



President's Message

Greetings HD Families-

Happy Summer! I hope this newsletter finds you will. We are in the midst of trying to navigate our new norm, but still work to serve you the best that we can.

National HDSA just held their first virtual convention, and it was a great event that they put on. This year whether you live near or far Convention was brought to you in the comfort of your own home. If you missed a session or want to go back and watch something that you might have missed the sessions are all on the hdsa.org website. The team at the National HDSA office put in a lot of time to convert to the virtual format. There is something for everyone to watch, from our youth to those that want to know what is happening in the research side of HD.

At the state level we have been working hard to transition as well and still work on ways to serve you, our family! Emily Zivin, our social worker and I have worked to make our Support Groups still meet. Even though we cannot meet physically in person we are doing it via Zoom, so we can still see each other and smile and be together. We feel it is working well. It is our goal that we can still be there for you even when we cannot be physically with you. Dave and Susie Hodgson put on an amazing 16th annual Team Hope Walk kicking off the Walks for our state! Great job! The Galesburg and Bloomington Team Hope Walks are still unknown to whether they will be in person or virtually. Keep an eye on our Illinois HDSA Facebook page, and our website Illinois.hdsa.org for updates on our events. The decision on our Baggo Tournament is unknown as well at this time but keep your eyes open for information as the decisions are made. The golf outing is still a go for now, but as we know now things can change. We are doing our best to make sure that we are still raising awareness and hoping for the cure for Huntington's Disease.

This pandemic has brought everyone to the mind frame of thinking how we can still be there for our people. Our 3 Centers of Excellence are working very hard to still "meet" with everyone, and they are producing and making resources available to our families that they can access from their home. If there are questions that you may have for them, reach out to them. They are working to serve you.

Emily is not only our social work for the chapter, but she is also working with National HDSA on the side of the National Youth Alliance (NYA). Emily is working to get our youth educated and involved in working towards the mission of the NYA.

The Illinois HDSA Board is still working to serve you, our family. We want to make sure that you are still getting the care and information that you need. Please remember to take care of yourself. As we navigate these times please do not hesitate to reach out and ask for help. We are here for all of you!

Take care and be safe!

Larry Haigh
President, HDSA Illinois Chapter



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Managing Chorea

By Neil Shetty, MD, Movement Disorders Fellow
Northwestern Medicine HDSA Center of Excellence

There is a new clinical trial called KINECT-HD. In this trial patients with Huntington's disease (HD) receive a medication intended to treat the most common motor symptom of HD called chorea. HD causes symptoms in three domains: motor (movement), psychiatric (behavior and mood), and cognitive (thinking and memory). In this article, we will focus on chorea and other motor symptoms of Huntington's disease in more detail.

As we've mentioned, the most common motor symptom of Huntington's disease is a type of abnormal movement called chorea. Chorea is an involuntary, purposeless, dance-like movement that flows randomly from one body part to the next. It can involve any part of the body (face, head, trunk, arms, and legs) and commonly involves the whole body. Chorea typically progresses over time. When mild, chorea may look like slight fidgeting or appear like a person is restless. When more severe, people can be constantly moving various parts of the body with larger, more noticeable movements. It is important to know that people with chorea do not typically feel restless and may not be bothered by their chorea. In fact, it is common for people with HD not to be constantly aware of their chorea and for it to be more bothersome to family members than to the person experiencing the movements. However, even when people are not directly bothered by chorea, it can still contribute to problems with coordination, balance, speech, swallowing, and weight loss. When chorea is contributing to such problems or is bothersome from a social perspective, treatment should be considered.

Currently, the only FDA-approved medications for Huntington's chorea are tetrabenazine (Xenazine) and a similar medication called deutetrabenazine (Austedo). These medications are meant to deplete the release of dopamine, a chemical that facilitates excessive movement. They are typically taken 2-3 times per day. The newly enrolling KINECT-HD trial will be studying another similar medication called valbenazine (Ingrezza), which has the potential benefit of once per day dosing. This drug is already available and approved for a different condition, and is now being studied for HD. There are numerous other medications that may be helpful for Huntington's chorea though they do not have specific FDA approvals for this indication. Some of the more commonly used ones are a group of medications called antipsychotics (which may also be helpful for behavior, irritability, and mood) and amantadine (which may also be helpful for apathy and fatigue). Before starting any of these medications, your physician should discuss with you which, if any, of these options may be best for you as well as the possible side effects.

