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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.

## President's Message



Dear HD Families,

I hope all of you are having a great 2023. The Illinois board is committed to supporting the HD community and making 2023 a successful year. There are many activities planned for 2023. We are very excited to celebrate the 19th Annual Team Hope Walk at the Naperville Riverwalk on May 21. I want to thank Larry Haigh and Karen Bennett for their leadership in organizing this fantastic event that Dave and Susie Hodgson started. Please register for this event if you are planning to attend the walk. I look forward to seeing many of you at this HDSA IL hallmark event. We have other magnificent events planned for the summer and early fall. Planning is underway for the annual Baggo tournament on July 29, organized by Larry Haigh and Debbie Cyr. As a result of last year's successful horse track fundraiser, Wayne Galasek, is leading another "A Day at the Races" fundraising event at the Hawthorne Racecourse on August 20. Please stay tuned for more registration information for these events.

I'm also delighted to see the 38th Annual HDSA Convention is in full force this year from 6/1 – 6/3 in New Orleans, LA. I had the good fortune of attending last year's convention in Atlanta, GA, and I look forward to attending the convention this year. I am also pleased to hear that planning is underway for an HD education symposium on November 11, led by the Northwestern COE.

The HD Illinois Chapter members will continue supporting and serving the community to the best of their abilities in 2023. Don't hesitate to get in touch with members of the board or me if you have ideas or require any support.

I look forward to seeing you at many great 2023 summer events!

Arvind Sreedharan  
President, HDSA Illinois Chapter





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## COMPLEMENTARY AND INTEGRATIVE STRATEGIES FOR HUNTINGTON'S DISEASE SYMPTOMS

*Authored by: Sushma Kola, MD; Northwestern Medicine Movement Disorders Fellow*

Huntington's disease (HD) is a genetic neurodegenerative condition that causes a broad spectrum of movement, cognitive, and psychiatric disorders. Symptoms are progressive and can significantly impact a person's functional status, as well as their ability to interact with the world around them. Conventional treatments involve using medications to help manage symptoms. While there isn't a cure for HD, a variety of complementary and integrative therapies can be important adjuncts to optimizing quality of life.

As an essential part of integrative medicine, mind-body practices can offer relief to individuals affected by HD. These interventions focus on the interactions among the brain, mind, body, and behavior that can influence physical, emotional, cognitive, and spiritual well-being.

### Meditation

Meditation is a practice in which an individual uses a technique to train their attention, broaden awareness, and deepen concentration, with the goal of achieving mental clarity and emotional tranquility. There are many types of meditation, including mindfulness, deep breathing, guided imagery, and Tai Chi. While many people assume that the benefits of meditation are limited to relaxation and stress reduction, there is growing evidence that a meditative practice and mental discipline can physically change brain functioning. In HD, these results suggest that meditating may help enhance cognition, improve sleep, reduce anxiety, and preserve motor control. Meditation may be best for those in **early stages** of HD (pre-symptomatic or mildly symptomatic) and their care partners.

### Music & Art Therapy

Music and art therapy can help combat the loss of self-expression and communication skills that arise in HD. They can be valuable tools for individuals in **all stages** of the disease. By creating, singing, or listening to music, people's cognitive and emotional states can be heightened. Dancing to music has the added benefit of addressing abnormal movements and rigidity, while simultaneously boosting balance, strength, and gait. Art therapy enriches concentration, fine motor skills, and hand eye coordination. It can also provide the individual a sense of accomplishment. Overall, expressive therapies are great mood enhancers and foster connections with loved ones.

Mind-body medicine draws from a range of practices to help mitigate stressors and to promote favorable health practices. It is important to note that the interventions promoted in integrative medicine are not substitutes for conventional medical care and should be used along with standard medical treatment. Make sure to always tell your health care provider about new interventions you are exploring!

