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Hopes & Dreams
is the official publication of the
Illinois Chapter of Huntington's Disease Society of America, Inc.,
P.O. Box 1454, Lake Villa, IL 60046
(630) 443-9876 ~ www.hdsa.org/il

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.

President's Message



Dear HD Families,

I hope all of you had a relaxing holiday. Happy 2023! 2022 was a year of transition and challenging times due to the pandemic. We had many live events where HD families could connect with one another.

In 2022 as President of the Chapter, I learned a great deal at events I could attend, and from HD families I interacted with at local events and the HDSA convention. I continue to be impressed by the determination and resiliency of the HD families, considering the challenges with disease and HD clinical trials.

As a chapter, we had a number of excellent events, highlighted by the Team Hope Walk at the Naperville Riverwalk on May 15th. We had over 450 attendees and this long-standing trademark event for the Illinois chapter. It was wonderful to see and meet with so many members of the HD community on a beautiful summer day. I am looking forward to another great Team Hope Walk event in 2023.

I want to thank Jennifer Placek and Charlotte Rybarczyk for their service on the Illinois Board. Both Jennifer and Charlotte made tremendous contributions to the board, and they will be missed. I want to specifically thank Charlotte for being a pillar of leadership, serving in every board role possible multiple times for the last 25 years.

Our mission as a Chapter is the carry out the HDSA mission, which is to improve the lives of everyone affected by HD and their families. I am committed to supporting this effort and thank you in advance for your commitment to carrying out this mission at the local level. As always, please feel free to reach out for any support and or help.

I look forward to a great year ahead and seeing you at many great events planned in 2023!

Arvind Sreedharan
President, HDSA Illinois Chapter



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Falls, Fall Prevention and Huntington's Disease

Patients who have Huntington's disease develop problems with walking and balance as the disease progresses. Studies tell us that 79% of Huntington's disease patients will have falls and injuries occur in up to 73% of Huntington's disease patients due to falls.

Where, How and Why do Huntington's Disease Patients Fall?

Huntington's disease patients frequently fall in a familiar environment, such as where they live. In fact, 57% of Huntington's disease patients, when surveyed, say that they fall in their home. Self-reported causes include obstacles on the floor (25%), slippery or uneven surfaces (17%) and climbing of stairs in 20%. Huntington's disease patients may fall due to these environmental factors or other factors related to the individual patient. Chorea, the extra movements that occur in Huntington's disease, can affect balance. Some patients will have slowness of movement or "ataxic" walking, which can be described as wobbly or uncoordinated.

"Multiple task" situations play a major role in falls in Huntington's disease. This is best described as walking while doing another task, like looking at a phone. Falls related to multi-tasking when walking may be more common as patients with Huntington's disease develop cognitive impairment.

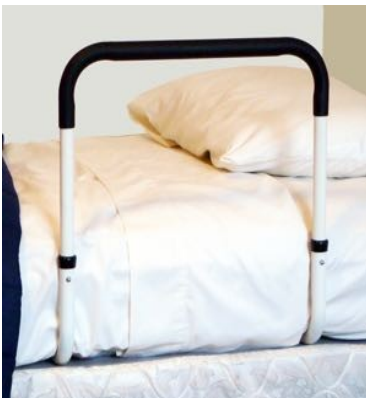
What can be done to prevent falls?

Walking Aids

Some patients with Huntington's disease will benefit from a walking aid. Options include canes or walkers, which come in a variety of types. Frequently, the clinician will have a physical therapist work with the patient to try various walking aids to see which one is best to stabilize the walking. A cane may work very well for some patients but may actually increase risk of falling for others. This may be the case for walkers as well. For this reason, walking aids need to be tailored to the individual patient.



Environmental Adjustments



Many patients find that a time of fall risk is around transferring from bed to standing or sitting. Patients and families might want to consider adding grab bars or a bar to the side of the bed to help stabilize the patient. Falls out of bed can also occur, so some families may consider placing the mattress on the floor, putting a soft mat next to the floor, or using a "bumper" of blankets or foam wedges to prevent falls. For patients who have difficulties with transfers in or out of the car, there are devices that can be purchased to use as handles to help.