Motor manifestations of HD are different from person to person. A movement disorders neurologist will assess you for symptoms beyond chorea as well. Aside from chorea, some other potential motor symptoms of Huntington's disease are impaired dexterity and coordination, problems with walking and balance, changes in posture, abnormal twisting muscle contractions (called dystonia), slurred speech, and impaired swallowing. Stiffness and significant slowing of movements can occur later in the course of the disease or can be seen at the onset for patients who develop motor symptoms at an unusually young age (childhood or adolescence). Medications to treat these other motor symptoms are more limited but include the medications used for chorea as well as botulinum toxin injections. Treatment of these motor symptoms, as with chorea, is best addressed by a multidisciplinary team that includes physical, occupational, and speech therapists. Comprehensive care that includes education, social support, medication, and rehabilitation services has been shown to be the most effective approach in improving quality of life for people with Huntington's disease.

MEDICAL RESEARCH CORNER

**Study recruitment is impacted by Covid-19
and will resume as soon as possible.



NORTHWESTERN MEDICINE HDSA CENTER OF EXCELLENCE

Kinect - HD Study for Chorea

Northwestern Medicine is participating in a new study of a treatment for chorea associated with Huntington's disease. The study is of a medication called Valbenazine to treat chorea and is being conducted by the Huntington Study Group and Neurocrine Biosciences. The study involves 9 visits and will last 18 weeks. There is the opportunity to stay on the drug after the first part of the study is over. Participants will be randomly selected to receive the drug or placebo at first. We are very excited to participate as one of several sites around the country. If you or someone you know is interested in taking part in KINECT-HD, please contact our study coordinator ZsaZsa Brown at 312-503-4121 or email zsazsa.brown@northwestern.edu.

Telemedicine for Huntington's Clinical Care

Individuals with Huntington's disease are invited to participate in the study "TeleHD" to determine the feasibility and value of telemedicine visits for HD patients and their care partners. This research study is conducted by Dr. Danielle Larson and Dr. Danny Bega.

Who is Eligible?

- Have a diagnosis of Huntington's Disease
- Ages 18 to 70
- Have a computer, laptop, tablet or phone with a camera, microphone, and internet access
- Fluent in English

What will you be asked to do?

- Complete two telemedicine visits (by camera at home) in addition to your two regular in-person Huntington's Clinic visits over a 6-9-month time.
- During the visits, a neurologic exam will be performed, and you will complete two cognitive tests. The telemedicine visits will likely take less than 30 minutes.
- After each clinic visit, you will be asked to record the time and travel burden of your visit.
- After all of the visits, you will be asked to complete a survey about your satisfaction with telemedicine visits.

Please e-mail research study assistant Robert Modiest at robert.jr3@northwestern.edu or call 312-503-5645 to let him know your interest, or if you have any questions.

CENTER OF EXCELLENCE AT RUSH UNIVERSITY MEDICAL CENTER

Uniqure, a gene therapy study for Huntington's disease

Rush University Medical Center is excited to participate in a new gene therapy trial for Huntington's disease, sponsored by Uniqure. The therapy is called AMT-130 and will hopefully slow the progression of HD by lowering the level of huntingtin protein in the brain. "Gene therapy" works by targeting genetic abnormalities that contribute to us getting sick. Administration of the therapy involves a small incision in the skull through which AMT-130 is delivered to the brain. Researchers are looking for people aged 25 to 65, with at least 40 CAG repeats in their huntingtin gene, and specific brain structure that will be assessed by MRI. Eligible participants will be randomized to receive the real treatment or a "sham" surgery involving a small mark made on the skin without making an actual incision. Study duration is approximately 5 years, during which time participants will complete physical assessments, treatment dosing, lumbar punctures, blood draws, and MRIs. Assessments and treatment will be completed across multiple sites. If you or someone you know would like to take part in the Uniqure study, please reach out to Jacob Hawkins at 312-563-5563, or email Jacob_Hawkins@rush.edu.

