

Spring 2024



### Illinois Chapter HDSA President's Message

Dear HD Families,  
I hope all of you are having a great 2024. The Illinois board is committed to supporting the HD community and making 2024 a successful year. There are many activities planned for 2024. We are very excited to celebrate the 20th Annual Team Hope Walk at the Naperville Riverwalk on May 19. I want to thank Larry Haigh and Karen Bennett for their leadership in organizing this fantastic event. 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, which will be extremely special, celebrating 20 years of great efforts to raise awareness for HD.

We have other magnificent events planned for the summer and early fall. Planning is underway for the annual Baggo tournament in the summer, organized by Larry Haigh and Debbie Cyr. Wayne Galasek is leading another "A Day at the Races" fundraising event at the Hawthorne Race Course on August 25. Please stay tuned for more registration information for these events. We continue to explore opportunities for future fundraising activities and potential education days in 2024.

I'm also delighted to see the 39th Annual HDSA Convention is in full force this year from 5/30 - 6/1 in Spokane, Washington.

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 great 2024 summer events!

Arvind Sreedharan  
President, HDSA Illinois Chapter

### Chapter Officers

**PRESIDENT – Arvind Sreedharan-**  
avs2004@comcast.net

**VICE PRESIDENT – Larry Haigh-**  
larryhaigh@gmail.com

**TREASURER – Miha Ugarcovici-**  
mih101@yahoo.com

**SECRETARY – Debbie Cyr-**  
dcyr0374@gmail.com

### Board Members

**Karen Bennett –** karben22@hotmail.com

**Kathy Chastain –** katzcorner@hotmail.com

**Sarah Cozad –** cozinn.sc@gmail.com

**Wayne Galasek -**wgalasek@aol.com

**Andy Hucker -** ahucker1549@comcast.net

**Debbie McGee -** debimcgee3@gmail.com

**Lillie Paxson -** lillie789@yahoo.com

**Taryn Reneau –** tarynReneau@aol.com

(Social Media)

### Other Chapter Members

**Erica Bohac – Chapter Social Worker**  
ebohac@hdsa.org

**Camille Colletti – Regional Director**  
847-849-0680 ccolletti@hdsa.org

Hopes & Dreams  
is the official publication of the  
Illinois Chapter of Huntington's Disease Society of America, Inc.,  
P.O. Box 453, Northbrook, IL 60065  
(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.

# Socialize with the Illinois HDSA Chapter Social Worker



## What Does the Chapter Social Worker Do, Anyway?

**Erica Bohac, LSW**

*Illinois HDSA Chapter Social Worker*

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

So, I'm the Illinois Chapter Social Worker for HDSA... What does that mean? What is my role and how might it be different from other social workers or members of your HD team?

Often as a social worker, I feel like I wear a lot of hats - in a good way! Social workers are trained to understand individual behaviors and needs, family dynamics and stress, and how to connect people to crucial resources and information in their environment. The goal in having social workers specifically trained in HD is that we can provide all of this support with a focus on and expertise in the unique context of HD.

So what can I help with?

- Individual troubleshooting, support, and brainstorming, via phone, virtual platforms, or in-person (including in-home visits)
- Facilitate in-services and trainings to the staff of nursing facilities, caregiving agencies, or assisted living communities; continue to serve as a resource and support for the staff caring for someone with HD
- Connection to HDSA resources, including support groups, disability experts, research opportunities, and genetic testing
- Information about community resources, including day programs, in-home care, or medical equipment
- Other community training - for first responders, mental health counselors, primary care providers, etc.
- Coordinating education events for persons with HD and their families / support systems, especially for those who may not be connected with a Center of Excellence
- Facilitate support groups virtually or in-person (or connect you to another support group that better fits your schedule or unique needs)
- Help make connections with Centers of Excellence or facilitating communication with your care teams there
- ...and more!

As I've spent a bit more time in this role, I'm learning along with you how I can best serve individuals and families in the HD community in Illinois. What I'm finding is that we have the freedom and ability to work together to determine what that looks like! If there's something you think could be beneficial to you or to others in the community, get in touch! I love being creative to find the best ways to provide support.

If I can be of assistance with any of the above, 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

## Apathy in Huntington's Disease

**Deborah Hall, MD PhD**

*Rush University Medical Center, Neurology, HDSA Center of Excellence*



### What is apathy and how often does it occur?

Apathy is characterized by a lack of motivation in some or all of these three areas:

- Emotion – some patients will have “emotional indifference”
- Cognition – patients will have decreased interest and lack plans or goals
- Behavior – patients will have lack of effort, initiative and productivity.

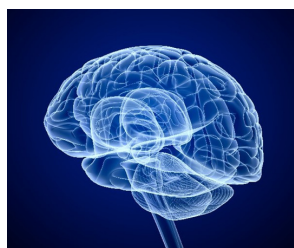
In many cases, patients usually will not complain of apathy, but may describe feeling less motivated than they used to be (when they are asked). Families may describe patients as being disengaged, withdrawn, or “depressed.”



