



President's Message

Greetings Friends,

My name is Larry Haigh and I am honored to be serving as the President of the Illinois Chapter of HDSA. Here is a little about myself. I was born and raised in a rural area in East Central Illinois called Chebanse (an hour South of Chicago). After attending Illinois State University, I made my way back home, and I am living close to the same area still around my family. I am the Agriculture Instructor and FFA Advisor at Herscher High School. I have a passion for helping others and being involved with the community. 4-H and FFA runs in my blood, as well as the desire to help those with Huntington's disease.

My HD journey started over 10 years ago. I was in college and the family started to notice some changes in my grandmother. Huntington's disease was not mentioned much in our family. My grandmother was diagnosed with HD officially, and for our immediate family it brought us a little bit closer. We are in this together. Two of my cousins had gone to a National HDSA Convention and joined the NYA (National Youth Alliance). Their excitement for the NYA and learning more about ways we can help those with HD sparked a fire in me. A couple of the Illinois cousins went to Michigan to help the family up there with different events. After helping with a few things in Michigan, I decided I needed to help the people in my state. I reached out to the Illinois HD Board and they welcomed me with open arms. In 2016, my mother tested negative for HD. Since she is negative, then I am negative for becoming symptomatic as well. I joined the Illinois HD Board in 2017, served as Vice President in 2018, and now I am serving as your President. I have spent some time attending and helping with various projects to spread awareness and education about HD from our education days to our various fundraisers.

We have some exciting news to share. **Illinois now has 3 Centers of Excellence!** Our newest Center of Excellence is the *OSF HealthCare Illinois Neurological Institute in Peoria* under the direction of Dr. Lamichhane. Welcome! Our other two facilities are Northwestern HD Clinic under the direction of Dr. Bega, and Rush HD Clinic under the direction of Dr. Hall. Our Centers of Excellence are great resources and places that are available to help our HD families.

As we dive into Spring, we have several different events taking place. We just had our first event of the year and it was a new event, the Spring Fling. All who were there had a great time! In April we have one of our Education Days and in May we have our very popular, and well attended, Illinois Team Hope Walk. This year marks the 15th year for the walk, and this walk will also bring the total money raised to over \$1 million for HDSA! Later this summer we have a Golf Outing, Baggo Tournament, 2 more Team Hope Walks, and a symposium in Central Illinois. All these events are ways you can get involved.

If you are looking for ways to become involved, we are more than happy to talk to you about finding ways for you to help. Please feel free to reach out to any of our AMAZING board members or myself about any questions you may have!

Hope to see you soon,

Larry Haigh
President, HDSA Illinois Chapter





The Power of Positivity

Illinois State Conference

Saturday, April 13, 2019

Moraine Valley Community College -Building M, 9000 W. College Parkway, Palos Hills, IL 60465

Cost \$10.00

Three (3) ways to register

We ask that you 1) register online @ hdsa.org/il to help us continue to keep costs down and ensure that we are not incurring excessive food and beverage costs. If you are unable to do so, 2) please send a request to register to holly.fraleigh@gmail.com and we will process your registration for you. 3) Register in-person the day of the event (please only use this as a last resort) at the front door.

Enter the Campus off 111th Street and proceed to Bldg M.

AGENDA



8:30 - 9:10	Registration and Welcome
9:10 - 10:00	Living your best Life HD Positive (Seth Rotberg)
10:00 - 10:15	Break
10:15 - 11:15	Breakout Options: <ul style="list-style-type: none"> At-Risk Support Group (Emily Zivin, LCSW, MPA and Danielle Marino) Occupational Therapy Show and Tell (Mary Ellen Stoykov, PhD, OTR/L) Advocacy (Seth Rotberg) HD 101 (Dr. Bega, MD, MSCI)
11:15 - 11:30	Break
11:30 - 12:30	Research and Clinical Trial Update - Drs. Bega, MD
12:30 - 1:15	Lunch
1:15 - 2:15	Breakout Options: <ul style="list-style-type: none"> Caregiver Support Group (Brian Eads, LSW) Speech Therapy and Technology (Angela Roberts, PhD.) Genetic Testing and Reproductive Options (Lisa Kinsley, MS, CGC) Key Legal Documents and Considerations (Melissa Johnson)
2:15 - 2:30	Break
2:30 - 3:30	Ask the Experts - Panel Q&A (All Presenters)
3:30	Adjourn



