Hopes and Dreams

Huntington's Disease Society of America - Illinois Chapter Quarterly Newsletter

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President's Message

Dear HD Families,
I hope all of you are having a great summer. The Illinois Board continues to make strides to make 2023 a successful year. I want to begin by recognizing Larry Haigh and Karen Bennet for their efforts in making the 19th Annual Team Hope Walk at the Naperville Riverwalk on May 21 a huge success. We had over 350 attendees and many members of the IL. board at this hallmark event on a beautiful summer afternoon in Naperville. We have two more events planned this summer. First is the annual Baggo tournament on July 29, which Larry Haigh and Debbie Cyr organized. For more information, please get in touch with Larry Haigh at larryhaigh@gmail.com. In addition, we have "A Day at the Races" fundraising event at the Hawthorne Racecourse on August 20. For more information, please get in touch with Wayne Galasek at 708-289-1273 OR wgalasek@aol.com. Finally, we have an HD education symposium on November 11, led by the Northwestern COE. For more questions, please get in touch with Emily Zivin at emily.zivin@northwestern.edu
I had the great opportunity with several board members to attend th e 38th Annual HDSA Convention in full force this year from 6/1 – 6/3 in New Orleans, LA. It was fantastic to meet new HD families from IL and other states. The event was extremely well attended, and I'm looking forward to next year's HDSA Convention in Spokane, Washington.

I am pleased to introduce our new Illinois Chapter Social Worker, Erica Bohac. Erica is an experienced social worker who years of experience supporting family members and caregivers of patients with neurological diseases. We are very fortunate to have Erica supporting HD families in Illinois. Please see page 6 of this newsletter for more information about Erica's background and contact information.

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 or me if you have ideas or require any support.

I look forward to seeing you at many future 2023 HD events!

Arvind Sreedharan
President, HDSA Illinois Chapter

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SWALLOWING PROBLEMS IN HUNTINGTON'S DISEASE

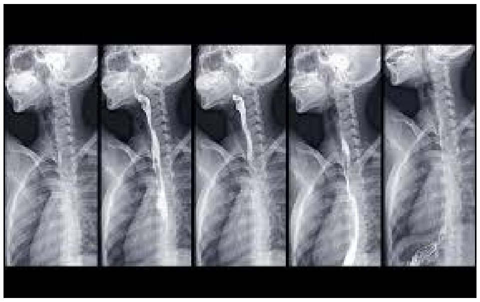
What Type of Swallow Problems Occur in HD?

In our Huntington disease program, we get frequent questions and phone calls from patients who are experiencing problems with their swallowing. Swallowing issues can occur at any time in the illness and a number of different symptoms might be noticed by the patient. The following are examples of the types of symptoms patients will report:

- *A sensation that food is caught in the throat.*
- *Coughing or choking during eating which indicates food is going into the airway*
- *Taking too big of a bite of food or drink of liquid leading to coughing or choking*
- *Difficulty swallowing pills and drooling*
- *Holding food in the mouth and having problems initiating a swallow*
- *Uncoordinated swallowing when breathing*
- *Incomplete swallows – where food remains in the mouth or throat*
- *Excessive belching or burping*
- *Rapid, uncontrolled swallowing*

How Do We Evaluate Swallowing Problems in HD?

When patients describe these or related symptoms in the clinic, we will frequently give the patient a prescription to see a speech-language pathologist, who is a provider who specializes in speech and swallowing disorders. Many of the speech-language pathologists may not be familiar with HD, but the types of problems experienced in HD can be seen in many other disorders. There are three types of swallowing assessments:



1. ***Clinical swallow assessment:*** The speech-language pathologist will first observe the patient swallowing and recommend strategies to reduce coughing or choking (see below). The patient may be referred for one of the following tests if needed.
2. ***Modified Barium Swallow:*** In this test, patients are asked to swallow different consistencies of barium, a chalky drink that can been seen on an X-ray as it passes from the mouth to the stomach. This test can help the speech-language pathologist identify where the problem is located.
3. ***Fiberoptic Endoscopic Examination of Swallowing:*** The provider will view the airway through a scope with a lens on the end and allows the provider to see the inside of the throat and mouth.

