

Summer 2024



Illinois Chapter HDSA 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 2024 a successful year. I want to begin by recognizing Larry Haigh and Karen Bennet for their efforts in making the 20th Annual Team Hope Walk at the Naperville Riverwalk on May 19 a huge success. We had over 400 attendees and many members of the IL. board at this hallmark event on a beautiful summer afternoon in Naperville. I'm excited to share that four more events are planned this summer and fall. First is the Illinois Baggo tournament on July 27, organized by Larry Haigh and Debbie. For more information, please contact Larry Haigh at larryhaigh@gmail.com. In addition, we have "A Day at the Races" fundraising event at the Hawthorne Race Course on August 25. Last year's event was a huge success, and we look forward to another successful event this summer. For more information, please contact Wayne Galasek at 708-289-1273 OR wgalasek@aol.com. We are also fortunate to have IL Chapter HDSA night with the Chicago White Sox on 8/31 at Guaranteed Rate Field. For more information, please contact Larry Haigh at larryhaigh@gmail.com. Finally, we have a 2024 Team Hope Walk in Central Illinois, organized by Sara Cozad on 9/21. For more information, please get in touch with Sarah Cozad at cozinn.sc@gmail.com

The HD Illinois Chapter members will continue supporting and serving the community to the best of their abilities in 2024. 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 2024 HD events!

Arvind Sreedharan
President, HDSA Illinois Chapter

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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.

Socialize with the Illinois HDSA Chapter Social Worker

A Weekend Out West: HDSA 2024 Convention

Erica Bohac, LSW

Illinois HDSA Chapter Social Worker

Tel: 630-443-9876 or E-mail: ebohac@hdsa.org



Most of you probably don't know, my very first task as the Illinois Chapter Social Worker for HDSA was to attend the 38th Annual Convention in New Orleans, LA. I love learning, travel, and a good oyster, and I was ready to jump in headfirst, so I was all in. HD was brand new for me so I spent last year networking with other social workers and feverishly taking notes in every education session I could attend. One of our Illinois HD family members said when I met him in NOLA, "This must be like drinking from a firehose for you!" And it was! But I also can't think of a more comprehensive training or better way to start working with this community.

This year, the 39th Annual Convention was located in Spokane, WA. I still networked with my fantastic colleagues from HDSA Chapters and Centers of Excellence throughout the country. I still have a tremendous amount to learn, so I was still pretty feverishly taking notes. But I made it my goal to spend more time connecting. Really listening to the stories of individuals and families, both in one-on-one conversation and in panel discussions. Hearing folks' lived experiences - the challenges, the triumphs, and everything in between. Last year, I left convention feeling inspired by information. This year, I left feeling inspired by connection. And don't even get me started on the NYA Talent Show... There wasn't a dry eye in the house.

If you haven't been (or even if you have), I hope you'll consider joining me at a future convention. (Next year will be a little closer to Illinois... Indianapolis, Indiana June 26-28, 2025!) If you have questions about my experience or HDSA's support options to help folks attend, please let me know. And whether it's at convention or elsewhere, I look forward to connecting and learning with you!

If I can be of assistance, or if you have a new idea, please reach out via phone (630.443.9876) or email (ebohac@hdsa.org). I'm looking forward to meeting or hearing from you soon!

HDSA Center of Excellence Doctor's Corner



Danny Bega, MD

Northwestern Medicine, Neurology, HDSA Center of Excellence

The following has been provided by Juan R Deliz, MD a Fellow at Northwestern University HD Clinic.