Bathing can be a time of risk for many patients. Shower chairs, soap alternatives that may not slip out of hands, or other options may be helpful to keep the patient safe. Patients will frequently fall in the bathroom at night. Having adequate light on the way into and in the bathroom at night and locating grab bars may be helpful. Other adjustments to the environment may be necessary, such as removing throw rugs that patients can trip on, keeping pathways clear, removing objects that are easily knocked over, and padding the corners of furniture or sharp edges.



Some patients may need to be monitored for safety, even if they are able to walk on their own. In some situations, the clinician



may recommend a “fall button” that can alert the family or a service if the patients falls. The family and patient will need to discuss what type of device and who it should alert would be most beneficial. If caregivers need to leave a Huntington’s disease patient and wants to make sure they are safe, in home monitors can be used. Many of them are “two-way” and the family can communicate with the patient from afar. For patients who need assistance with walking, there are other strategies that can be used. Many patients with Huntington’s disease may jump up

and start to walk, even if they need help. For patients in this situation, a bed alarm to wake the bed partner or caregiver may be necessary. These devices can be purchased on line and can make noises, send a signal to a phone, or alert the care partner in other ways.



Physical Therapy and Exercise

Clinicians will frequently refer their patients with Huntington’s disease for physical therapy. Physical therapists are health professionals who use movement, mechanical force, manual therapy, exercise therapy and other modalities to restore and improve mobility and maintain function. Gait training or fall prevention techniques can be taught during physical therapy sessions and can also be learned by caregivers. Physical therapy and exercise have also been shown to help improve fitness, walking endurance and overall physical activity in Huntington’s disease, with several research groups are working to develop specific recommendations to providers in the future.



Occupational Therapy

Occupational health professionals help patients coping with physical or cognitive illness better navigate activities of daily living. In Huntington’s disease, occupational therapists can perform a safety evaluation in the home to decrease falls. For example, they may suggest adjustments to the way a patient bathes, counsel on the installation of grab bars, or suggest certain ways to safely transition.

Summary

Some of these techniques may help families and patients stay safe and prevent falls. If you are unsure of which of these to employ, a fall diary can be started to understand fall patterns of where or how the patient is falling. This information can be discussed in the visits with the clinician or health provider to make a plan to keep you or your family member safe. There are many resources through HDSA that may also be helpful.

Other resources:

- <https://hdsa.org/wp-content/uploads/2015/02/15703.pdf>
- <https://hdsa.org/wp-content/uploads/2015/02/Physical-Therapy-and-Huntington-s-Disease-kloos.pdf>
- <https://hdsa.org/wp-content/uploads/2015/02/11423.pdf>



Deborah Hall MD PhD, Director, Huntington’s Disease Center of Excellence, Rush University

Memorials and Tributes

In Memory of Rich Whitlock from Chad & Apsara Sorensen; Ellyn & Dennis Sorensen; Marlon & Betsy Huls; Ellen West; William & Jill West; Mark Lukoskie.

MEDICAL RESEARCH CORNER

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



NORTHWESTERN MEDICINE HDSA CENTER OF EXCELLENCE

Sage HD Clinical Trial – Now Recruiting

A Randomized, Placebo-Controlled, Double-Blind Study to Evaluate the Effect of SAGE-718 on Cognitive Function in Participants with Huntington's Disease. The primary purpose of this study is to evaluate the effect of SAGE-718 oral capsules on cognitive performance and functioning in participants with premanifest or early manifest HD. This study requires up to 136 days of study participation. If you are interested in learning more about the study and how to get involved, please reach out to study coordinator ZsaZsa Brown at 312-503-4121.

Development of the Virtual Unified Huntington's Disease Rating Scale (vUHDRS) – Now Recruiting

The purpose of this study is to assess the reliability of virtually administered UHDRS compared to the in-person administration of the UHDRS to establish the use of the vUHDRS for clinical trial and regulatory purposes. This study will require up to 6 weeks of study duration. If you're interested in learning more about the study or how to get involved, please contact Destiny Gomez at 312-503-2778 or destiny.gomez@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 period.
- 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.