KINECT-HD, a phase three drug trial of Valbenazine for Huntington's chorea

Rush University Medical Center is recruiting participants for a clinical trial evaluating a drug called Valbenazine for the treatment of chorea. Valbenazine is already an FDA approved medication for another type of movement disorder that causes involuntary movements called tardive dyskinesia. The study is sponsored by the Huntington Study Group and Neurocrine Bioscience. Researchers are looking for people aged 18 to 75 with motor manifest Huntington's disease to be randomized to receive Valbenazine or placebo for 18 weeks. Participants will come to Rush for 9 research visits to take surveys, complete physical exams, and have their blood drawn. If you or someone you know would like to take part in KINECT-HD, please contact Jacob Hawkins at 312-563-5563 or email Jacob_Hawkins@rush.edu.

ENROLL-HD, a prospective registry study in a global Huntington's disease cohort

Researchers at Rush University Medical Center are looking for patients affected by Huntington's disease and their first-degree blood relatives to take part in an ongoing observational study. The data gathered in ENROLL-HD will be used to help doctors and scientists learn more about Huntington's disease and hopefully develop new treatments. Participation involves an annual visit conducted in the Rush Section of Movement Disorders at Rush University, where participants will complete surveys, cognitive tasks, family histories, and a blood draw. If you or someone you know would like to take part in ENROLL-HD, please contact Jacob Hawkins at 312-563-5563 or email Jacob_Hawkins@rush.edu.

Cortical Control of Balance and Walking in HD

A neuroimaging study investigating brain activation during cognitive, balance, and walking assessments in people with Huntington's disease. We are looking for individuals with a clinical diagnosis of HD, 35 years of age and older, who can stand and walk unassisted. Participants will come to Rush University Medical Center for 1-2 visits to complete a neuropsychological exam and walking and balance assessments while wearing a lightweight imaging cap. Recruitment will begin as soon as COVID-19 restrictions are lifted and continue for approximately two years. If you or someone you know would like to take part in this study, please contact Nicollette Purcell at Nicollette_L_Purcell@rush.edu.

Optimization of Telegenetic Counseling for Huntington's Disease

Rush University Medical Center will be offering telegenetic counseling services to HD patients and families as part of a new study that aims to assess feasibility and patient satisfaction of a telegenetic counseling program. Lack of access to genetic counseling has been recognized as a critical gap in care for many HD patients and their family members. 35 symptomatic or pre-symptomatic participants aged 18 or older will be recruited for this study and randomly assigned to a group that receives in-person genetic counseling first, followed by telegenetic counseling, or a group that receives telegenetic counseling first, followed by in-person genetic counseling. In-person visits will occur at Rush's HD Center of Excellence, while telegenetic counseling visits will occur via a video platform provided by Rush. Participants will then be administered a post-visit survey with questions regarding content of counseling, format of delivery, and their preferences. If you or someone you know would like to take part in this telegenetic counseling study, please contact Marc Rosenbaum at 312-563-0665, or email Marc_Rosenbaum@rush.edu.

REMINDER: September 20th will be the Team Hope Walk in Bloomington. At this time, we are not sure if it will be in person or virtual but please check our website for details as they become available.

HUNTINGTON'S DISEASE

Northwestern Medicine Virtual Patient and Family Symposium

Saturday, August 8 | 9:30 - 12:30

Topics:

Clinical research and updates
Physical therapy at home
How to access community resources

RSVP: email to HD@nm.org

Learn more about our COE at: <https://www.nm.org/conditions-and-care-areas/neurosciences/movement-disorders/huntingtons-disease>

Yes! Count me in!!

2020 Pledge Drive



Your pledge helps to support the HDSA mission to improve the lives of everyone affected by Huntington's disease and our vision of a world free of Huntington's disease.

- Research efforts
- Family services
- Advocacy
- Support groups
- HD awareness
- Our chapter social worker
- In-Service Presentations to Care Facilities

Please complete the information below and return with your pledge:

Your Name _____

Email Address _____

- ☐ Benefactor (\$500.00 [donation](#)) ☐ Patron (\$250.00 donation) ☐ Angel (\$100.00 donation) ☐ Supporter (\$50.00 donation)
☐ Member (\$25.00 donation) ☐ Friend (\$_____ donation)

Make your check payable to **Huntington's Disease Society of America** and mail to:

P.O. Box 1454, Lake Villa, IL 60046

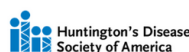
To make your pledge online go to [HDSA.org/il](https://hdsa.org/il), click DONATE and click on PLEDGE DRIVE CONTRIBUTIONS.

