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
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!
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.
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!!

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!
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

**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.

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

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 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.
Save The Date!

Saturday, July 27th
Chebanse, IL 60922

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

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
Phone: 1-312-695-7950
Social Worker: Emily Zivin, LCSW
Email: 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
Phone: 1-312-563-3796
Social Worker: Key’Aira Glasper, MSW, LSW
Email: 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); clrogers111@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

### 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

### 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

### ***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 amyturneraladow@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.
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