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>

Nutrition in Huntington's Disease

Primary Author – Danielle Larson, MD, Movement Disorders Fellow at Northwestern University HD Clinic

Practicing good eating habits plays an important role in decreasing symptom burden and improving quality of life in HD. Individuals with HD can have various problems related to nutrition including weight loss, decreased appetite, picky eating habits, and difficulty chewing or swallowing. It is important to recognize if you or your loved with HD is dealing with these problems and talk with your doctor about ways to address it.

Unique Nutrition-related Features of HD

- People with HD have a lower average weight.
- People with HD have a higher caloric need, which could be due to chorea or metabolic changes.
- Symptoms of HD can interfere with eating:
 - Motor symptoms can cause problems with chewing and swallowing.
 - Cognitive and behavioral symptoms can cause individuals to be overwhelmed by mealtime and easily distracted, eat too quickly, or have low appetite and picky eating habits.

Strategies to Improve Nutrition

- Make eating enjoyable! Have desired foods readily available and for eating at any time.
- Encourage high-calorie intake. Use calorie-dense foods such as avocado, nuts and nut-butters. If needed, use high-calorie and high-protein shakes like Boost® or Ensure.®
- Introduce mealtime modifications.

Environment Modifications

- Quiet calm, environment with little distraction (Turn off the TV)
- Focus on eating: avoid complex conversations and decision making
- Allow extra time to finish the meal

Tableware Modifications

- Weighted and rubber-handed utensils
- Comfortable, well-lit seating
- Dishes with sides and cups with covers to prevent spills

Recognize Swallowing Difficulty

Choking can happen with liquids or solid foods and can prevent adequate food intake. Report any swallowing difficulty to your doctor, as a formal evaluation of swallowing by a Speech Pathologist may be needed. Nutritionist/dietician evaluations may also be useful for some people.

Easy modifications to help prevent choking:

- Eat slowly, take small bites, and chew well
- Cut, mash, or puree foods
- Use a straw for liquids
- Add moisture with butter, cream, or gravy
- Thicken liquids with cornstarch, Thickit® or ThickenUp®

FAQ: Are any specific foods or supplements recommended?

Studies have not shown any specific supplements to be particularly effective for the symptoms or progression of HD. In general, we recommend foods rich in antioxidants - "phyto-nutrients" - such as fruits and vegetables. It is important to discuss any supplements with your doctor before taking them.

**15th
Annual
Team
Hope
Walk**

**Sunday,
May 19,
2019**

Mark Your Calendar NOW!

The Illinois Chapter of HDSA's 15th Annual Team Hope Walk will be held on Sunday, May 19, 2019, at the beautiful Grand Pavilion on the Naperville Riverwalk. Our award winning, nationally recognized, Team Hope Walk is one of the biggest fundraisers for HDSA in the nation! Over the past 14 years, the HD families and friends have raised approximately \$900,000.00! This year we hope to go over the one-million-dollar mark!! The two mile walk along the DuPage River begins and ends at the Grand Pavilion.

Fee:

Pre-register is
\$20/person

Day of the Walk
is \$25/person

T-shirts for
first 400
walkers who
pre-register!

This is a family friendly walk for everyone. The path is perfect for both wagons and strollers. Dogs on a leash are more than welcome to attend. Lunch is included in your registration fee (\$20.00 per person if you pre-register, \$25.00 if you pay the day of the walk). Be sure to bring plenty of non-alcoholic drinks for everyone in your party as well as lawn chairs. Don't forget water for your pet.

For Pre-registration: <http://www.hdsa.org/thwnaperville>

The first 400 walkers who pre-register is guaranteed a correctly sized T-shirt.