### Practice Some Mind-Body Strategies on Your Own

#### **Box Breathing**

1. Inhale for 4 counts
2. Hold for 4 counts
3. Exhale for 4 counts
4. Hold for 4 counts

#### **4-7-8 Breathing**

1. Inhale for 4 counts
2. Hold for 7 counts
3. Exhale for 8 counts

#### **Belly Breathing**

1. Sit or lie down with one hand over your heart and the other hand over your belly
2. Breathe in through your nose and let the air fill your belly
3. Notice how the hand on your belly moves while the hand on your heart stays still
4. As you exhale through your mouth, draw your belly button in towards your spine
5. Feel as the hand on your stomach retreats back

#### **Guided Imagery**

1. Sit or lie down in a comfortable space with minimal distractions
2. Close your eyes and take several slow, deep breathes to get into a relaxed state
3. Think of yourself in a place where you feel calm and at ease, such as your favorite vacation spot
4. Create all the details in your mind, including the sights, sounds, smells, and colors of this special place
5. Think of how you feel when you are experiencing this place
6. Relax in your scene for several minutes, taking slow, deep breaths and enjoying your "surroundings"
7. When you are ready to return to reality, count to 3 and open your eye

# MEDICAL RESEARCH CORNER

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



## **NORTHWESTERN MEDICINE HDSA CENTER OF EXCELLENCE**

### **We have been approved for the Enroll HD Study**

Enroll HD is an observational, multi-center study looking to enroll HD patients and their family members to build a large database of clinical information and biospecimens (blood samples) that will serve as a basis for future studies aimed at developing tools and biomarkers for progression and prognosis, identifying clinically relevant characteristics and establishing more precise information for drug studies. Participants will be enrolled at their routine standard of care visit and study visits will take place yearly. Participants will complete questionnaires and provide blood samples. Over 20,000 people with HD and their family members are already included in this important study.

### **GENERATION HD2 - Recruiting soon**

A Study to Evaluate the Safety, Biomarkers, and Efficacy of Tominersen Compared With Placebo in Participants With Prodromal and Early Manifest Huntington's Disease. People can take part if they have prodromal (very early subtle signs of HD) or early manifest HD and have a person who can act as a 'study companion' throughout the trial. People with HD who take part in this clinical trial will be given the clinical trial treatment Tominersen OR a placebo every 4 months for at least 16 months and will continue to receive treatment until all clinical trial participants have completed 16 months of treatment.

### **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](mailto:destiny.gomez@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 [zsabsabrown@northwestern.edu](mailto:zsabsabrown@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.

## **HDSA CENTER OF EXCELLENCE AT RUSH UNIVERSITY**

### **Unique, 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 Unique study, please reach out to Jacob Hawkins at 312-563-5563, or email [Jacob\\_Hawkins@rush.edu](mailto: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](mailto: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](mailto: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. Please contact Jacob Hawkins at 312-563-5563 or email [Jacob\\_Hawkins@rush.edu](mailto: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](mailto: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 ( $\geq 40$  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](mailto:Nicollette_L_Purcell@rush.edu)) if you, or someone you know, are interested in participating and would like additional information.



# TIME TO REGISTER

Sunday • May 21, 2023

Naperville Riverwalk Grand Pavilion  
912 Honorary Sindt Memorial Ct., Naperville, IL

**Register your team today! Start your fundraising page!**

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



You can help the Huntington's Disease Society of America find hope for HD families, and provide help to the 41,000 Americans with HD and the 200,000 who are at risk.

Register online at the URL below or the QR code to the left! **REGISTER BY APRIL 12<sup>TH</sup>** to guarantee your t-shirt. Registration to walk is \$30 for adults and \$20 for children 12 and under. Early registration is encouraged. During registration you can join a team or create a team of your own 'participant page' and begin fundraising! We hope to see you there!



SUNDAY, MAY 21, 2023  
LUNCH, LIVE DJ & FAMILY FUN!

