President’s Message

Dear Friends,

Fall is upon us and once again, it is a time to reflect on some the achievements of our chapter this year.

In March we had our State Convention Education Day, held at Harper Junior College. The event was co-chaired by Emily Zivin and Holly Fraleigh who, once again, did an awesome job in presenting a day full of programming to meet the needs of our families. This great duo has also worked with the staff at The Illinois Neurological Institute at OSF St. Francis in Peoria to schedule a half day symposium in October. (Look for details elsewhere in this newsletter).

In May we held our 14th annual Team Hope Walk. Once again, the walk was one the largest walks in the nation, passing the $900,000 mark. The goal of the Illinois Chapter Team Hope Walk is to pass the 1-million-dollar mark in donations raised during the 2019 15th annual Team Hope Walk to be held at the Naperville Riverwalk, on Sunday, May 19, 2019. Louise Vetter, HDSA CEO, plans to be on site for this historic event. We hope you will be too.

In August Dave and I had a blast representing "Grumpy Old People, Inc." as the 'BAGGO-NATORS' at the 2nd annual Baggo Tournament. No, we didn’t win, but we had a great time!! We hope that you will join us next year for the 3rd annual Baggo Tournament. Congratulations to all who helped and participated in this event, and I can’t wait until next year!

September saw the 1st annual Central Illinois Team Hope Walk and it was a HUGE success! They had over 110 walkers and raised over $15,000. Kudos to Larry Haigh and his awesome committee!!

Don’t forget one of our new events for next year, because it starts NOW!! ‘PLANTING AWARENESS 4 HD’. Purchase and plant any lily bulb this fall, and when it blooms next year, take a picture with you and your flowering lily and submit it with a $20.00 registration fee. (Details on submission to be announced at a later date) All entries will be judged by a certified A.I.F.D. designer professional florist.

There are several other new events in the works so stay tuned for more information as it becomes available. This is also a time filled with hope for the future. Never has there been so much excitement on the horizon about a new treatment for lowering the HD protein.

Don’t forget, we still need YOU! We need board members and volunteers. Have you thought about becoming a board member, but are concerned it would take too much of your time? Being a board member does not take but a few hours of your time for the whole year. There are 6 meetings during the year, 3 of the meetings are held in person (where we all meet together) and the other 3 are phone conferences. We do our best to keep board meetings to an hour and a half. Yes, there are times that it will go a little longer and times that they are a little shorter. Anyone 18 or older can become a board member. We are looking for anyone willing to give a little time and to share their ideas with us. Not sure you would like to join the board but you would like to do something more? Ask how to volunteer to help on one of our events or how to get your own event started! We are here for you, but we need you to help us to continue to grow and do great things. Anyone wanting more information please contact myself or any of the chapter board members. Their names and contact information can be found elsewhere in the newsletter.

My contact: Home phone: 815-498-6092 Cell: 815-508-2370. Email: susiehodgson53@gmail.com
Wishing each one of you a wonderful and happy fall season!

Susie Hodgson
President, HDSA Illinois Chapter
Huntington’s Disease Patient and Family Symposium

You’re invited to a patient and family symposium

Sponsored by the Huntington’s Disease Center of Excellence at Northwestern Memorial Hospital

Saturday, November 17, 2018
8:30 am - 12:00 pm

Northwestern Medicine Parkinson’s Disease and Movement Disorders Center

Huntington’s Disease Patient and Family Symposium

Topics
Behavioral Challenges of Huntington’s Disease
Personal Story
Research Pipeline in Huntington’s Disease
A Team Concept: Multidisciplinary Huntington’s Care
Tackling Social Issues

There will also be a question and answer session with physician experts, and a support group for at-risk or pre-symptomatic individuals. Breakfast will be served.

This symposium is complimentary and attendance is recommended for individuals who are newly diagnosed or at risk for Huntington’s disease. Family members and caregivers are also encouraged to attend.

To RSVP
Call 877.926.4664 or register online at classes.nmh.org.

Location and parking
Northwestern Memorial Hospital
251 East Huron Street
Feinberg Pavilion
Third Floor, Conference Room A
Chicago

Free parking is available with validation at 222 East Huron Street.