Northwestern Movement Disorders Center Biorepository

The Movement Disorders Center (MDC) Biorepository is a registry aimed to collect biologic and clinical information, such as blood and tissue samples, and family and medical histories from patients diagnosed with a movement disorder. The purpose of studying materials from the registry is to identify factors that either cause these neurologic conditions or increase one's risk for developing them. Samples collected for this biorepository include a blood sample (or a saliva sample) and a skin biopsy. Participants may choose to donate one or both samples.

KINECT - HD: Recruitment complete

This is a study for a new treatment for chorea associated with Huntington's disease. If you have chorea that is not currently being treated we need you. 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.

KINECT - HD 2 Study: Now Recruiting

Northwestern Medicine will be participating in an open-label extension study of Kinect-HD. The purpose of this study is to continue to gather safety and efficacy data on Valbenazine for the treatment of Huntington's chorea, while also providing study subjects who participated in Kinect-HD continued access to the study drug. In this open-label study, all subjects are given Valbenazine, even if they received placebo during Kinect-HD. Kinect-HD 2 is open to research subjects who completed participation in Kinect-HD. For more information on Kinect-HD 2 contact Zsa Brown at 312-503-4121 or zsazsabrown@northwestern.edu.

Hi-DEF Scale Study: Recruitment complete

Individuals with Huntington's disease are invited to participate in the Hi-DEF Scale Study. The purpose of this study is to learn more about impact of Huntington's disease on cognition and everyday functioning. The study involves a one-time commitment that lasts about 2.5-3 hours. Participants will be asked to complete some online questionnaires and two online cognitive tests. Once finished, the participant will be compensated for their time. If you're interested in learning more about the study or how to get involved, please contact Destiny Gomez at 312-503-2778 or destiny.gomez@northwestern.edu.

PROOF-HD - Recruitment complete

Northwestern is excited to be participating in the PROOF-HD Study. This is a phase 3, randomized, placebo-controlled study evaluating the efficacy and safety of an oral drug called Pridopidine in patients with early-stage Huntington's disease. The objective is to see if Pridopidine can *slow down functional decline* in Huntington's disease when compared to a placebo pill. If you are interested in learning more about the study and how to get involved, please reach out to study coordinator ZsaZsa Brown at 312-503-4121.

HDSA CENTER OF EXCELLENCE AT RUSH UNIVERSITY

Uniqure, a gene therapy study for Huntington's disease

Rush University Medical Center is excited to be participating 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. We anticipate being ready to enroll patients in the next few months.

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.

KINECT-HD 2, an open label rollover study for continuing Valbenazine administration for the treatment of chorea associated with Huntington disease

Rush University Medical Center is excited to participate in the open label extension study of Kinect-HD, a clinical trial of Valbenazine for the treatment of Huntington disease chorea. The purpose of this "rollover" study is to gather more safety and efficacy data on Valbenazine. Valbenazine is an FDA approved medication used to treat another type of disorder that causes involuntary movements called tardive dyskinesia. In this open label study, all subjects will be given real Valbenazine for up to two years. Kinect-HD2 is now open to all qualifying patients, not just those who participated in Kinect-HD. Researchers are looking for people aged 18-75 with motor manifest Huntington's disease. Participants will come to Rush to take surveys, complete physical exams, and have their blood drawn. The study is sponsored by the Huntington Study Group and Neurocrine Bioscience. If you or someone you know would like to take part in Kinect-HD2, please contact Jacob Hawkins at 312-563-5563 or email him at 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.

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 balance and walking under single-task and multitask conditions in people with Huntington's disease. We are looking for individuals with a clinical diagnosis of HD, 30 years of age and older, who can stand and walk unassisted. Participation requires one, 3.5-hour visit to *Rush* University Medical Center. This study is actively recruiting both healthy control and HD participants. Please contact Nicollette Purcell (Nicollette_L_Purcell@rush.edu) if you are interested in participating and would like additional information.