**REGISTER YOUR TEAM TODAY!**

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

## WALK DAY SCHEDULE

9:30am	Registration
10:30am	Walk

# Save the Date



## A Day at the Races



## Hawthorne Race Course

3501 S. Laramie  
Stickney/Cicero, IL 60804

**A fun summer day of racing,  
food, games, silent auction items!**

**August 20th Sunday 1 PM**

**Proceeds Benefit the HDSA Illinois Chapter**

**Wayne Galasek, wgalasek@aol.com, 708-289-1273**

## Roche Phase II GENERATION HD2 study underway

*Roche released a community letter in early 2023, to share that their Phase II clinical trial to study the huntingtin-lowering drug, Tominersen, is now underway. In this article, we summarize the latest news about this huntingtin-lowering drug.*

*By Dr Rachel Harding February 14, 2023 Edited by Dr Leora Fox*

Roche released a community letter last month, detailing how their Phase II clinical trial to study the huntingtin-lowering drug, tominersen, is now underway. Learn more about what this means in this article and at the recent HDSA Research Webinar, with representatives from the company.

### The ups and downs of huntingtin-lowering

Tominersen is a type of drug called an ASO, which aims to lower levels of the huntingtin protein, and is delivered through spinal injections. People with Huntington's disease make an expanded form of the huntingtin protein, due to an expansion in their huntingtin gene. By reducing the amount of the expanded huntingtin protein, scientists working on these drugs hope they might slow or halt the progression of symptoms of Huntington's. Many companies are working on huntingtin-lowering using different types of drugs, including Roche, Wave, uniQure, and PTC therapeutics.



Roche scientists then spent a long time poring over all the findings from GENERATION HD1 and uncovered some trends suggesting that tominersen may have benefitted some trial participants

The path of tominersen from the research lab to this most recent clinical trial has certainly been a bumpy one. A study of tominersen which concluded in 2019 was the first to show that it was possible to lower levels of the huntingtin protein. It also appeared to be safe in people for the duration of the 3-month trial. In a subsequent Phase III trial, called GENERATION HD1, more than 800 participants were enrolled to test if tominersen might improve signs and symptoms of Huntington's. Unfortunately, GENERATION HD1 was cut short due to safety issues. We still don't fully understand the reasons for this, but participants who received the highest and most frequent dose of the drug did worse by many measures than patients who were given the placebo, the exact opposite of what we had hoped for.

Roche scientists then spent a long time poring over all the findings from GENERATION HD1 and uncovered some trends suggesting that tominersen may have benefitted some trial participants, especially those who were younger and began the trial with less prominent symptoms of HD. This type of analysis where scientists pick back through subsets of the data is called "post hoc". The original GENERATION HD1 study was not designed to answer the question of whether the drug is better for this category of Huntington's patients, but there does seem to be a potentially promising pattern. To address this question properly, Roche scientists need to run another clinical trial and this is how GENERATION HD2 came about.

### GENERATION HD2 - a fresh approach to questions about tominersen

This new trial will try to answer a few different questions about the possibility of using tominersen as a treatment for Huntington's, focusing on the safety of the drug and whether it's properly hitting its target (huntingtin).

- First, scientists will hope to answer if lower doses of tominersen are safe as a long-term treatment for this younger, less progressed subgroup of Huntington's patients. As with previous trials, lots of different measures will be taken to check for participant safety.
- Second, they will investigate if tominersen has impacts on biomarkers of Huntington's, things that can be measured in blood or spinal fluid to get a picture of brain health. This will include a protein called NfL, levels of which go up in people suffering symptoms of neurodegenerative diseases.
- Thirdly, they will assess how well the drug is hitting its target in this more focused patient group. This will include a measure of the huntingtin protein itself, which we expect to be lowered, as we have seen in previous tominersen studies.

- Lastly, they'll also look at how tominersen affects peoples' thinking, movements, and behaviour.

Everyone recruited into this trial will be randomly assigned to one of three groups, where they will either receive a low 60 mg dose of tominersen, a higher 100 mg dose of tominersen, or a placebo dose. Both doses are lower than the 120 mg tested in GENERATION HD1. As per previous tominersen trials the drug will be given by spinal tap, but in this trial, everyone will receive their dose every 4 months for a total of 16 months of treatment and monitoring. Data collected will be assessed approximately every 4 months by an independent data monitoring committee (iDMC) which will monitor the trial safety and look at the clinical and biomarker data to see how things are progressing. This is confidential, unless there are serious issues, and completely independent of Roche's own analysis of the data which will happen when the trial ends.