For any questions, please contact Dave Hodgson at dchodgson1946@gmail.com or 815-498-6092. Feel free to start collecting pledges now using the pledge sheet in this issue of Hopes & Dreams. Stay tuned to our Illinois Chapter Facebook page as well as our Chapter webpage for more information!



TEAM HOPE - PLEDGE SHEET

Your challenge...have at least 10 FRIENDS sponsor you!



Collect pledges from family members, friends, co-workers, neighbors, church members, teachers or anyone who would like to join you in your personal fight against HD. Please place pledge sheet and collected donations in a sealed envelope with your name and total collected on the outside of the envelope. Please turn in your pledges on Walk Day.

Team Hope – Walk for a Cure – 5K Walk

	NAME	ADDRESS	AMOUNT
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			

OFF TO A
GOOD
START

Getting
Closer

You did it!

KEEP
ON
GOING

Name: _____

Address: _____

City: _____ St: _____ Zip: _____

Email: _____ Phone: _____

This form may
be reproduced.

Waiver: I hereby waive all claims against the Huntington's Disease Society of America, sponsors or any personnel for any injury I might suffer from this event. I attest that I am physically fit and prepared for this. I grant full permission for organizers to use photographs of me to promote this event.

Signature _____

SAVE THE DATE

Continue to check the IL Chapter website
for additional details on future events:
<http://hdsa.org/il>



Golf Outing to benefit the HDSA IL Chapter
Saturday, July 13th (Village Greens of Woodridge)



3rd Annual BAGGO Tournament-Rolling Meadows, IL
Saturday, August 24th

EDUCATION
SYMPOSIUM

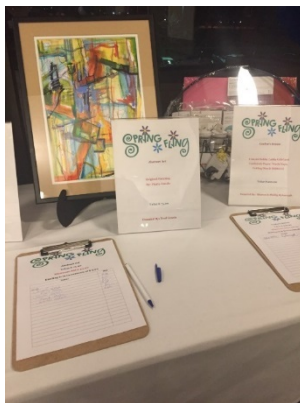
HDSA IL Chapter Education Symposium-Peoria, IL
Saturday, November 9th

Inaugural a Success!

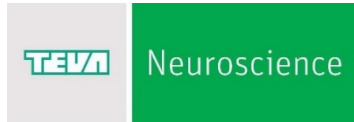
The IL Chapter's first annual Spring Fling was held on Saturday, March 30th and drew a crowd of 100 attendees who enjoyed music, trivia, Late-Night Bites, and a silent auction. The evening started out with music by D.J. Robb of Rolo Entertainment who was happy to take requests. After a brief welcome speech by Spring Fling Chairperson Charlotte Rybarczyk, the crowd moved on to team trivia, played in 3 rounds and featuring a round of Huntington's disease and HDSA trivia. Next, guests were treated to "Late-Night Bites" featuring pizza from Wayne's, Sliders and Wings from Rep's Place, and "Pups" from Vienna Beef.



Nothing Bundt Cakes and Costco rounded out our menu with delicious desserts and Team McCallum provided a popcorn machine with popcorn to munch on all evening long. During the evening guests were busy "outbidding" each other over the 30 gift baskets in the silent auction. Everything from beer to massages were available to bid upon. Add in some dancing, a cash bar, and the pleasure of good company, and consider this event a success. The best part? Over \$10,000 raised for the HDSA IL Chapter to provide services for our HD families!



A Special Thanks to Our Sponsors!



Less Er's More Ah's

And Way to Go Committee!



Jenny, Sharon, Paula, Mary, Charlotte, Barb, Holly, Peggy, Candy, Larry

WELCOME to our newest



OSF HealthCare Illinois Neurological Institute

200 E. Pennsylvania Avenue
Peoria, IL 61603
Main Number: 309-624-4000
Fax: 877-464-6806

Dronacharya Lamichhane, MD, Director

www.ini.org

Clinic Hours: Monday - Friday, 8:00 a.m. – 5:00 p.m.