Optimization of Telegenetic Counseling for Huntington's Disease

A neuroimaging study investigating brain activity during balance and walking under single-task and multitask conditions in people with Huntington's disease. We are looking for individuals with a clinical diagnosis of HD (≥ 40 repeats), 30 years of age and older, who can stand and walk unassisted. A study visit requires participants to come to Rush University Medical Center to perform cognitive assessments and walking and balance tasks while wearing a portable neuroimaging cap, followed by an MRI at the nearby University of Illinois-Chicago. Testing can be completed in one visit or split into two shorter visits. This study is actively recruiting both healthy control and HD participants. Individuals will be compensated for their participation. Please contact Nicollette Purcell (Nicollette_L_Purcell@rush.edu) if you, or someone you know, are interested in participating and would like additional information.



Information and registration at:
www.HDSA.org/Convention



Family is everything



SAVE THE DATE

Sunday • May 21, 2023

Additional information will be added to the Walk website soon.

<http://www.hdsa.org/thwnaperville>

Location: Naperville Riverwalk Grand Pavilion



*Huntington's disease research news.
In plain language. Written by scientists.
For the global HD community.*

DISAPPOINTING NEWS FROM NOVARTIS ABOUT BRANAPLAM AND THE VIBRANT-HD TRIAL

Novartis have announced that they are ending development of the drug branaplam in Huntington's disease. Here, we review this latest news and its impact on the HD community. 12/9/2022: By Dr. Rachel Harding and edited by Dr. Jeff Carroll

The pharmaceutical company Novartis has released a community update which announces that they are ending development of branaplam, a huntingtin lowering drug, for possible treatment in Huntington's disease (HD). This news comes following recent bad news about side effects of branaplam in HD patients, being tested in the VIBRANT-HD clinical trial, dosing of which was paused earlier this year. In this article we will break down this announcement and what this news means for the HD community.

Huntingtin-lowering therapies are being pursued in the clinic by many companies

Many companies are exploring huntingtin-lowering as a strategy for treating HD. HD is caused by a mutation in the huntingtin gene, which leads to the production of a faulty version of the huntingtin protein. The faulty protein causes all sorts of problems in the brain and including the death of nerve cells, which results in the symptoms of HD. Huntingtin-lowering drugs aim to reduce the levels of the faulty huntingtin protein in the brain, with a goal of slowing or stopping HD's progression.

Huntingtin-lowering treatments are being developed using a variety of different approaches, such as anti-sense oligonucleotides (Wave Life Science and Roche) or viral gene therapies (uniQure). One problem is that the drugs these companies have developed cannot easily spread through the whole body, so they are given to patients through an infusion into the spinal fluid, or by direct injection into the brain. Giving drugs this way is expensive and demanding for patients so this type of therapy could not be trivially rolled out to the global HD community.

To overcome these problems, researchers are keen to develop "small molecule therapies" which would be cheaper to manufacture and administer. Small molecule drugs can be formulated to be taken orally as a pill or syrup, like most common medicines you may already be taking, such as pain killers or an allergy medication. Because they can hitch a ride in the bloodstream, small molecule drugs are also better at spreading to nearly all the organs of the body. Some small molecule drugs, although not all, can even make the leap from the blood into the brain – enabling treatment of the body and brain with a single drug.

Branaplam lowers huntingtin but was originally designed to treat another disease, SMA

Two different companies, Novartis and PTC Therapeutics, are both testing small molecule drugs which can lower huntingtin in HD patients. The drugs from both companies are called splice modulators because they target how our cells which edits genetic messages, a process call splicing. Each genetic message can be thought of like a story book, and when the story is over, the final part of the message reads the genetic equivalent of "the End" to tell the cell that the sequence for that message is complete. Splice modulator drugs rejig the pages of the story book so "The End" is read the ending, so the cell destroys the message and doesn't make the associated protein at all. Just like you would toss a book that made no sense with a premature ending and read, "Once upon a time, The End".

The splice modulator developed by Novartis is called branaplam, a drug originally developed for a completely different disease called spinal muscular atrophy (SMA), because it also changes the levels of a protein called SMN2, which underlies that disease. Very unexpectedly, scientists at Novartis discovered branaplam also changes the levels of the huntingtin protein in different models so wanted to explore if this drug might be a good treatment for people with HD in a trial called VIBRANT-HD.