#### **Who will be enrolled into this new trial?**

This new trial will last 16 months, and approximately 360 participants will be enrolled. To follow up on their post hoc analysis from GENERATION HD1, this study will be enrolling participants aged 25-50 years old who have only the very early signs of Huntington's. You may have read the terms "prodromal" or "early manifest," which is the science-y way doctors and researchers refer to people with Huntington's right around the time that movement symptoms appear.

The study will take place across 4 continents with sites in 15 countries spread across North America, Europe, South America and Oceania. Precise information about the sites will become available once they are each approved and will be posted on clinical trial directories such as [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (global) and [www.hdtrialfinder.org](http://www.hdtrialfinder.org) (North America), but sites are expected in Argentina, Austria, Australia, Canada, Denmark, France, Germany, Italy, New Zealand, Poland, Portugal, Spain, Switzerland, UK and the USA. Each site may have slightly different rules about participant recruitment i.e., how close to the site you need to live to be considered for enrollment, and not all of the sites from previous tominersen trials will participate in the GENERATION HD2 trial. Keep in mind that most clinical trials recruit through strong relationships between doctors and patients.

Those individuals who were previously in a trial testing tominersen would only be eligible for enrollment in GENERATION HD2 if they had received the placebo dose. Roche stated that their decision to exclude individuals who previously received tominersen was not made lightly and was made "following extensive consultation with HD experts and community leaders." This news, and the narrower age range for eligibility, may be very disappointing for some. But Roche is committed to answering important safety questions about tominersen, based on previous data. Although this trial will focus on younger people with less advanced HD symptoms, Roche emphasized that they have not forgotten the complete range of patients which comprise the HD community, nor the commitment of previous participants, and there may be other opportunities for these folks in future.

#### **How can I learn more about GENERATION HD2?**

Roche participated in an HDSA Research Webinar last week where more of the specifics of the trial were discussed, including the precise criteria for participant enrollment and members of the Huntington's community put their own questions directly to the scientists at Roche. You can rewatch this webinar [here](#) until early April, 2023. Stay tuned on HDBuzz for more news as things progress.



**Information and  
Registration at:  
[www.HDSA.org/Convention](http://www.HDSA.org/Convention)**

**Join us June 1-3, 2023 in New Orleans, Louisiana for  
the 38th Annual HDSA Convention!**



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/joinMeeting/register/tZEld-GhrTkoHNfbC63ikQa6Spu2OhOfjM2E>

**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); cdrogers111@comcast.net  
or Monica at 219-616-1393**

### **\*\*\*IN PERSON\*\*\***

#### **Northwestern Caregiver Support Group**

**April 12<sup>th</sup>/June 21<sup>st</sup>/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](mailto:emily.zivin@northwestern.edu)

### **Rush University Medical Center Virtual Group**

**4<sup>th</sup> 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](mailto:devonda_chambliss@rush.edu)**

### **\*\*\*IN PERSON\*\*\***

#### **Northwestern General HD Support Group**

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

**2<sup>nd</sup> 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](mailto: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 89<sup>th</sup> Avenue, Pavilion B,  
1<sup>st</sup> Floor Conference Room, Merrillville, IN 46410**

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



May 21st	HDSA IL Chapter Team Hope Walk – Naperville, IL
June 1-3 <sup>rd</sup>	HDSA National Convention – New Orleans
July 29 <sup>th</sup>	HDSA IL Chapter Baggo Tournament
August 26 <sup>th</sup>	HDSA IL Chapter Day at the Races for HD
November 11 <sup>th</sup>	Northwestern Medicine HD Patient & Family Symposium
December 3 <sup>rd</sup>	HDSA Celebration of Hope Brunch

**<https://hdsa.org/il>**



**SPRING 2023**