NEW & RETURNING patients: 309-624-4000

RETURNING patients: 309-624-4000

Clinic Coordinator: Alaine Robinson, BSN, RN

Phone: 309-655-6405

Email: alaine.robinson@osfhealthcare.org

Social Worker: Tonya Welch

Phone: 309-624-8500

Email: tonya.h.welch@osfhealthcare.org

Genetics Counselor: Jennifer Burton

Phone: 309-624-9584

Email: jeburton@uic.edu



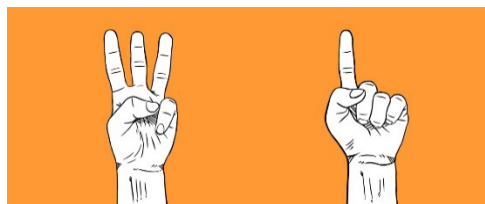
When interrupting is good: genetic hiccups that protect against Huntington's disease

Multiple teams find small differences in the 'CAG repeat' bit of the Huntington's disease gene. They don't directly change the huntingtin protein, but do alter the age of symptom onset. What's behind this enigma and what does it mean for patients?

Multiple new studies have identified what may be the most important new fact about the genetics of Huntington's disease since the gene was discovered in 1993. At least two research groups around the world simultaneously report that a tiny genetic hiccup in the HD gene has a big impact on HD symptoms.

What's CAG and why do we care about it?

Huntington's disease is caused by a single mutation in a single gene. Because of its relationship to HD, we usually refer to it as the **HD gene**, though scientists formally refer to it as *HTT*. Everyone has two copies of the HD gene - one each inherited from mom and dad.



Three 'letters' in the DNA, like CAG or CAA, instruct the cell to add one amino acid building block, such as glutamine, to a protein it's making.

Each gene is a recipe - a set of instructions on how to make a protein. Our genes are written in the language of DNA, which uses four chemical letters that scientists abbreviate A, T, G and C. If you zoomed way into a cell and looked at the DNA you wouldn't see these letters, but they help scientists understand and

decode the language of genes.

Very near the beginning of the HD gene is a long, repetitive, stretch of the DNA letters **C-A-G**. Even in people without HD, this sequence repeats itself, on average around 17 times.

CAG size is important for HD onset

In every person destined to develop HD, this stretch of CAGs in DNA is longer than normal. The average HD patient has something like 44 repeats, and some have many more. In general, the more CAGs found in a person's HD gene, the sooner we would expect them to develop HD symptoms – though this varies a lot between individual patients.

Extremely long CAG repeats give a clear example of this effect. Very long repeats (over about 65) tend to cause very early onset of HD, or juvenile-onset Huntington's disease (JHD).

Very recently, two separate research groups published the same startling discovery about these CAG repeats. Before we describe their findings, we must get just a little bit into the weeds.

CAGs and glutamines

The first thing to understand is that the protein-making instructions in DNA work in a very specific way. The DNA has a 4-letter alphabet: A, C, G and T. Proteins, on the other hand, are made from long strings of building blocks called amino acids. There are **twenty** different amino acids to choose from, like twenty differently-shaped beads that can be threaded onto a string one by one in any order.

To get from 4 letters in the genetic alphabet, to twenty amino acids to choose from in the protein-making world, our cells have a rule that DNA is interpreted in 3-letter chunks. For example, C on its own doesn't mean anything, and nor does CA. But CAG is an instruction to add the building block called **glutamine** to the protein that's being built.

Because of all this, there is a direct correspondence between how many CAG repeats someone has in their HD gene, and the number of glutamines in the resulting protein, called **huntingtin**. Someone who inherited a CAG repeat of 42 from their HD-affected parent should make HD proteins with 42 sequential glutamines. We think therefore bigger CAG repeats cause HD symptoms to emerge earlier: more CAGs in the gene means more glutamines in the protein. We don't know how exactly, but this seems clear.

But wait, it gets weirder!

