2019 also known as COVID-19 is a new disease which first caused illness in China and has now been detected in many countries around the world, including the United States. It is a viral respiratory illness. The spread of the disease has been closely documented in the media, but for the most accurate information about the virus, please focus on reliable websites such as the <u>Centers for Disease Control & Prevention (CDC)</u>.

Many people with Parkinson's disease (PD) may be wondering if this virus will affect them any differently because they have Parkinson's disease.

The answer is not clear cut because we currently have limited information. The best we can do at this time is extrapolate from experiences of:

* People with PD and other viral respiratory illnesses

*People with other chronic diseases and COVID-19

PD and other viral respiratory illnesses

PD motor and non-motor symptoms can be exacerbated by any medical illness, including a viral respiratory illness like COVID-19. This means that in addition to the respiratory symptoms of the virus, people with PD may feel that they are slower and stiffer and that their medications don't seem to be working as well. Hallucinations may start in a person who never experienced that symptom before. Recovery from the illness can be more drawn out. It would be reasonable to assume that someone with PD who contracts COVID-19 could experience these complications as well.

Because of these reasons, people with PD are always strongly encouraged to protect themselves from any infection as much as possible. Vaccines such as the flu vaccine are strongly recommended. (COVID-19 does not yet have a vaccine because it is so new).

Steps to take to prevent contracting COVID-19

Frequent hand washing is the best way to stop transmission of this and most other viruses. The CDC also recommends:

Avoid close contact with people who are sick.

Avoid touching your eyes, nose, and mouth.

Stay home when you are sick.

Cover your cough or sneeze with a tissue, then throw the tissue in the trash.

Clean and disinfect frequently touched objects and surfaces using a regular household cleaning spray or wipes.

As stated above, the CDC has recently revised their guidelines about actions that communities should take to prevent transmission of the virus. As of March 15, the CDC "recommends that for the next eight weeks, organizers cancel or postpone in-person events that consist of 50 people or more throughout the United States". Events of any size should be reconsidered and modified to be made virtual if possible. They also recommend avoiding "gatherings of more than 10 people for organizations that serve higher-risk populations." Should I take more precautions than the above because I have PD?

As discussed above, it is probably prudent to consider people with PD to be in the higher-risk population when it comes to precautions concerning COVID-19.

The CDC states: "If you are at higher risk for serious illness from COVID-19 because of your age or because you have a serious long-term health problem, it is extra important for you to take actions to reduce your risk of getting sick with the disease." They recommend that you:

Stock up on supplies.

Take everyday precautions to keep space between yourself and others, also known as social distancing. Avoid crowds as much as possible and adhere to the guidelines re: public gatherings. Avoid non-essential travel.

Stay home as much as possible to further reduce your risk of being exposed, especially if there is a COVID-19 outbreak in your community

Consider ways of getting food brought to your house through family, social, or commercial networks. It is important to note that the risk of COVID-19 varies depending on where you live in the country and this information is changing rapidly day by day. In some communities it is spreading more rapidly than in others so stay tuned to information from your local health authorities to determine specific risks within your community. What if you are quarantined?

Around the country, there have been cases of people needing to be quarantined because of an inadvertent contact with someone who has a confirmed case of COVID-19. A quarantine is a public health tool used to stop interactions between people by keeping them confined to their homes or a specific area in order to slow an infection from spreading. In anticipation of possible quarantine, people should make sure now that they have enough medication and supplies on hand to get through a 14-day quarantine, just in case.

So, what can you do when you can have your normal classes? Don't become a couch potato!!