To RSVP: Call 877.926.4664 or register online at classes.nmh.org.
HDSA Central Illinois Symposium
Mind & Body
Saturday, October 13, 2018
8:00 am – 1:00pm
OSF Healthcare Jump Trading Simulation & Education Center
1306 N. Berkeley Avenue
Peoria, Illinois 61603
$10/participant

Symposium Program

HD 101 - Melissa A. Glass, CNP
Behavioral Aspects of HD - Dr. Luis Zayas, MD, PT
Nutrition & Weight Management for all Stages of HD - Dagmara Sniezek-Malinowska, RD, LDN
Advocacy - Emily Zivin, LCSW, MPA
Navigating Genetic Disease Testing – A Personal Story
Research and Clinical Trials Update - Dr. Dronacharya Lamicchane, MD

3 Ways to Register

In an effort to continue to keep costs down we request that you register for the conference online @ hdsa.org/il. Select the link to HDSA Central Illinois Symposium.

If you are unable to do so, please contact us at holly.fraleigh@gmail.com or 708.790.9618 to register.

You may also register in-person the day of the event at check-in.

This event is funded by the Huntington’s Disease Society of America through an unrestricted educational grant from Teva.
Danny Bega MD, MSCI
Associate Professor, Department of Neurology,
Division of Movement Disorders
Northwestern HD Clinic
Galter Pavilion, 675 N. St. Clair, #20-100
Chicago, IL  60611
312-695-7950 (main)
312-695-5747 (fax)
hd@nm.org (email)
http://huntingtons.nm.org

Sleep Problems in Huntington’s Disease

Insomnia is a common problem in HD and may have many causes including chorea, lack of daytime stimulation, depression, apathy, irritability, medication side effects, or deterioration of the sleep-wake cycle. Disturbed sleep has negative consequences on the overall quality of life. It is important that patients discuss their sleep complaints with their physician.

Possible Causes of Sleep Problems
- An intrinsic part of the HD itself
- Medication side effects
- Uncontrolled mood disorder – depression, anxiety, irritability, etc.
- Pain
- Motor disturbances – i.e., uncontrolled chorea
- Urinary issues
- Poor sleep hygiene
- Sleep disordered breathing (i.e., sleep apnea)

Generally, chorea in HD tends to fade during sleep, but may make it difficult to fall asleep in the first place or go back to sleep after nighttime awakening. In such cases, medications used to suppress chorea may solve the problem. Many medications used to treat chorea can cause sleepiness as a side effect which may be an advantage if these are taken at night. However, some people experience the opposite effect and feel more “on edge” after taking certain medications – keep your doctor informed of your experience.

Remaining awake and active throughout the day is also important to counteract under-stimulation and achieve restful sleep at night. This may also help with apathy or depression. Furthermore, if medications make you sleepy during the day, it may be hard to sleep at night.

There is no ideal sleeping aid for HD patients, but sedating antidepressants or antipsychotic medications may be used judiciously. Benzodiazepines and other prescription sedatives have the potential of causing confusion and should be used cautiously.

In cases where sleep disordered breathing is suspected (i.e. when there is snoring, or when someone stops breathing for short periods during sleep), an overnight sleep study may be needed to make the diagnosis and determine appropriate treatment.

Appropriate sleep hygiene assists in a good overnight sleep.
- Get regular exercise each day.
- A warm drink may help you relax.
- Keep a consistent and regular time out of bed 7 days a week.
- Keep clock face turned away from you if you wake up a night.
- Do not eat or drink heavily for 3 hours before bedtime. And, avoid heavy meals and spices in the evening.
- Keep your room dark, quiet, well-ventilated, and at a comfortable temperature throughout the night.
- Use a bedtime ritual e.g. reading before lights-out.
- If you wake at night, do not try too hard to sleep; instead, concentrate on relaxing.
- Be sure mattress is not too soft or too firm, and pillow is right height and firmness.
- Use bedroom only for sleep; do not work or do other activities that lead to prolonged arousal.
- If possible, make arrangement for night-time (sleep-time) care-giving activities (for children, others, pets).

Good sleep makes a big difference in how you feel and how your overall motor, psychiatric, and cognitive symptoms manifest. Don’t forget to discuss your sleep concerns with your neurologist.
LOL 4 HDSA

a celebration of hope

Benefiting HDSA Centers of Excellence at
Northwestern University & Rush University Medical Center

HDSA is a 501(c)(3) organization: EIN# 13-3348972 • Make checks payable to HDSA Great Lakes Region • PO Box 14252, Chicago, IL 60614

Please visit www.hdsa.org/coh-chicago to register

Yes! Count me in!!

2018 Pledge Drive

Your pledge helps to support the HDSA mission to improve the lives of everyone affected by Huntington’s disease and our vision of a world free of Huntington’s disease.