Apathy can occur in as much as 60% of patients with Huntington's disease. **In fact, it is the most common psychiatric symptom in Huntington's disease.** Many times, it may be difficult to determine if the patient also has depression, as there is overlap with the type of symptoms that may be seen. Many patients with Huntington's disease have BOTH apathy and depression and distinguishing between them may need to be done by your doctor/provider.

### What causes apathy and when do patients with Huntington's disease get apathy?

There are several areas of the brain that are associated with apathy. In Huntington's disease, the frontal lobes of the brain and their connections to the caudate nucleus are most likely the culprit. The communication from these two areas becomes weaker when patients have Huntington's disease. Studies have shown that apathy is more likely to occur after having the disease for three years or more. It can also worsen as the disease progresses or as memory gets worse over time.



# Apathy in Huntington's Disease- Continued...

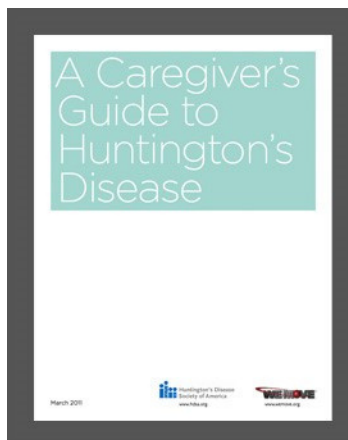
## What are some strategies to help apathy?

Studies have shown that apathy is associated with worse quality of life among both patients and caregivers. For this reason, behavioral interventions and strategies may be helpful.



1. Educate others about apathy in HD and encourage them to include the person in activities.
2. Family members may want to seek counseling to deal with the stress and frustration of dealing with apathy in a person with HD.
3. Telling a person with HD that they are lazy will increase tension.
4. Use calendars, schedules and regular routines. Phone/tablet alerts or reminders or texts from others can encourage or facilitate participation.
5. Provide clear guidance and focus on the first step if the activity is complex and includes multiple steps.
6. The activity may need to be “jump-started,” by having someone demonstrate or co-participate in the activity.
7. Regular physical activity may help reduce aspects of apathy.
8. Practicing mindfulness has also been shown to help reduce apathy.
9. Gently guide behaviors, but they may need to be done in shorter bursts and if a HD person says “no”, it means no.
10. Discuss apathy with your health care provider to see if the person with HD needs an evaluation or treatment for depression.

Additional information about apathy and other symptoms of the disease can be found in this free guide found on the HDSA website.



*A special thanks to David Gonzalez, PhD Rush neuropsychologist for resources related to apathy.*

# SIGN UP TODAY!!



## 20th Team Hope Walk! Sunday, May 19th, 2024

Naperville Riverwalk Grand Pavilion  
912 Honorary Sindt Memorial Court  
Naperville, IL 60540

[www.hdsa.org/thwnaperville](http://www.hdsa.org/thwnaperville)



SCAN ME

### **Walk Day Schedule:**

**9:30am- Registration Open**

**10:30am- Walk Begins**

**All Day- Family FUN!**

Enjoy lunch compliments of Calabria Imports Restaurant/Deli once finished walking!

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 or the QR code! **Register by April 5th** 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 and begin fundraising!

Recognition/Awards will be presented to the top fundraising teams as of their online fundraising as of May 18th. We hope to see you there!!



**Save the Date:**  
**Northwestern Medicine Patient and Family  
Huntington's Disease Symposium 2024**  
**Saturday, November 16th, 2024**



## **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 [zsazsabrown@northwestern.edu](mailto:zsazsabrown@northwestern.edu)

### **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

### **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.

# Clinical Research Updates at Rush Medical Center:

## Enroll HD Study

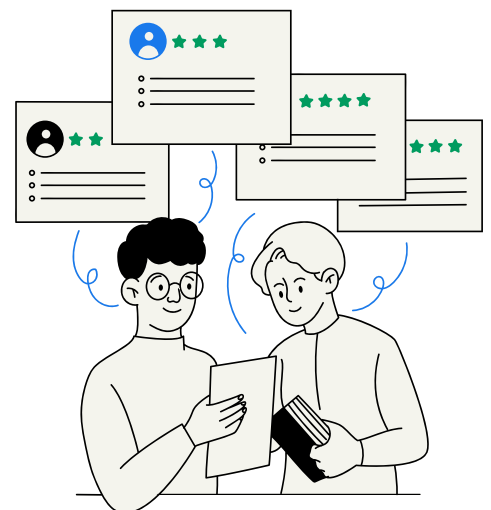
The Enroll HD study is currently enrolling at Rush University Medical Center. This multi-center, observational study aims to collect clinical information and biospecimens from patients with Huntington's Disease to enhance the understanding of HD, develop future treatments, and improve clinical care. 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 Tyler Svymbersky at 312-563-0676 or [tyler\\_svymbersky@rush.edu](mailto:tyler_svymbersky@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](mailto:tyler_svymbersky@rush.edu).