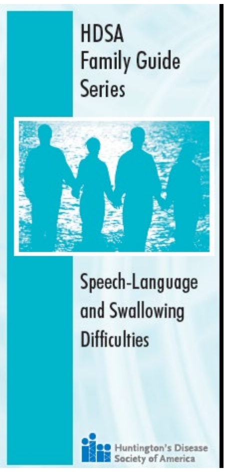
How Can I Manage My Swallowing Problems?

There are several strategies that can be used to manage swallowing difficulties in HD. Your speech-language pathologist can create an individual program for each patient. The following are general tips and techniques that can improve eating, chewing and swallowing.

- Always sit upright when eating, drinking and taking pills. Sitting upright for 30-60 minutes after eating is also recommended.
- Chew small amounts of food and swallow it all before eating more.
- Put your fork down between bites to slow yourself down.
- If food feels stuck, swallow multiple times after every bite.
- Take small sips when drinking and do not tip your head back when drinking.
- Be careful with straws and water bottles. Straws should be kept at the front of the tongue when sipping. Water bottles with a small, removable cap are preferred (without a valve-type nozzle) and you should keep your chin slightly down and parallel to the table when drinking.

- Focus on eating and do not talk with food in your mouth.
- Minimize distractions during meals.
- Eat several smaller meals during the day rather than three large meals.
- Use your tongue to clear any food in your mouth prior to the next bite.
- Have supervision when you eat.

In some cases, speech-language pathologists will ask the patient to change their diet by using a thickener or avoiding certain foods.   In summary, swallowing issues are common in patients with HD and can occur throughout the illness. Speak with your provider about next steps for evaluation or tips for your individual symptoms. HDSA also has excellent resources for patients that can be ordered from the HDSA website.



HDSA
Family Guide
Series

Speech-Language
and Swallowing
Difficulties

Huntington's Disease
Society of America

SCAN ME

On Saturday, July 29th we will have the Illinois HDSA Baggo Tournament in Chebanse, IL. The event will be a friendly competition while spending time together, and spreading awareness about HD. In preparation for this event, we are able to gain the support of many donors and sponsors. We cannot thank our donors and sponsors enough for their generosity and support. There is still time to become a donor and sponsor. Please reach out to Larry Haigh if you have any questions.

The Baggo Tournament will begin at 1:00pm. (Check in and registration will begin at 12:30pm). There are a lot of opportunities that day to support HD. Reach out if you are interested in being a sponsor. You can be a team of 2 or a spectator. There will be 50/50 raffle opportunities. Visit the website (https://illinois.hdsa.org/baggo) for more information and to register. We hope to see you there!

Tournament Location
at the home of Russell & Dawn Haigh, 3751 West 8000 South Road, Chebanse, Illinois

$60/team ~ $20/spectator
(Vienna hot dogs, beef sandwiches and lemonade included)

Winning team receives $100! Other prizes available.
Your donation is 100% tax deductible.

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 – Now Recruiting

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.

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 Valbenizine 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.

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

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. 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.

Please welcome our new Illinois Chapter Social Worker, Erica Bohac!

Erica is a Nebraska native who received a bachelor's degree in Dance from the University of Iowa in 2012. After two years of teaching, coaching, and choreographing dance, Erica relocated to Chicago to pursue a master's degree in Social Work from Loyola University Chicago, graduating in December of 2015 with a specialization in health and mental health. Erica completed her first-level practicum as a client services intern at the Chicago Women's AIDS Project and her second-level practicum as a social services intern at Warren Barr Gold Coast, a Chicago post-hospital facility for rehabilitation. In August of 2015, Erica was asked to join Warren Barr's social work team as a full-time social worker, and subsequently worked as the Director of Social Work and Assistant Administrator at the facility.

In October of 2017, Erica joined Renewal Care Partners as a Director of Care Management, a home services organization serving adults with conditions like Alzheimer's disease, Parkinson's disease, Frontotemporal Dementia and other neurocognitive conditions. In this role, Erica became committed to working beyond the goals of clinical and medical care to help clients lead lives rich in connection, purpose, and meaning, while also supporting family members, caregivers, and other loved ones.