Family is everything

Your contribution is tax deductible to the extent allowed by law.

THANK
YOU

VIRTUAL 35TH ANNUAL HDSA CONVENTION RECORDINGS



VIRTUAL 35TH ANNUAL HDSA CONVENTION

BY THE NUMBERS



1,536
EMAIL
REGISTRANTS



6,200
LIVE
VIEWS



942
APP
DOWNLOADS



93
COUNTRIES
REPRESENTED



3,211
VIRTUAL EXHIBIT
HALL VISITORS

Memorials and Tributes

In Memory of Dennis Ross from Lillian and Julian Bucher, Peggy Crapple

In Memory of Barb Weigler from Minnie Weigler and Cynthia Sims

In Memory of John David Hodgson from Denise and David Survant

In Memory of Sharon Burritt from Louise and Richard Brattland

volunteer
do good, feel good



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Hopes & Dreams

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This newsletter attempts to report items of interest relating to the individuals with Huntington's Disease, their families, healthcare professionals, and interested friends and supporters. HDSA and the Illinois Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Illinois Chapter.

Recap of 16th Annual Illinois Chapter Team Hope Walk - Naperville

By Dave Hodgson

This year's 16th Annual Team Hope Walk in Naperville was held on May 17, 2020...with a twist.

Due to the Covid-19 pandemic the walk was switched to a virtual walk. While COVID-19 disrupts everyone's lives, HD continues to impact the lives of so many families near and dear to us. You're a crucial part of the Illinois community that supports HD's mission to improving the lives of everyone affected by Huntington's disease. From community services and education to advocacy and research, HD is the world's leader in providing help for today, hope for tomorrow for people with Huntington's disease and their families.



This year's walk was broadcast through ZOOM over Facebook Live. Guest speakers before the walk kicked off included HD's CEO, Louise Vetter, representing one of our national sponsors, Genentech, Connor Fogarty, and U.S. Representative Lauren Underwood. While not all the results are in, we're confident that the Naperville Walk will be the biggest in the nation with over \$110,000.00 in donations so far.

Thank you to everyone who participated and donated to make our walk a great success again! The Top Dog (home of THE NOW Famous Hot Dog Lunch) Team was Haydock's Warriors; Top Dog Individual was Wally Haydock; and the Top Dog Video was John Stecyk's "Walking On Sunshine." Trophies will be mailed to the winners. T-shirts for this year's walk are being processed and should arrive soon! Mark your calendars now for next year's walk: Sunday, May 16, 2021.



News from Our Illinois Chapter

Social Worker

Emily Zivin, LCSW

Huntington's Disease Society of America
Tel: 630-443-9876 or E-mail: ezivin@hdsa.org

During the current COVID-19 pandemic, friends and family members continue to provide caregiving to their loved ones. It is recommended that caregivers develop strategies to maintain their own health and well-being. Some tools and tips to help during this difficult time include:

Stay Informed about Covid-19

Continue to monitor the current state of Covid-19 in Illinois and your area. A resource for up to date information includes: <https://coronavirus.illinois.gov/s/>

Reduce the risk of transmitting Coronavirus

Wash your hands often
Avoid close contact
Use a face mask when around others
Cover coughs and sneezes
Clean and disinfect

Follow CDC recommended protocols for personal hygiene

<https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html>

Take care of yourself

Eat balanced, healthy meals
Exercise
Maintain a regular sleep routine
Stay connected to friends or families

Watch for Signs of Burnout

Caregiver burnout is heightened during times of stress. You might be experiencing caregiver burnout if you are experiencing any of these:

- Increase anxiety/depression
- Hopelessness
- Sleep problems
- Difficulty coping with everyday tasks

If you are experiencing caregiver burnout, try to make more time for yourself. Take breaks and engage in activities that make you happy.

Find Opportunities to Relax

Practice mindfulness exercises such as meditation
Connect with your religious community
Take a walk

Stay connected

Reach out to family and friends regularly
Connect virtually
If you live with other family ways, find ways to support and help one another.



What does COVID-19 mean for Huntington's disease families and HD research?