Many amino acids therefore have **multiple** three-letter genetic codes that result in the same one being added to the growing protein. For glutamine – the important amino acid in HD – CAG is the most famous three-letter sequence that

Let's see if you are any different! Can you find the CAA interruption in this CAG tract?

Genetic testing of CAG size

New findings - GEM-HD

At the same time, the group detected another very rare variation that appeared to do the **opposite**, and actually **delayed** the onset of symptoms. This quirk was seen in about one in a hundred people. These folks had **two** CAA interruptions in their CAG tract, rather than the more common single CAA.



The effects of these two rare genetic variations tell a very compelling, if very surprising, story. Seeing both a bad and good version of the variation suggests this effect is real. It also means that a lot of the variation we see between HD patients could be influenced not by the length of the CAG length, but on how 'interrupted' it is.

What's spooky about this is that whether there's a CAA or a CAG in the HD gene, the cell will build the same protein by adding the same glutamine building block. But if the protein is the bad guy, as most researchers still believe, why does it matter whether that glutamine came from a CAA or a CAG in the gene?! We'll come back to that shortly.

Like every piece of science, this finding needs to be repeated and validated. But if it's found to be correct, it has very important impacts on how we think about HD.

New findings – UBC

Luckily, we didn't have to wait long for confirmation, because another study led by Michael Hayden, at the University of British Columbia, was released at the same time as the GEM-HD study. This was a totally independent investigation carried out in Hayden's lab, which houses a very large bank of DNA samples from HD families.

The UBC researchers found sixteen people whose CAG repeat was missing that CAA interruption. These folks developed HD symptoms quite a bit earlier than one would expect - maybe as much as decades earlier, based on their traditionally-measured CAG size.

Next, they examined how common this loss of repeat was, in a unique population of HD mutation carriers.

Some people who inherit a CAG size between 36 and 38 develop HD, but others survive to old age without any symptoms. Hayden's database of HD family DNA includes 45 people who inherited a CAG size of 36, 37 or 38. Fifteen of these people already had HD symptoms, and thirty did not. And strikingly, among the people with these very low CAG sizes *and* HD symptoms, **a majority of them were missing the CAA interruption.**

Remember, in general, lacking the CAA is very rare - so the fact that so many people with short CAG counts and HD symptoms are missing it, is very unlikely to be due to chance. It strongly implies that missing the CAA somehow accelerates the onset of HD.

But how?

Having two renowned research groups make simultaneous discoveries like this is really exciting. It suggests that we need to start thinking about how HD works in a slightly different way.

Remember that CAG and CAA in the gene both instruct cells to add a glutamine when building the protein. That means that for any given length, the huntingtin protein is totally identical, whether or not the CAG tract has a CAA interruption.

These game-changing insights were made possibly by the thousands of HD family members who volunteered to take part in research projects. Ongoing large studies like Enroll-HD and HDClarity remain incredibly valuable sources of scientific progress in HD.

Logically, the explanation must lie in the DNA, not the protein – and it's probably related to the curious tendency of CAG tracts to grow over time in certain cells.

We know that after death, the brains of Huntington's disease patients contain some cells with much larger CAG counts than expected, compared to the CAG length measured in blood tests done when they were alive. It's still not clear why, but evidence from recent genetic studies suggests that this is down to long stretches of repetitive DNA being difficult to repair when they get damaged.

Our DNA frequently experiences wear-and-tear from things like UV radiation. This causes little nicks and breaks from time to time, and our cells have a whole bunch of machinery for repairing this damage, to prevent harmful changes to our genes. It seems the long stretch of CAGs confuses the machinery, and occasionally extra CAGs get added during the repair process. That lengthening of the CAG **does** produce a protein with more glutamines, which is expected to be more harmful. It's possible – but not yet proven – that the presence of a CAA interruption among the CAGs makes it **easier** for the DNA repair machinery to do its job more accurately, perhaps by keeping the two DNA strands better lined up when breakages occur, or by giving the repair equipment something to grab onto. And when the CAA is missing, it seems lengthening of the CAG tract is more likely to occur. Ultimately this means some cells will produce huntingtin proteins with more glutamines, which are more harmful.

