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Hopes & Dreams
is the official publication of the
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P.O. Box 1454, Lake Villa, IL 60046
(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.

President's Message



Dear HD Families,

I hope all of you had a relaxing holiday. Happy 2024! 2023 was another successful year for the IL HDSA chapter, with many live events where HD families could connect with one another.

In 2023, as President of the Chapter, I continue to be impressed by the determination and resiliency of the HD families, considering the challenges with the disease and HD clinical trials.

As a chapter, we had a number of excellent events, highlighted by the Team Hope Walk at the Naperville Riverwalk on May 21st. We had over 500 attendees and this long-standing trademark event for the Illinois chapter. It was wonderful to see and meet with so many members of the HD community on a beautiful summer day. In addition, we had another successful Baggio event and Day at the Races over the summer, along with a Meat raffle to end the year. I want to thank all the event organizers and IL board members for all their support in making these events a success. I'm looking forward to more successful fundraisers in 2024.

I want to thank Mary Bos for her service on the Illinois Board. Mary has been a longtime supporter and IL board member.

Our mission as a Chapter is to carry out the HDSA mission to improve the lives of everyone affected by HD and their families. I am committed to supporting this effort and thank you in advance for your commitment to carrying out this mission at the local level. As always, please feel free to reach out for any support or help.

I look forward to a great year ahead and seeing you at many great events planned in 2024!

Arvind Sreedharan
President, HDSA Illinois Chapter

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News from our Illinois Chapter Social Worker, Erica Bohac, LSW

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

Gifts for Yourself: Winter and Holiday Self-Care

Winter is upon us and holiday season is in full swing. That means the nights are longer, the days are colder, and schedules are busier than ever. This time of year can be filled with magic, togetherness with family and friends, and joyful traditions. But for many, it can also be a time of stress and grief. Maybe it's a first holiday without a loved one. Or a relationship dynamic that has changed due to increasing care needs. Maybe it's difficult to manage the disruption of routine and normalcy that guides us the rest of the year. It can be a critical time to focus on caring for ourselves and protecting our wellbeing. But how?

Self-care doesn't have to be complicated. It doesn't have to be a spa day, a bubble bath, or a lavish vacation. Consider a few of these simple tasks that can help us navigate the cold, dark, and busyness of the winter months:

- **Time Outside:** Yes, even in the winter! Even when it's cold! Just a few minutes of fresh air and sunshine can boost Vitamin D levels, energy, and mood. Consider a quick walk around the block or just five minutes on a porch or balcony.
- **Movement:** Our bodies need movement to feel their best, both physically and mentally. This can be a favorite form of exercise, walking, or simple stretches from a standing or seated position.
- **Connection:** You may find that making social connections is more difficult in the winter. Maybe it's already harder to get outside with medical equipment, transportation barriers, and general care needs... then add snow and ice? It can feel daunting. Consider virtual forms of connection: call a friend, Facetime a family member, or join us in a virtual support group. Chances are, those you reach out to are craving connection as much as you are!
- **Routine:** It can be challenging when holidays and busy schedules shake up our routines. Are there parts of your routine that ground you? Consider prioritizing these, even in the midst of holiday celebrations and busy schedules. It might be something as simple as waking up and going to bed at the same time each day.
- **Hydration:** If you're feeling tired and sluggish, consider a big glass of water. Fatigue often comes from dehydration.
- **Alone Time and Rest:** Prioritize getting enough sleep. Feel comfortable saying no to extra plans that feel difficult to fit in your schedule or may make you feel rushed and stressed. Even the most extroverted among us can benefit from a few quiet moments alone to balance out our busy social calendars.



Family is everything



SAVE THE DATE

Sunday • May 19, 2024
20th Annual Walk

Additional information will be added to the Walk website soon.

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

Location: Naperville Riverwalk Grand Pavilion



- **Clinical Research Update Webinar**
January 9th at 5:30 PM, CST
Presenter: Dr. Danny Bega
https://northwestern.zoom.us/webinar/register/WN_01BYRz7nSdC5Qv5K5yEGtw
- **Day at the Races for HD at Hawthorne Racecourse** – Sunday, August 25th

Mark Your Calendar!

Join us for the 39TH ANNUAL HDSA CONVENTION
in Spokane, Washington, 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://www.hdsa.org/convention)

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

MEDICAL RESEARCH CORNER

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



NORTHWESTERN MEDICINE HDSA CENTER OF EXCELLENCE

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

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.

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.

MEMORIALS and TRIBUTES

In memory of Richard Smith from P. Scott & Barbara Shearer; Judith Roe; Kalwin & Ann Lindsay; Maurice Sprout, Hugh & Sara Larkin, Richard & Carolyn Smith, Daniel & Pamela Kelley, David Guth, Stephanie Weller, Edwina & Gary Christiansen, Donna Schultz, Nancy O'Neill, Marlene Hitch, Raymond & Helen Hanks, Ray & Carol Ropp, Lyle & Kathleen Tallon, Joseph & Marleta Jones, Lowell & Wanda Hoffman, Paul Dunham & Paula Jo Teopke, John & Jane Rosenbohm, Inda Klawitter, Anita Nafziger, David & Patricia Sowerby, Mary Ann Bye, Margaret Shawgo, Samuel & Elizabeth Deal, David & Rebecca Getty, Kent & Karen Meister, James & Barbara Ely, Brian & Ginny Pulley, Carlton Jenkins, David & Suetta Overhold, Arlene Pennie, Chris & Linda Witte, Gary & Janet Brent

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

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.

 **SAVE THIS DATE!**

May 19th

20th Annual HD Illinois Chapter Team Hope Walk

August 25th

Day at the Races for HD

<https://hdsa.org/il>

WINTER 2024