Branaplam has bad side effects for some people treated with this drug

VIBRANT-HD aimed to work out if branaplam was safe and effective at lowering huntingtin levels but, before recruitment was completed, dosing for the trial was paused due to safety concerns. The decision to pause the trial was made by an independent Data Monitoring Committee, who assess data generated by the trial before the doctors, patients, or study sponsor (Novartis) know the outcomes to ensure participants are safe in case issues arise.

We have since learned in this most recent announcement that Novartis has decided to end all development of branaplam for HD due to safety concerns associated with the drug. When dosing was paused back in August, information was released indicating that there were issues in some study participants with a condition called peripheral neuropathy – damage to nerve cells outside of the brain and spinal cord. In this most recent announcement, Novartis have provided further information about safety issues seen in many, although not all, participants.

As we expected to learn, symptoms and changes in neurological examinations consistent with peripheral neuropathy were confirmed as being observed in some participants. Some participants also had increased levels of neurofilament light chain (NfL), a lab test used to assess injury or damage to nerve cells. This means that there may be damage to the nervous system after branaplam treatment. Also of concern is the observation that there was an increase in the size of a region of the brain called the ventricles. The ventricles are a fluid filled space deep in the brain and an increase in the size of this region can mean several different things, which we don't yet have enough information to fully understand. In their letter, Novartis state that no clinical symptoms have been associated with these brain scan findings to date.

What does this mean for HD patients who received branaplam?

Novartis have stated that all study participants who received branaplam will continue to be monitored. We don't yet know if the side effects experienced by participants in the trial are permanent or whether they will get better now that dosing with the drug is stopped, so monitoring of symptoms is important.

What can we learn from trials that end this way?

Trial failures like this can be very hard-hitting and it is very normal to feel upset about this type of news, especially for the brave and dedicated members of the HD community who participated in this trial. Despite this sad development, there is still a lot we can learn from trials which don't turn out as we had hoped. Tons of data is collected throughout the course of trials and more will continue to be collected in the coming months as things formally conclude. This data can give us important insights into what might have happened so that the community can learn and move on from this trial. Novartis has stated that they are committed to sharing what they learn with HD families, researchers, and other professionals in the HD community.

Do we know why branaplam didn't work as we had hoped?

This announcement is the latest in a series of disappointing news regarding HD trials so what's going on? It's important to note that branaplam was not developed to treat HD. We knew unexpected side effects were possible, because as well as lowering huntingtin, branaplam also changes the levels of the SMN2 protein, as well as potentially others. Changing the levels of lots of different proteins can disrupt the intricate processes performed by nerve cells, which could explain some of the symptoms observed.

In fact, in some animal studies, Novartis note in their announcement that toxicity of the nerves was seen as a side effect of branaplam treatment, which is why they included robust safety monitoring procedures in the VIBRANT-HD trial. Interestingly, children with SMA treated with branaplam do not seem to have these symptoms, which is why there was still optimism that this would not prove to be a problem in HD patients. We will likely learn more about why this happened as more data from the trial is compiled and analyzed.

What does this mean for the other splice-modulator drugs to treat HD?

Other companies are working to develop a splice modulator to treat HD, including Roche who are doing pre-clinical research in this area. Another trial, called PIVOT-HD, will be testing the splice modulator PTC-518 developed by PTC therapeutics which is very similar to branaplam. This trial is underway in Europe and Australia although recruitment is paused in the US as PTC work to provide some extra data to the US regulatory agency, the FDA. It's important to note that PTC-518 was specifically designed for HD, and data from PTC indicates this drug spreads more efficiently into the brain than branaplam, so the hope is that the side effects observed for branaplam won't be an issue for PTC-518; we will learn more as the trial proceeds.

When will we learn more?

Novartis have vowed to keep the community updated as their analysis of the data from the trial proceeds. HDBuzz will write another article as soon as we learn any more information about branaplam or the VIBRANT-HD trial.

It's important to remember clinical trials are some of the biggest and most complicated experiments which we can run, with no guarantees of good outcomes, but each trial adds to our knowledge and brings us closer to finding drugs to treat HD. We are extremely grateful to the brave and selfless HD community members who participated in this trial.