Loud Crowd is live steaming a class every morning at 10:00am on their Facebook Page. It is about a 30-minute class and if you can make it at 10:00am you can go to their page and find it any time. <u>https://www.facebook.com/ParkinsonVoiceProject/</u>

There are also some shorter videos on their main website https://www.parkinsonvoiceproject.org/ShowContent.aspx?i=2447

The St Louis APDA Chapter has some exercise videos on their YouTube site. These video start about 5 or 6 minutes into the video so don't give up right at the start. <u>https://www.youtube.com/channel/UC71A1FouZukPAYBrb3yEJig/feed</u>

The Brian Grant Foundation has some short exercise videos https://briangrant.org/exercise-videos/

Rock Steady has some Videos on their site, while these are not demonstration type, they are interesting; <u>https://rocksteadyboxing.org/about/videos/</u>

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

APDA Spotlight on Parkinson's Disease; <u>https://www.apdaparkinson.org/webinar/</u>

Michael Fox Foundation; https://www.michaelifox.org/webinars

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

Here is a online seminar that will cover 3 days I would highly recommend that you sign up for the free version and check out some parts of it. <u>https://www.insightintopd.com/</u> Here is a link to the program. <u>https://www.insightintopd.com/2020-program-outline/</u> Australian time is 16 hours ahead of us, so use this link to convert the time. <u>http://www.timebie.com/std/aest.php</u>



INSIGHT has become the largest ONLINE GLOBAL CONFERENCE for people living with Parkinson's. It runs for three days in April and is delivered entirely online with over 60 speakers presenting on a range of topics and live panels. The event is FREE for people to attend for the first 3 days of the broadcast with a premium upgrade option available to those who wish to revisit or re-watch some of the content. It is anticipated that in 2020, INSIGHT will attract up to 10,000 delegates from over 60 countries.

INSIGHT 2020, Future Frontiers, offers an opportunity for people living with Parkinson's, as well as their loved ones and associated health professionals the opportunity to hear from world leading experts, academics, specialists, clinicians and other people living with Parkinson's in a convenient and accessible ONLINE platform unlike anything else! INSIGHT brings the entire conference directly to you in your living room on ANY internet enabled device 24/7! Watch the presentations, re-visit them in your own time, join the online conversation, and visit the exhibition booths...

Here are five reasons to join us at INSIGHT 2020!

First three days are FREE! If you want more, you can upgrade to stream-on-demand for another 30-day access.

You get 60+ World Class speakers direct to your living room

All of the ticket profits go to our registered Charity Partners to support Parkinson's research and support services globally

INSIGHT is a World First event and the largest online annual event in Parkinson's

You can connect with over 5,000 researchers, academics, clinicians and other people living with Parkinson's from all around the world!

Stay Safe, Stay Healthy, Stay Active, Stay Loud

Here is the link to the trailer of the Movie, Pilgrimage to Enlightenment – The Journey to Becoming an Advocate

On YouTube <u>https://youtu.be/bZLalc7Om24</u> On Facebook <u>https://www.facebook.com/PilgrimagetoEnlightenment/</u>



The final epic chapter of the award-winning documentary '10 Mountains 10 Years'.

After 2,400 years a group of Alzheimer's & Parkinson's patients and advocates return to the birthplace of Healthcare & Medicine.

Follow the journey of a team of advocates on the final chapter of the epic '10 Mountains 10 Years' project. Hiking the cammino Magna via Francigena in Sicily. The Magna Via Francigena, the great road of the Frankish knights, follows the ancient route between Agrigento and Palermo that was used for millennia by pilgrims and travellers. After centuries of oblivion, this suggestive trail has come to a new life.

Was healthcare abandoned? In eons since the temple stones were laid everything has changed, but in the modern age why are so many still in need of assistance and fighting for their lives? After two millennia, in a world of super science and technology how much more time will it take to find the cures people seek? An international team of notable Alzheimer's and Parkinson's Disease advocates take an introspective journey through the searing heat of the Sirocco winds across the Island of Sicily. On foot the team walks the Magna Via Francigena, a recently discovered pilgrimage route to the 2,400-year-old ruins of the Temple of Asclepius - the birthplace of healthcare and medicine.

In the world beyond this ancient island they have each built legions of advocates fighting to shine light on the need to cure these diseases. But, in the absence of a perfect health care system, what can they do to save themselves and the people they love?

PRODUCTION: World Up Films WRITER & PRODUCER: Vincent Roland Simone DIRECTOR: Luke Chadwick-Jones FIELD PRODUCER: Jim Daley MUSICAL SCORE: Fractured Light Music - James Tumilty Leadbitter