COVID-19 update: what does it mean for HD families, how does it impact HD research, and how has it changed the way science works?

By Dr. Sarah Hernandez and Dr. Ed Wild April 06, 2020 Edited by Dr. Rachel Harding

COVID-19, short for coronavirus disease 2019, has taken the world by storm in almost every sense – many people have been infected with the SARS-CoV-2 virus, it's created shopping pandemonium in stores, and many people are isolated at home. But behind that frenzied storm, scientists around the world have been working tirelessly to move research forward at an unprecedented speed so that we can understand the virus and develop a treatment or vaccine. How does this situation affect the HD community? And what does COVID-19 mean for HD research?

What does COVID-19 mean for HD patients and families?

“On its own, having the genetic mutation that causes HD doesn't make anyone more or less susceptible to COVID-19 than someone without HD. What would make an HD individual more susceptible to COVID-19 is if they had any underlying conditions that put them in the “high-risk” category.”

To stay safe and healthy we should all continue doing what the WHO recommends – wash our hands regularly for 20 seconds with hot water, clean surfaces with a disinfectant, and practice social distancing. Social distancing means only coming in contact with members of your household and only going out for essential things, like an essential job, grocery store run, or to get medication from the pharmacy. Everyone should also remain vigilant for the symptoms of COVID-19, which include fever, a dry cough, shortness of breath, and fatigue.

Some HD patients at particularly high risk may need to isolate themselves even more strictly. You should seek advice from the above sources and your health provider if you are concerned.

What does COVID-19 mean for HD research?

Many scientists who usually spend all day in the lab studying HD have been asked to stay home so that they can practice social distancing and remain safe. This means that HD-related research will slow for the short time during this pandemic. A big concern is ensuring that precious samples are kept safe, and experiments that had to be shut down were paused in a way that preserves them to be restarted once it's safe to hang out in the lab again.

While HD researchers may not be going into lab every day, they're still hard at work to combat this disease. They may not be doing experiments at the bench, but they're reading papers to develop their next idea, compiling data to better understand HD, and writing papers to disseminate what they've learned to the world. The labs may be quieter, but HD researchers are still hard at work in their fight against HD.

An unprecedented global collaboration is occurring to advance COVID-19-related research rapidly, with publications increasing by the day. The dramatic rise in COVID-19 literature has been graphed at LitCovid, where related publications are currently available for free!



What about clinical trials?

With many countries' entire healthcare systems turned over to providing care for people with COVID illness, and many doctors and nurses diverted from research into frontline care, an impact on Huntington's disease clinical trials is inevitable. However, all those involved are doing everything they can to minimize the impact and carry on with whatever trial activity they can.

In practice, the impact will vary quite a bit from one site to another, and from one trial to another. Some sites may still be enrolling new patients, while many will be forced to pause recruitment of new participants and focus on continued care and dosing of patients already involved. Many sites will likely convert onsite trial visits into telephone calls or postpone visits until it is safer to carry them out in person.

Decisions about what activity can carry on are largely determined locally, by the hospitals and local and national governing bodies that direct healthcare resources. Trial sponsors (companies like Wave, Roche and UniQure) fund, support and organize the trials. So far, all the trial sponsors we've heard from have indicated that they continue to be committed to running and completing the trials despite the interruption the viral pandemic may cause.

It may be that some modifications need to be made later, to compensate for trials that were unexpectedly interrupted. For instance, they might need to treat existing patients for longer, or recruit additional patients to make up for lost time. And later, the regulatory agencies like the FDA might need to be more flexible when considering data from trials with higher than normal levels of missing data. With so much unknown about how long COVID will impact things, it's difficult to be more specific, but the smart people who invented this cool generation of HD drugs and brought them to trials, are now working full time to keep those trials running as well as humanly possible.

"While HD researchers may not be going into lab every day, they're still hard at work to combat this disease."

Could there be a silver lining?

Science and research, and public policy informed by science not superstition, are the key to getting humanity through this crisis. The challenge has already changed scientific research for the better, in some quite fundamental ways, that could provide benefits long after COVID-19 is an unhappy memory.

In a very short time, scientists from around the world have united to study the virus and share their findings to benefit everyone. The number of scientific publications about COVID-19 is rising dramatically week after week.