## Sage-HD Clinical Trial

The Sage-HD Clinical Trial is currently enrolling at Rush University Medical Center. Sage HD is a randomized, placebo-controlled, double-blind study to evaluate the effect of SAGE-718 on Cognitive Function 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 may be eligible to participate. Your participation in this study may last up to 140 days (20 weeks) and you will be asked to complete 9 study visits. For more information or to enroll, contact Tyler Svymbersky at 312-563-0676 or [tyler\\_svymbersky@rush.edu](mailto:tyler_svymbersky@rush.edu).



# Mark Your Calendar!

Join us for the 39<sup>TH</sup> ANNUAL HDSA CONVENTION  
in Spokane, Washington, May 30 - June 1, 2024

 Huntington's Disease  
Society of America  
**HDSA**  
39<sup>TH</sup> ANNUAL  
CONVENTION  
MAY 30 - JUNE 1, 2024



## Convention at-a-Glance

*Three days of education, support and camaraderie!*

### THURSDAY

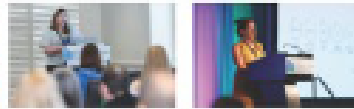
- Exhibit Hall
- HDSA Team Hope Walk
- Opening Ceremony and Welcome Reception

### FRIDAY

- Educational Workshops
- Luncheon
- HDSA's National Youth Alliance Talent Show

### SATURDAY

- Research Keynote
- Educational Workshops
- HDSA Convention Gala and Awards



*For further information, please visit us online at [HDSA.org/convention](https://HDSA.org/convention)*

*HDSA images at left are from our 2023 Convention in New Orleans, LA.*

# Save The Date!



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

**More details to come.**  
**Contact Larry Haigh for more information:**  
**[larryhaigh@gmail.com](mailto:larryhaigh@gmail.com)**



# A Day At The Races for HD

## Sunday, August 25, 2024 @ 1:00pm



SCAN ME

[illinois.hdsa.org/races](http://illinois.hdsa.org/races)

Hawthorne Race Course  
3501 South Laramie  
Stickney/Cicero, IL 60804

Contact Wayne Galasek  
[wgalasek@aol.com](mailto:wgalasek@aol.com) or 708-289-1273

# Mark Your Calendar!

## Central Illinois Team Hope Walk



Saturday, September 21st  
Lake Storey  
1572 Machen Drive  
Galesburg, IL

More details to come.  
Contact Sarah Cozad for more  
information:  
[cozinn.sc@gmail.com](mailto:cozinn.sc@gmail.com)

#LetsTalkAboutHD

HD

 Huntington's Disease  
Society of America

**May is  
Huntington's  
Disease  
Awareness  
Month**

**Interested in being part of the  
Illinois HDSA Chapter??**

**We would love to talk to you!!**

**Contact Karen Bennett  
(karben22@hotmail.com) or  
Sarah Cozad  
(cozinn.sc@gmail.com) for more  
information!**

 Huntington's Disease  
Society of America  
**Centers of  
Excellence**

**HDSA Center of Excellence at  
Northwestern University  
259 E Erie St Suite 1900  
Lavin Family Pavillion  
Chicago, IL 60611**

**Director: Danny Bega, MD**

**Phone number to make appointments:  
1-312-695-7950**

**Clinic Coordinator: Emily Zivin, LCSW  
Email: [hd@nm.org](mailto:hd@nm.org)**

**Phone: 1-312-695-7950**

**Social Worker: Emily Zivin, LCSW  
Email: [emily.zivin@nm.org](mailto:emily.zivin@nm.org)  
Phone: 1-312-926-8048**

**HDSA Center of Excellence at  
Rush University Medical Center  
Section of Parkinson's Disease and  
Movement Disorders  
1725 W. Harrison Street Suite 755  
Chicago, IL 60612**

**Director: Deborah A. Hall, MD, PhD  
Phone number to make appointments:**

**1-312-563-2030**

**Clinic Coordinator: Melissa Quintana  
Email: [Melissa\\_Quintana@rush.edu](mailto:Melissa_Quintana@rush.edu)**

**Phone: 1-312-563-3796**

**Social Worker: Key'Aira Glasper, MSW, LSW  
Email: [KeyAira\\_Glasper@rush.edu](mailto:KeyAira_Glasper@rush.edu)  
Phone: 1-312-563-2900**



# 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](http://www.illinois.hdsa.org)



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

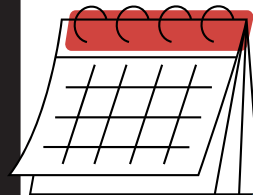
**X (Formally Twitter):  
@HDSA\_Illinois**

**Email:**

[illinois@hdsavolunteer.org](mailto:illinois@hdsavolunteer.org)



**Mail:  
PO Box 453  
Northbrook, IL 60065**



*Mark Your  
Calendar!*

**May 19th-  
20th Annual Illinois Chapter HDSA  
Team Hope Walk, Naperville**  
**July 27th-  
Illinois Chapter Baggo, Chebanse**  
**August 25th-  
Day at the Races for HD,  
Hawthorne Race Course**  
**September 21st-  
Central Illinois Team Hope Walk,  
Galesburg**