We invite all those diagnosed with Huntington’s Disease, their families, caregivers, and individuals who are at risk to attend our Support Group meetings. Meetings provide a supportive environment where participants can share concerns, challenges, and successes. In addition, participants can lend emotional support to one another and lessen feelings of isolation. Meetings are always free to attend, and all locations are accessible. Your involvement is important for our support groups! At a meeting you might learn about a community resource, discover a new research study, or hear from a guest speaker. Please consider joining us! For further information about any of the support groups, please contact 630.443.9876.

Cancellations may occur in the case of inclement weather. We will attempt to notify everyone with advanced notice by email. If you are concerned that a meeting may be cancelled, please call 630.443.9876 to confirm.

Illinois HDSA Chapter Virtual Support Group

3rd Tuesday of Every Month (7:00pm)

Register in advance for this meeting:

<https://hdsa-org.zoom.us/join/ztZElD-GhrTKoHNfbC63ikQa6Spu20hOfjM2E>

Questions? Contact Charlotte Rybarczyk at charlotte82963@gmail.com

MUNSTER, IN (not verified still being held, call first)

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

2022 Meetings: Contact Cindy Rogers for specific dates/format

Southside Christian Church, 1000 Broadmoor Avenue

Contact: Cindy Rogers (219-836-2369); clrogers111@comcast.net or Monica at 219-616-1393

*****IN PERSON*****

Northwestern Caregiver Support Group

Feb. 1st/April/June/August/October/Dec. (7:00pm)

**Winnetka Library, Community Room, lower level
768 Oak Street, Winnetka**

Due to library scheduling, meeting dates are set 2 months in advance. If you want to be added to the caregiver email list, please email emily.zivin@northwestern.edu

Rush University Medical Center Virtual Group

4th Saturday of Every Other Month (Mtg on Feb. 25th)

For more information and Zoom details please reach out to the following support group leader:

Devonda Chambliss, RN (312-563-2900); devonda_chambliss@rush.edu

*****IN PERSON*****

General HD Support Group

Jan/March/No Mtg in May/July/Sept/Nov.

2nd Sunday of Every Month (2:30pm)

**Logan Square Library
3030 W. Fullerton Ave., Chicago**

*****IN PERSON*** 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)**

*******IN PERSON*******

NORTHWEST INDIANA HUNTINGTON'S AWARENESS, SUPPORT & HOPE

3rd Thursday of Every Month (6:00 – 7:00pm CST)

**Methodist Hospital Southlake, 200 East 89th Avenue, Pavilion B,
1st Floor Conference Room, Merrillville, IN 46410**

Contact: Amy Turner Ladow (Mobile: 610-241-2753); nwiHDASH@gmail.com or amyturnerladow@gmail.com.

Here is the link to the NWI Facebook Meeting Event which has all the details in the body.

<https://www.facebook.com/events/1088870821982032>

Meeting Guidelines - We read the guidelines before each meeting to remind us that we are all responsible for following and committing to the group standards, which are in place to keep this group a safe place to share.

Share the airtime - Everyone who wishes to share has an opportunity to do so. No one person should monopolize the group time.

One person speaks at a time - Each person should be allowed to speak free from interruptions and side conversations.

What is said here stays here - This is the essential principle of confidentiality and MUST be respected by all participants.

Differences of opinion are OK - We are ALL entitled to our own point of view.

We are all equal - We accept cultural, linguistic, social, and racial differences and promote their acceptance.

Use "I" language - It's important to use "I" language because you are talking about yourself and not a vague person or group of people.

The use of "I" helps avoid someone feeling like they are being attacked - Examples include: "I feel like you handled that difficult situation the best that you could have" "I had good experiences with antidepressant meds in my family"

It's OK not to share - People do not have to share if they do not wish to.

It's everyone's responsibility to make the group a safe place to share We respect confidentiality, treat each other with respect and kindness, and show compassion.

 SAVE THIS DATE!

May 21st

HDSA IL Chapter Team Hope Walk – Naperville, IL

<https://hdsa.org/il>



WINTER 2023