In an effort to increase the pace of research about COVID-19, nearly all relevant scientific literature has been made open access, meaning it's currently available for free to everyone – for now at least. You can see just how much work is being done to understand and combat COVID-19 at LitCovid: <https://www.ncbi.nlm.nih.gov/research/coronavirus/>

Research has already told us a lot about the virus. We know it can be spread from person-to person, either through direct contact with someone else who has the virus or by coming in contact with droplets produced by someone who has the virus, such as a sneeze or a cough – similar to how the flu is transmitted. However, COVID-19 is unlike the flu in many ways – it's much more fatal, we currently have no vaccine against it, and it's a new virus so we still have a lot to learn.

To get a head start on finding drugs that will treat COVID-19, researchers are testing drugs that they think might work and have already been approved for safety.

It can take up to 14 days after SARS-CoV-2 exposure to bring on COVID-19 symptoms, which is why many doctors are recommending a 14-day isolation period. However, we are now learning that a portion of the population may remain asymptomatic. This means they show no symptoms but do have the virus and can pass it to other people. In fact, the asymptomatic portion of the population may be as high as 20 to 30%! This is why social distancing and staying at home when possible are critical for not spreading the virus – without widespread testing, we don't truly know who does or doesn't have the virus, so isolation is the key to staying healthy.

Dramatic rollout of drug trials

Many members of the HD community already have a head start on understanding how important clinical trials are for determining the safety and function of drugs before they're distributed widely. It's something HD patients and families are learning right now first hand with the Roche Phase III Tominersen trials (formerly Ionis-HTTRx and RG6042), and it's something that will also have to be done, in an accelerated way, for any drug used to combat COVID-19.

For COVID-19, researchers are trying to start on second base by repurposing drugs that are already approved by the FDA for something else but may have an alternative use for helping COVID-19 patients. Because they're already approved and on the market, they've already passed safety trials, making them faster to use.

The WHO (World Health Organization) prioritized 4 such drugs or drug combinations that they think have the best chance of working against COVID-19 and have established a global trial to determine how well these drugs work, called SOLIDARITY – a fitting name for the global effort that has come together to work against this virus.

Remdesivir is a drug that prevents viral replication, which means it stops the virus from increasing in number. It was initially designed to combat the Ebola virus, and has shown promise for COVID-19. The drug that has gotten the most attention, at least in the United States, is chloroquine, a derivative of which is called hydroxychloroquine. While some people remain eagerly optimistic about this drug, it has limitations and still needs to be tested. The third drug is a combination of ritonavir and lopinavir, which has been approved to treat HIV infections. The last drug is the same combination of ritonavir and lopinavir with the addition of interferon-beta. Interferon-beta helps regulate inflammation and has shown promise in treating a different viral disease, MERS (Middle East Respiratory Syndrome).

This too shall pass

This virus has undoubtedly brought a stressful and scary time for the entire world, but there have been a few bright spots. And while the pandemic will eventually fade away, we will be left with its silver lining. Many have been able to spend additional time at home with loved ones, even if that means having a computer on their lap. Scientific discoveries are being made at break-neck speed as the global research community comes together to fight a common goal. And last but not least, dogs around the world are rejoicing that their 2-legged friends are spending every night staying in. So stay safe and stay healthy, for this too shall pass.



The Spring Fling committee would like to thank everyone who made our event a success even though it had to be cancelled due to the Covid-19 pandemic.

Over \$5,000 was raised thanks to the registrants who donated their refunds and our sponsors who chose to donate even though the event could not be held!

Your support means so much to us!



Monson Rose Law



Joseph Rybarczyk

SUPPORT groups

NOTE: Face-to-face meetings CANCELLED due to COVID-19 until further notice. Please reach out to CONTACT info for your meeting for additional information as many of the local support groups will be utilizing zoom video conferencing.