- Research efforts
- Family services
- Advocacy
- Support groups
- HD awareness
- Our chapter social worker
- In-Service Presentations to Care Facilities

Please complete the information below and return with your pledge:

Your Name

Email Address

- Benefactor $500.00 donation
- Supporter $25.00 donation
- Patron $100.00 donation
- Member $25.00 donation
- Angel $75.00 donation
- Friend $25.00 donation

Family is everything

Your contribution is tax deductible to the extent allowed by law.

Make your check payable to HDSA Illinois Chapter and mail to:
P.O. Box 1883, Arlington Heights, IL 60006

To make your pledge online go to HDSA.org/il – click DONATE and choose pledge drive on the drop down menu for the solicit code
1st Annual Central Illinois Team Hope Walk

Sunday, September 16th in Bloomington, Illinois the 1st Annual Central Illinois Team Hope Walk was held. “We had an amazing turn out for our first event in this area,” said Larry Haigh, Chair of the event and Illinois HDSA Chapter Vice President. Over 100 participants turned out for this event, and over $15,000 was raised to help families affected by Huntington’s Disease.

It was a warm day for the event, but it did not stop everyone coming together to fight this horrible disease. The event started off with registration, and some doughnuts. The walk started with a ribbon cutting ceremony by, Todd Hochmuth with TEVA Pharmaceuticals. When the walkers returned from the walk they enjoyed hotdogs, chips, and cookies. The day was rounded out with announcing of the raffle winners, games, and chatting with one another.

Thank you to all the donors, sponsors, and participants for making this such a great event. Haigh said, “we are looking forward to doing this event again in 2019!”

We are so grateful to our friends at OPI Golf for donating the proceeds of this year’s golf outing to the HDSA-IL Chapter! On Saturday, June 23rd at the Village Greens of Woodridge, golfers set out to play 18 holes in the heat without the use of golf carts due to recent heavy rains. This hearty bunch took it all in stride and had a great time despite the weather! Golf was followed by a delicious Barbeque style dinner and silent auction. The Oak Park Invitational is held each year with proceeds going to a different chosen charity. HDSA-IL is honored to have been chosen this year! Pictured above, IL Chapter treasurer, Charlotte Rybarczyk, accepts this year’s check from members of the OPI Golf Committee.
2nd Annual BAGGO Tournament a Success!!

A HUGE THANK YOU to all the sponsors, participants, and volunteers who helped to make our second annual HDSA Illinois Chapter Baggo tournament a success! On Saturday, September 8th in Rolling Meadows, 17 teams played in a double elimination bracket vying to win $100 plus their choice of custom Baggo games built by R&R Custom Cabinetmaking. Everyone enjoyed beautiful weather and an Italian Beef and hot dog lunch provided by Vienna Beef. Our winners, Sully & John (AKA Team Freight Train), were new to the tournament this year and undefeated for the day! And, best of all, $7000 was raised for our HD families in Illinois! We look forward to next year’s event to be held on August 24th!

Sponsors

Winning Team – Freight Train

Rebecca & David Vogel
Planting Awareness for HD

Do you have a green thumb? Do you have a spot in your home garden to plant a lily bulb? Join our new fundraising event and spread both awareness for HD and beauty and fun for you and your family!

**Simple Rules:**

1. Buy a lily bulb or bulbs of your choice and color.
2. Plant the bulb(s) in the Fall.
3. When it blooms the following June or July, take a picture of it. Please make sure YOU are in the picture. Any photos sent in without you in the picture with your blooming lily will automatically be disqualified.
4. Submit the picture along with a **$20.00 by check made payable to:**
   Illinois Chapter-HDSA and mail to:
   Planting for HD
   75 Birch Drive, Sandwich, IL 60548
5. All pictures will be judged by a certified AIFD florist.
6. The winner receives 5 new lily bulbs to plant for next year’s contest.
7. You may enter as many pictures of different lilies you have planted, but each entry must be accompanied by a $20.00 entry fee.

All pictures will be posted to the HDSA Illinois Chapter Facebook page along with your name. There are no restrictions on the age of the participants. What a great way to have some family fun as well as spread some awareness for Huntington’s Disease!