Crucially, this expansion wouldn't necessarily be detectable by measuring the CAG tract in blood cells. There may just be some people with, say a CAG count of 44 on the blood test, who have some brain cells with much longer repeats, because their DNA is harder to repair accurately. Others with a CAG count of 44 would not have much expansion of the CAG in the brain. And that difference between people may be down to the presence or absence of the CAA interruption.

What does this mean for HD family members?

For now, this research is just a scientific finding. It's an unusually solid one, since it's been independently reported by two different research teams. In fact, a reliable source tells us a **third** major team has also reproduced the finding in another patient cohort and has additional data to flesh out the finding. That team's work has been submitted for publication in a scientific journal and is currently under peer-review.

The sequence changes the researchers found that modify the age of onset of HD symptoms are rare - only a very small number of HD family members carry them. That's why it took a pool of thousands of DNA samples from HD patients to find them at all.

In the future, as we understand these changes better, it may be that genetic testing procedures need to be updated to include sequencing people's CAG tracts one letter at a time, rather than just measuring the length. But for now, the most important impact of this research is that it sends researchers back to the lab to better understand the impact of these little genetic quirks. While it's not clear what we'll find, we do know that this research helps us understand HD much better and might point to new treatment approaches.

These new findings really show the value of research participation by HD families. None of the thousands of people who provided their DNA and other information knew that these important results would emerge. It's only by participating in studies like ENROLL-HD that we're able to set the stage for truly unexpected findings like these ones.



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

Advocacy happens when we educate, raise awareness, and speak up politically. As members of the Huntington Disease family, you are experts of this disease. It is important for people in your community to know how you and your family are impacted by HD. Advocacy can take place in your home, talking to your neighbor as well as reaching out to local politicians. The more individuals who know about Huntington's Disease, the more we can do to make a difference.

HDSA's national advocacy is focusing on improving access to health care and benefits for individuals affected by Huntington's Disease. The Huntington's Disease Parity Act legislation hopes to waive the two years waiting period for Medicare. Currently, an individual with Huntington's Disease who is receiving SSI/SSDI must wait two years for Medicare eligibility.

In addition, HDSA has 4 main priorities for healthcare reform. The current advocacy goals are to keep protections for the individuals with pre-existing conditions, maintain bans on lifetime and yearly care caps, preserve essential health benefits for insurance plans and protect Medicaid. These are important goals to ensure appropriate health care coverage.

Your voice is very important in our fight to educate and secure health care services for individuals with Huntington's Disease. Go to www.hdsa.org/takeaction to send a letter to your Representatives/ Senators. In addition to writing letters, face to face interactions with politicians is great way to influence policy change. Important talking points include education about Huntington's Disease, how HD has affected your life and how proposed legislation will impact your family. Let the politicians know what you want. Do not leave the office without asking for something.

All conversations about Huntington's Disease are an important part of advocacy. Your experiences and expertise can make a difference. You know how your family is impacted by the disease. Speak up and ask for change. We need to hear your voice. You matter!

New CAREGIVER Support Group

Location: Winnetka Library
Address: 768 Oak Street, Winnetka, IL 60093
Room: Community Room

First meeting: Tuesday, April 16th, 7-8:30pm
Future meeting location and time to be determined

Contact Person: Emily Zivin, ~ 630-443-9876 or
ezivin@hdsa.org

Memorials and Tributes

In Memory of Madelyn Holec from Gus & Mary Marchetti,
Charlotte & Steve Rybarczyk

In Memory of Ralph Short from Lois Short

In Memory of Nicole "Nikki" Thomas from Sharon & John
Wanner, S. Joanne Marshall

In Memory of J. Maxine Lunsford from Chuck & Nadine Palmer,
Robert & Susan Brown

In Honor of Scott McCallum from Madonna Reed Tideman

It comes with a deep sense of sorrow that Clarence Wiese, former HDSA Illinois Chapter board member, has passed away. Along with his wife Sharon, he was a bright light in the battle to find a cure. We will miss him dearly.