In February 2022, Erica joined Loyola University Medical Center as a Kidney Transplant Social Worker. Working with individuals with chronic and end-stage kidney disease, Erica evaluates patients for transplant candidacy and assists in eliminating or minimizing psychosocial barriers to a successful transplant course. This work involves supporting patients as well as caregivers and collaborating with community professionals to provide as much support as possible as they navigate life with a chronic illness and prepare for a potentially life-altering surgery.

In addition to social work, Erica is certified to teach group fitness through the Athletics and Fitness Association of America. When she isn't working or at the gym, you can find her reading a book next to her rescue dog Watson, planning her next travel adventure, or playing competitive bocce ball. Please feel free to contact Erica at ebohac@hdsa.org.

Day at the Races for HD!

Join your HD family, friends and supporters for a wonderful afternoon of exciting thoroughbred racing at ***Hawthorne Racecourse*** in Cicero, IL, on ***Sunday, August 20th***, from 1:00 – 6:00pm. Hawthorne is the oldest continually run family-owned racetrack in America and the last operating horse track in Illinois, offering both harness and thoroughbred racing seasons. Currently, they are also building the first "racino" in Illinois, combining both racing and casino operations - expected to open in 2024.

Our day will include a full racing card, direct access to the track, private event space, games, prizes, silent auction items and more. Guests of all ages are invited, and children will especially love to see the horses race by almost within touching distance! Easy to find, centrally located, plenty of free parking, food vouchers, roving track experts to help us learn the language of betting and more.

You can participate via attendance, direct donations/corporate gifts, by donating auction items - or all three! All proceeds go to supporting HDSA, the Illinois Chapter, public outreach and research for a cure. Use the QR code on the flyer or go to https://Illinois.HDSA.org/races for registration.

Hope to see you there!

Huntington's Disease Society of America

ILLINOIS CHAPTER

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

illinois.hdsa.org/races

SCAN ME

HDSA AND RARE-X LAUNCH HD DATA COLLECTION INITIATIVE TO ACCELERATE TREATMENTS FOR HUNTINGTON'S DISEASE

Contact:
Mynelly Perez - HDSA/Marketing & Communications - mperez@hdsa.org /212-242-1968
Lauren Alford - Global Genes/RARE-X Marketing Communications - lauren.alford@globalgenes.org / 919-616-7532

New York, NY (May 17, 2023) — The Huntington's Disease Society of America (HDSA) and RARE-X, the Global Genes patient-driven data collection platform, today announced a collaboration to establish a high-quality natural history study to accelerate knowledge development through effective patient-owned data collection, data connection and community pooling of data. The Huntington's Disease Data Collection Initiative (HD-DCI) will enable people with HD to better share their data to accelerate the development of treatments for HD.

With an estimated 41,000 people diagnosed with HD in the United States, it is difficult to gather longitudinal patient data and clinical natural history data for Huntington's disease. This information is critical for patients and their doctors to understand their diseases better, support researcher and biopharma investment in HD, and help determine meaningful clinical endpoints. This collaboration will help break down data silos to make rich natural history data accessible to the research and clinical science communities.

"The days where physicians were the sole keepers of medical insights are coming to an end," said Louise Vetter, President & CEO of HDSA. "For healthcare to achieve its potential, people with HD must be welcomed as true partners, contributing their personal health data and conducting self-assessments using validated online tools to fill in the gaps and create a dataset that truly captures the natural history of HD. The collaboration with RARE-X will help provide vital insights of patients and their caregivers to fill gaps in our understanding of HD and complement clinician-reported datasets."

Together with RARE-X, HDSA will develop and deploy innovative patient-centered models to accelerate research programs and clinical development. This will include a novel structure for engaging "pre-symptomatic" and at-risk individuals with built-in mechanisms to screen for emerging disease symptoms. Importantly, they will establish a novel Care Partner portal that will allow caregivers to provide vital insights to complement the person with HD's lived experiences.