The New Huntington's Disease Integrated Staging System (HD-ISS): A Framework to Advance Clinical Research

By: Juan R Deliz, MD (Fellow, Northwestern University HD Clinic)

For many years, the research paradigm for Huntington's disease (HD) predominantly focused on identifying people who had already developed the hallmark symptoms of the disease (such as chorea for example), rather than focusing on earlier biological changes that precede symptom onset. The clinical definition of HD predates the breakthrough discovery of huntingtin, the gene whose mutation is responsible for causing the disease. However, identifying people before symptoms begin may represent a unique opportunity to prevent or delay onset of symptoms. To address this gap, researchers (led by Dr Sarah Tabrizi in London) recently developed a new staging system for HD, called the Huntington's Disease Integrated Staging System (HD-ISS). This system allows researchers to classify people with HD at different points in their disease course – and for the purposes of research, this staging starts before any symptoms even begin, and go until the later stages when functional impairment occurs.

New Stages of the HD-ISS:

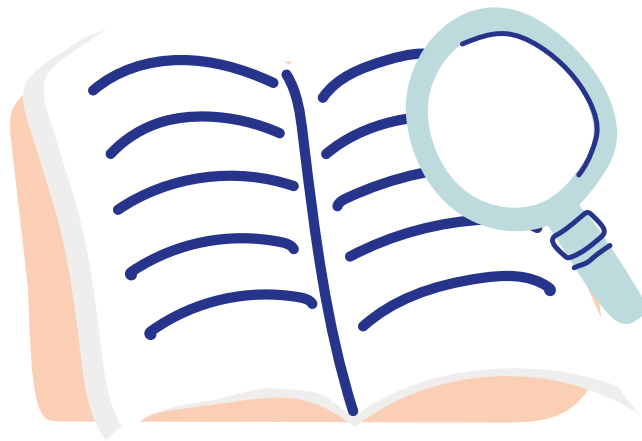
- **Stage 0:** This stage encompasses individuals with the HD mutation. However, there are no detectable signs of the disease at this point.
- **Stage 1 (Biomarkers):** This stage signifies the initial progression beyond genetics alone. Here, there are measurable indicators of underlying brain changes, such as shrinking in specific brain regions evident by brain imaging used for research. These changes typically occur well before any clinical symptoms appear.
- **Stage 2 (Clinical Signs or Symptoms):** This stage marks the emergence of recognizable clinical signs of HD, including movement, cognitive or psychiatric symptoms. This can include exceeding specific thresholds on assessments such as the Total Motor Score or the Symbol Digit Modalities Test, indicating motor or cognitive decline.
- **Stage 3 (Functional Decline):** This stage represents symptoms that are not just noticeable but lead to decline in a person's functional abilities. Daily activities become increasingly challenging as the disease progresses.

The New Huntington’s Disease Integrated Staging System (HD-ISS): A Framework to Advance Clinical Research Continued...

As you may notice, the HD-ISS provides a standardized framework for classifying individuals with HD across the entire disease spectrum and generally aligns with the natural course of the disease. Classification within Stages 1-3 is achieved through objective assessments (including imaging, spinal fluid analysis, examination, or questionnaires). Transitions between stages follows with disease progression over time. It is important to remember that the HD-ISS is primarily research staging system. An individual with very mild symptoms that are not impacting their life would already be classified as Stage 2. This is simply a fact stemming from stages 0 and 1 being “pre-symptom” stages, regardless of the severity of the individual’s symptoms.

The HD-ISS holds immense potential for clinical research for several reasons. First, it allows researchers to study new potential treatments at earlier stages, and we hope this will translate to more success in trials aimed at preventing or slowing down disease. Second, by creating a common language for classifying patients, the HD-ISS allows for standardization across HD trials. Additionally, while prior systems only focused on clinical aspects of disease progression, this system offers a more comprehensive understanding of Huntington's disease progression, encompassing biological, clinical, and functional aspects. Overall, the HD-ISS represents a significant advancement in Huntington's disease research, paving the way for more targeted therapies and improved clinical trials.

A special thanks to Juan R Deliz, MD (Fellow, Northwestern University HD Clinic) for providing this update.



THANK YOU!!



Without you we would not have been able to make the 20th Illinois Chapter Team Hope Walk a success!

We cannot thank you enough!

We look forward to seeing you at other events this year!

Stay tuned as we have exciting events and announcements to come!