Please submit your entries using the form below

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Name __________________________________________________________________________________________
Street Address ____________________________________________________________________________________
City __________________________________________________________________________________________
State ________________________________  Zip_________________________________
Email address ___________________________________________________________________________________
Phone __________________________________________________________________________________________
Name of Lily ____________________________________________________________________________________

Questions? Contact Dave Hodgson at dchodgson1946@gmail.com

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We are a 501c(3) non-profit charity (EIN 13-3349872)
Illinois Chapter-HDSA, PO Box 1883, Arlington Heights, Illinois 60006
News from Our Illinois Chapter
Social Worker
Emily Zivin, LCSW
Huntington’s Disease Society of America
Tel: 630-443-9876 or E-mail: ezivin@hdsa.org

PREPARING FOR THE HOLIDAYS
The holidays are often filled with togetherness, happiness and laughter. For Individuals living with HD and their families, the holidays can be filled with disappointment, stress and sadness. Here is a list of suggestions for creating some happy memories for you and your family.

Preparing family and friends
Familiarize family and friends with any changes in behavior and/or appearance you have noticed. Give your guests tips for how to communicate and watch for increased anxiety that might arise.

Try not to feel compelled to hang onto established family traditions if they are no longer practical. Start new activities that might work better and become new traditions.

Communication tips
• Remember to be good listener
• Be patient and supportive
• Talk very slowly and wait for answers
• Show your interest by maintaining eye contact
• Provide comfort and assurance
• Don’t argue and/or criticize
• Aid if your loved one is struggling to find words
• Focus on feelings
• Limit distractions

Keeping organized
• Consider smaller holiday meals with fewer people
• Have everyone wear name tags
• Create a buddy system for the person living with HD. Have someone monitor the anxiety, overstimulation or tiredness that can be triggered
• Have a quiet room available for relaxation
• If your loved one is in a care facility, take a special meal to him/her

Offer quiet time
• Have a favorite movie or music available
• Be prepared with simple activities
• Allow some time to get outside and take a walk
• Have family albums ready to share

For the caregiver
• Take time for yourself
• Do things that make you happy
• Do not host meals and events that will add extra stress
• Enjoy your family
• Relax
Again, TAGI pharmacy is trying to meet the needs of the HD community. They now have an agreement with the healthcare warehouse to offer a cash plan for tetrabenazine/xenazine. They listened to us as we complained to them about patients with high copays, hospice patients and those with no insurance or those ordering from Canada. Healthcare warehouse does not operate in all 50 states so please look at the details here. This is not a perfect solution but certainly an option. The medication is manufactured in the US so quality


https://www.healthwarehouse.com/tetrabenazine-12-5mg-tablets.html

If you have questions about tetrabenazine/xenazine, please reach out to Ryan Anderson at TAGI, 410-919-3111 or randerson@tagipharma.com.

Questions? Contact Anne Leserman at Aleserman@hdsa.org or 212-242-1968 ext. 240

Thank you!!