*****Whether you have HD, are at-risk, a caregiver, friend or just someone who wants to know more about HD, you are welcome!*****

CENTRAL ILLINOIS

2nd Sunday of Even Months (2:30 – 4:30pm)

2020 Meetings: 2/9, 4/13, 6/14, 8/9, 10/11 (no Dec. meeting)

OSF PromptCare Fort Jesse, 2200 Fort Jesse Road, Normal, IL
Contact: Larry Haigh (815-383-1877); larryhaigh@gmail.com

ROCKFORD

2nd Sunday of Every Month (2:00 – 4:00pm)

OSF St. Anthony Medical Center, 5666 E. State Street,
St. Anthony Room (Use main entrance – second one back from
parking lot entrance. As you enter building, you'll see a counter
staffed by volunteers. Turn right, before you reach the counter.
St. Anthony room is straight ahead)

Contact: Charlotte Rybarczyk (847-528-7354);
charlotte82963@gmail.com

GENEVA

3rd or 4th Sunday of Odd Months (2:00 – 3:30pm)

2020 Meetings: 1/19, 3/29, 5/17 (no mtg), 7/19, 9/20, 11/15

Northwestern Medicine – Delnor Hospital, 300 Randall Road
Conf. Room #4, Medical Office Building 351 (park near the south
entrance to the hospital and enter at the southeast corner of the
building. Turn left, go past the gift shop and cafeteria, then
follow the sign for Building 351. Conference Room #4 is a short
ways down the hall on the right)

Contact: Joe Wiedemann (847-505-3933);
joseph.wiedemann@gmail.com

LAKE COUNTY

2nd Monday of Every Month (7:00 – 8:30pm)

Advocate Condell Medical Center, 801 Milwaukee Avenue,
West Tower, Libertyville, IL

Contact: Marilyn & Barry Kahn (847-975-2403);
marilynkahn1@gmail.com
(Call for additional information and directions)

MUNSTER, IN

2nd Tuesday of Even Months (7:00 – 8:30pm)

2020 Meetings: 2/11, 4/14, 6/9, 8/11, 10/13, 12/8

Southside Christian Church, 1000 Broadmoor Avenue
Contact: Cindy Rogers (219-836-2369); cdrogers111@comcast.net

CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL

Saturdays (see dates below) (10:00 – 11:30am)

2020 Meetings: 1/18, 3/7, 5/16, July, Sept, Nov. TBD

Logan Square Library, 3030 W. Fullerton Avenue, Conference
Room (Free ground-level parking available; building is
handicap-accessible)

Contact: Emily Zivin (630-443-9876);
emily.zivin@northwestern.edu

CHICAGO – RUSH UNIVERSITY MEDICAL CENTER

3rd Saturday of Every Month (10:00am – 12:00pm)

2020 Meetings: 1/18, 2/15, 3/21, 4/18, 5/16, 6/20, 7/18, 8/15, 9/19,
10/17, 11/21, 12/19

Rush Oak Park Hospital, 520 S. Maple, Oak Park, IL 60304
Conference Room 1B

Parking is Free; Refreshments will be provided
Each group will have a short presentation from a professional
(dietician, therapist, etc.)

Contact: Samantha Lunde, AM, LSW (312-942-2163) or
Samantha_R_Lunde@rush.edu

SOUTH SUBURBAN

2nd Tuesday of Odd Months (7:00 – 8:30pm)

2020 Meetings: 1/14, 3/10, 5/12, 7/14, 9/8, 11/10

Thomas Cellini Huntington's Foundation, 3019 East End Ave.
South Chicago Heights, IL

Contact: Maryann Moynihan (708-955-3080);
shamrock1959@att.net OR TCHF Office (877-687-8243)



Caregiver Support Group

Wednesdays (see dates below) (7:00 – 8:30pm)

2020 Meetings: 2/19, 4/15, 6/17, 8/12, 10/21, 12/2

Northfield Branch Library, 1785 Orchard Lane, Northfield, IL 60093

The library is difficult to find. It is in the same building as the post
office. The librarian will be able to direct you.

Meeting will be held in the Community Room

Contact: Emily Zivin (630-443-9876); ezivin@hdsa.org



 **SAVE THIS DATE!**

August 8, 2020	Northwestern Medicine 'Virtual' Patient & Family Symposium
August 29, 2020	HDSA IL Chapter Baggo Tournament – Rolling Meadows, IL
September 13 th	HDSA IL Chapter Team Hope Walk - Galesburg, IL
September 20 th	HDSA IL Chapter Team Hope Walk – Bloomington, IL
September 27 th	Golf Outing benefiting the HDSA IL Chapter

<https://hdsa.org/il>



SUMMER 2020