In the meantime mark your calendars for May 18th, 2025 as we look forward to seeing you at the 21st Team Hope Walk!



We cannot thank you all enough for your support and generosity to the 20th Illinois HDSA Chapter Team Hope Walk in Naperville!

If you were unable to attend and would still like to support the walk you may do so by using the QR code.

We would like to thank our sponsors again, Calabria Imports Restaurant/Deli, Floods Royal Flush, Arlington Construction Services, and Raimonde Drilling Corporation.

We hope to see you at our other events through the rest of the year! We have a lot of opportunities to spread HD Awareness and gather as a family!





Clinical Research Updates at Northwestern:

Enroll HD Study - Now Recruiting

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 HD 2 - 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. For more information on Generation HD2 contact Zsa Zsa Brown at 312-503-4121 or zsabsabrown@northwestern.edu

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.

Save the Date:

**Northwestern Medicine Patient and Family
Huntington's Disease Symposium 2024**

Saturday, November 16th, 2024

10am-2pm

To Register Call: 877-926-4664

Clinical Research Updates at Rush Medical Center:

Enroll HD Study

The Enroll HD study is currently enrolling at Rush University Medical Center. This multi-center, observational study aims to collect clinical information and biospecimens from patients with Huntington's Disease to enhance the understanding of HD, develop future treatments, and improve clinical care. Over 20,000 people are currently participating in this study. Enroll HD is open to anyone who has HD or is at risk. Participants can enroll anytime, or at the time of a routine clinic visit. Follow up visits will occur annually. For more information or to enroll, contact Nathan Krinickas at 312-563-4771 or nathan_krinickas@rush.edu.

UniQure (AMT-130) Clinical Trial

The UniQure clinical trial is a double-blind investigational gene therapy study aimed to test the safety, tolerability, and efficacy of AMT-130. AMT-130 is an investigational compound that may lower the amount of abnormal huntingtin protein and slow the progression of HD. This compound is administered directly into the brain during a one-time neurosurgical procedure. People who have early manifest HD and have a reliable study partner may be eligible to participate. Your participation in this study may last up to 5 years. Rush University Medical Center is not currently enrolling patients, but recruitment is expected to start in the coming months. For more information, contact Tyler Svymbersky at 312-563-0676 or tyler_svymbersky@rush.edu.

Sage-HD Clinical Trial

The first Sage-HD Clinical Trials have wrapped up, but a new extension study will be enrolling soon at Rush University Medical Center. This study will be a Phase 3, Open-Label safety study to evaluate Sage-718 in patients with Huntington's Disease. SAGE-718 is a capsule taken by mouth once-a-day that may improve memory, thinking, learning, and decision-making in patients who are experiencing mild cognitive impairment or dementia. People who are experiencing difficulty with thinking, memory, learning, or decision making but have no difficulty with day-to-day function may be eligible to participate. Your participation in this study may last up to 365 days (52 weeks). For more information or to enroll, contact Tyler Svymbersky at 312-563-0676 or tyler_svymbersky@rush.edu.

Rush Movement Disorders Repository

The Rush Movement Disorders Repository is a clinical and research collaboration collecting video recordings and DNA samples via blood collection. Videos and DNA samples taken may be used in future research studies or in the training of future healthcare professionals and movement disorder specialists. One in-person study visit is required for participation. For more information or to enroll, contact Vijay Palakuzhy at vijay_g_palakuzhy@rush.edu.



Save The Date!



**Saturday, July 27th
Chebanse, IL 60922**

Register: <https://illinois.hdsa.org/events/2024-il-baggo-tournament>

**More details to come.
Contact Larry Haigh for more information:
larryhaigh@gmail.com**



A family friendly summer day of racing, food, games, silent auction and raffles, and more!

Children 18 & Under Attend FREE-

Please consider purchasing a food voucher for your child(ren) if needed.

AND FREE PARKING!