Memorials and Tributes

In Memory of Ann Marie Purcell from Mrs. Yvonne Storey, Pat & Vera Purcell

In Memory of Ralph Short from Lois Short
<table>
<thead>
<tr>
<th>Date/Time</th>
<th>Additional Information</th>
<th>Contact Information</th>
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<td><strong>CENTRAL ILLINOIS</strong></td>
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| 2nd Sunday of even months | TIME: 2:00 to 4:00pm  
LOCATION: St. Joseph Medical Center, Bus. Conf. Center  
– Room 2, 2200 E. Washington Street, Blooming, IL | 2018 Meetings: 2/11, 4/8, 8/12, 10/14 (No meeting in June because of Natl Convention)  
Dave or Susie Hodgson  
(815) 498-6092  
dchodgson1946@gmail.com |
| 3rd or 4th Sunday of odd numbered months | TIME: 2:00 to 3:30pm  
LOCATION: Northwestern Medicine - Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot)  
* Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome. | Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left.  
Joe Wiedemann  
(847) 505-3933  
joseph.wiedemann@gmail.com |
| **GENEVA**         |                                                                                       |                                                          |
| 2nd Monday of every month | TIME: 7:00 – 8:30pm  
LOCATION: Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville, IL | Call for additional information and directions.  
Marilyn and Barry Kahn  
(847) 975-2403  
marilyn.kahn1@gmail.com |
| 2nd Sunday of every month | TIME: 2:00 – 4:00pm  
LOCATION: OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room, Rockford, IL  
* Use the main entrance - second one back from the parking lot entrance. As you enter the building you'll see a counter staffed by volunteers. Turn right, before you reach the counter. The St. Anthony Room is straight ahead. | Open to people with HD, family members, caregivers, and interested professionals.  
Cheryl Sutton  
(815) 262-4889  
cjs@hdsupportrockford.org |
| **LAKE COUNTY**    |                                                                                       |                                                          |
| 2nd Tuesday of odd months | TIME: 7:00 – 8:30pm  
LOCATION: Thomas Cellini Huntington’s Foundation, 3019 East End Avenue, South Chicago Heights | 2018 Meetings: 1/9, 3/13, 5/8, 7/10, 9/11, 11/13  
Maryann Moynihan  
(708) 955-3080  
shamrock1959@att.net  
TCHF Office (877) 687 8243 |
| **ROCKFORD**       |                                                                                       |                                                          |
| 2nd Tuesday of even months | TIME: 7:00 – 8:30pm  
LOCATION: Logan Square Library, 3030 W. Fullerton Ave., Chicago, IL – Room: First Meeting Room  
TIME: 10:00am – 11:30am  
(Free ground-level parking lot)  
**Please note, the November 17th group will meet after the HD Symposium at Feinberg Pavilion (see details on page 2 of newsletter) | Valet parking is available in front of 1620 W. Harrison. Parking at both venues will be validated in full.  
For more info, contact Sarah Mitchell Chen, LSW (312) 942-6445  
Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD  
Emily Zivin  
(630) 443-9876  
ezivin@hdsa.org  
A group to build connection and support to those affected by HD.  
Cindy Rogers  
(219) 836-2369  
crrogers111@comcast.net |
| **SOUTH SUBURBAN** |                                                                                       |                                                          |
| 2nd Sunday of even months | TIME: 7:00 – 8:30pm  
LOCATION: Rush University Medical Center, 1620 W. Harrison Street, Tower Resource Center, Tower, 4th Floor, Suite 04527, Chicago, IL  
* Parking is available at the Rush garage on the southeast corner of Paulina and Harrison Streets. From the 4th floor, follow the signs to the Tower. | 2018 Meetings: Please call for specific dates  
For more info, contact Sarah Mitchell Chen, LSW (312) 942-6445  
Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD  
Emily Zivin  
(630) 443-9876  
ezivin@hdsa.org  
A group to build connection and support to those affected by HD.  
Cindy Rogers  
(219) 836-2369  
crrogers111@comcast.net |
| **CHICAGO – RUSH UNIVERSITY MEDICAL CENTER** |                                                                                       |                                                          |
| 2nd Tuesday of odd months | TIME: 7:00 – 8:30pm  
LOCATION: St. Joseph Medical Center, 1000 Broadmoor Ave., Munster, IN  
**Please note, the November 17th group will meet after the HD Symposium at Feinberg Pavilion (see details on page 2 of newsletter) | 2018 Meetings: 2/13, 4/10, 6/12, 8/14, 10/9, 12/11  
Cindy Rogers  
(219) 836-2369  
crrogers111@comcast.net |
| **CHICAGO – NORTHWESTERN MEDICINE** |                                                                                       |                                                          |
| 2nd Sunday of even months | TIME: 7:00 – 8:30pm  
LOCATION: Northwestern Medicine - Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot)  
* Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome. | Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left.  
Joe Wiedemann  
(847) 505-3933  
joseph.wiedemann@gmail.com |
| **MUNSTER, INDIANA** |                                                                                       |                                                          |
| 2nd Tuesday of odd months | TIME: 7:00 – 8:30pm  
LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN | 2018 Meetings: 1/9, 3/13, 5/8, 7/10, 9/11, 11/13  
Maryann Moynihan  
(708) 955-3080  
shamrock1959@att.net  
TCHF Office (877) 687 8243 |

Sadie Foster, M.A., L.C.P.C., has a telephone Information & support call service for HD families. This call is held the fourth Sunday of every month at 7pm. To participate dial 630-300-6276 and when asked, enter code 702087#. You do not need to identify yourself on the call.

For additional support you may call:  
Sadie Foster, MA, LCPC, at the College of Medicine Huntington's Disease  
Clinic Tel: 815-271-7101 or E-mail: sadie@sfoster.com  
Sarah Mitchell Chen, Rush University Medical Center Social Worker  
Tel: 312-942-6445 or E-mail: sarah_mitchell@rush.edu
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<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
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<tr>
<td>October 13, 2018</td>
<td>HDSA IL Chapter Half-Day Symposium – Peoria, IL</td>
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<tr>
<td>November 17, 2018</td>
<td>HD Patient &amp; Family Symposium @ Northwestern Memorial Hospital Chicago, IL</td>
<td>Chicago, IL</td>
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<td>December 1, 2018</td>
<td>HDSA Celebration of Hope – Chicago, IL</td>
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<tr>
<td>June 27 – 29, 2019</td>
<td>HDSA 34th Annual Convention – Boston, MA</td>
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https://hdsa.org/il