"Patient-reported data is critical to rare disease innovation," said Charlene Son Rigby, CEO of the nonprofit rare disease patient advocacy organization Global Genes, which operates the RARE-X patient data sharing platform. "As rare patient communities like Huntington's disease gather and share their data with collaborating researchers, clinicians, and companies around the globe, they will accelerate diagnosis, disease understanding, and development of future treatments and cures for people with Huntington's disease and may also shed light on other conditions as well."

HDSA and RARE-X recognize the many data gaps that exist in rare disease research and understand the importance of data sharing and data interoperability for researchers. RARE-X offers an automated and structured platform to support standardized data collection while enabling patient communities with proper governance, consent, and technology that can support a data ecosystem built for discovery.

"The creation of a patient-led, virtual data collection initiative addresses some of the persistent inequities in healthcare research. This partnership with RARE-X allows people who can't travel to the sites where most research and clinical trials occur to engage in a large-scale natural history study from their own home," said Dr. Arik Johnson, Chief Mission Officer at HDSA. "The HD-DCI will empower people living with HD to become true partners in research, owning their data and sharing their HD experiences as they chose."

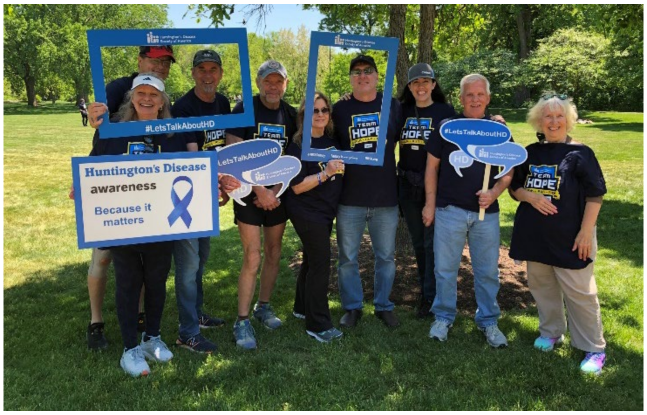
Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities during their prime working years and has no cure. Every child of a parent with HD has a 50/50 chance of carrying the faulty gene. Today, there are approximately 41,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

The symptoms of HD are described as having ALS, Parkinson's & Alzheimer's – *simultaneously*.

Recap of 19th Annual Team Hope Walk in Naperville

Sunday, May 21st brough the 19th Team Hope Walk in Naperville. The committee worked very hard to put on this event. It brought us great joy to see over 400 participants in Naperville to walk and spread awareness of HD. We had a beautiful day, and a great turn out of supporters. It was great getting to catch up with old friends and meet some new friends too. **We would like to thank our sponsors of the 2023 Walk: Calabria Imports, Flood Brothers, and Raimonde Drilling Corporation.** We appreciate our two Centers of Excellence stopping by and having a space to meet with our community. Thank you, Northwestern and Rush, for of your support. We cannot thank everyone enough for their donation and support in this Team Hope Walk event! Mark your calendars for the **20th** Team Hope Walk in Naperville… Sunday, May 19, 2024! The committee is already brainstorming ideas to celebrate Illinois HDSA walking for 20 years! Looking forward to seeing you then if not before! Thank you again for all your continued support

Some of the HDSA Illinois Chapter Board Members: Back left to right: Larry Haigh and Andy Hucker.
Front left to right: Arvind Sreedharan, Miha Ugarcovici, Jenny Placek, Mary Bos, Karen Bennett, Charlotte Rybarczyk, Debbie Cyr, Wayne Galasek and Taryn Reneau.


#LetsTalkAboutHD
Huntington's Disease
awareness
Because it matters
#LetsTalkAboutHD
#LetsTalkAboutHD


TEAM PAXSON


TEAM HOPE
WALK · RUN · RIDE


TEAM HOPE

SUPPORT groups

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/meeting/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); clrogers111@comcast.net or Monica at 219-616-1393

IN PERSON
Northwestern Caregiver Support Group

April 12th/June 21st/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
Northwestern General HD Support Group

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.
Its 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!

July 29th	HDSA IL Chapter Baggo Tournament
August 26th	HDSA IL Chapter Day at the Races for HD
November 11th	Northwestern Medicine HD Patient & Family Symposium
December 3rd	HDSA Celebration of Hope Brunch

https://hdsa.org/il

SUMMER 2023