**Contact: Wayne Galasek
708-289-1273 OR wgalasek@aol.com**





Illinois Chapter HDSA Night with the Chicago White Sox

A night of baseball fun and HD awareness!

Saturday, August 31st at 6:10pm
at Guaranteed Rate Field

Mets vs. White Sox

A portion of all ticket sales will be given to Illinois HDSA, but you must use the link provided to purchase your ticket.

<https://fevo-enterprise.com/event/Huntingtonsdisease>

Questions? Contact: Illinois HDSA-Larry Haigh- larryhaigh@gmail.com



Illinois and Missouri HDSA Chapters Day with the St. Louis Cardinals

A day of baseball fun and HD awareness!

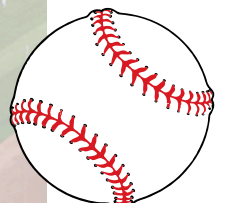
Sunday, September 8th at 1:15pm
at Busch Stadium

Mariners vs. Cardinals

A portion of all ticket sales will be given to the Illinois and Missouri HDSA Chapters, but you must use the link provided to purchase your ticket.

<https://www.mlb.com/cardinals/tickets/specials/huntingtons-disease>

Questions? Contact: Illinois HDSA-Larry Haigh- larryhaigh@gmail.com





CENTRAL IL



APPROXIMATELY 10% OF HD CASES AFFECTS CHILDREN & PROGRESS MORE RAPIDLY THAN ADULT ONSET HD
THERE IS CURRENTLY NO CURE

National Team Hope Sponsors
teva **NEUROCRINE** BIOSCIENCES
Regional Team Hope Sponsors

SATURDAY, SEPTEMBER 21, 2024

uniQure



LAKE STOREY
1572 Machen Drive
Galesburg, IL 61401

SARAH COZAD
EMAIL: COZINN.SC@GMAIL.COM
PHONE: 309-299-0284

TEAM HOPE WALK ENTRY FEE - \$30

CHECK-IN - 10:00AM

START TIME - 10:30AM

WWW.HDSA.ORG/THWCENTRALIL



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)

This meeting is being transitioned to RingCentral instead of Zoom. If you could like to be added to the support group email invitation, please reach out to Erica Bohac (ebohac@hdsa.org).

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

2nd Tuesday of Even Months (7:00 – 8:30pm) 2024 Meetings:
 Contact Cindy Rogers for specific dates/format
 Southside Christian Church, 1000 Broadmoor Avenue Contact:
 Cindy Rogers (219-836-2369); clogers111@comcast.net or
 Monica at 219-616-1393

*****IN PERSON*** @ 7:00pm Northwestern Caregiver Support Group**

February/April/June/August/October/December
 Winnetka Library, Community Room, lower level
 768 Oak Street, Winnetka
 Email emily.zivin@northwestern.edu for more information

Rush University Medical Center Virtual Group

4th Saturday of Every Other Month
 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

Northwestern General HD Support Group

Virtual via Zoom
 2nd Wednesday of the month at 7:00pm
 January / March / May / July / September / November
 For meeting link, please email emily.zivin@northwestern.edu

*****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.

**PO Box 453
Northbrook, IL 60065**

Stay Connected

Website:

www.illinois.hdsa.org



**Like Us on Facebook:
HDSA Illinois Chapter**

X (Formally Twitter):

@HDSA_Illinois

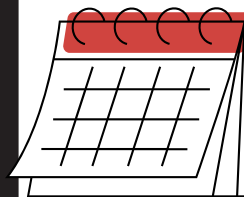
Email:

illinois@hdsavolunteer.org



Mail:

**PO Box 453
Northbrook, IL 60065**



*Mark Your
Calendar!*

July 27th-

Illinois Chapter Baggo, Chebanse

August 25th-

*Day at the Races for HD,
Hawthorne Race Course*

August 31st-

HD Day with Chicago White Sox

September 8th-

HD Day with St. Louis Cardinals

September 21st-

*Central Illinois Team Hope Walk,
Galesburg*