CLARENCE W. WIESE 1931 - 2019

Clarence W. Wiese, age 88 of St. Charles, Illinois. Formerly of Glen Ellyn and Downers Grove. US Air Force Staff Sergeant Veteran. Retired Systems Analyst for Material Service in Chicago. Beloved husband of the late Sharon L. Loving father of Nannette MacHale, Michael Wiese, Diane Wiese and the late Cathie (Thomas) Ulbrich. Proud grandfather of Nicole (Michael), Jessica (Steven), Gretchen (Garrett), Jason (Stacey), Heather and Joshua. Great grandfather of Dexter, Morgan, Aiden and Lincoln. Dear brother, uncle and friend of many. In lieu of flowers donations to HDSA-Illinois Chapter at illinois.hdsa.org. A memorial service will be held at a future date. Arrangements by DuPage Cremations, Ltd. and Memorial Chapel (630) 293-5200

CHAPTER OFFICERS

PRESIDENT – Larry Haigh
815-383-1877 ~ larryhaigh@gmail.com

VICE PRESIDENT – Dave Hodgson
815-498-6092 ~ dchodgson1946@gmail.com

TREASURER – Charlotte Rybarczyk
847-259-3593 ~ charlotte82963@gmail.com

SECRETARY – Jenny Placek
630-995-6440 ~ jenniferplacek09@gmail.com

BOARD MEMBERS

Holly Fraleigh – holly.fraleigh@gmail.com
708-790-9618

Wayne Galasek – wgalasek@aol.com
708-289-1273

Andy Hucker – ahucker1549@comcast.net
224-715-0729

Barry Kahn – barrykahn1@gmail.com
847-975-2403

Marilyn Kahn – marilynkahn1@gmail.com
847-204-2403

Ann Terry – ann_terry5@yahoo.com
312-339-9356

OTHER CHAPTER MEMBERS

Emily Zivin – Social Worker
630-443-9876 ezivin@hdsa.org

Deb Boyd – Regional Director
dboyd@hdsa.org

Maryann Moynihan – Newsletter Editor
708-955-3080 shamrock1959@att.net

Hopes & Dreams
is the official publication of the
Illinois Chapter of Huntington's Disease Society of
America, Inc.,
P.O. Box 1883, Arlington Heights, IL 60006-1883
(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.





Date/Time	Additional Information	Contact Information
CENTRAL ILLINOIS		
2nd Sunday of even months <u>TIME:</u> 2:30 to 4:30pm <u>LOCATION:</u> Grace Church, 1311 W. Hovey, Normal, IL 61761	2019 Meeting Notes: No Meeting in December	Larry Haigh (815) 383-1877 larryhaigh@gmail.com
GENEVA		
3rd or 4th Sunday of odd numbered months (see dates in next column) <u>TIME:</u> 2:00 to 3:30pm <u>LOCATION:</u> Northwestern Medicine - Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot)	Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left. 2019 Meetings: 1/20, 3/24, 5/26, 7/21, 9/15, 11/17	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com * Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome.
LAKE COUNTY		
2nd Monday of every month <u>TIME:</u> 7:00 – 8:30pm <u>LOCATION:</u> Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville, IL	Call for additional information and directions.	Marilyn and Barry Kahn (847) 975-2403 marilynkahn1@gmail.com
ROCKFORD		
2nd Sunday of every month <u>TIME:</u> 2:00 – 4:00pm <u>LOCATION:</u> 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.	Dave or Susie Hodgson (815) 498-6092 dchodgson1946@gmail.com
SOUTH SUBURBAN		
2nd Tuesday of odd months <u>TIME:</u> 7:00 – 8:30pm <u>LOCATION:</u> Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	2019 Meetings: 1/8, 3/12, 5/14, 7/9, 9/10, 11/12	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH UNIVERSITY MEDICAL CENTER		
4th Tuesday of even months <u>TIME:</u> 7:00 to 8:30pm <u>LOCATION:</u> 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.	Valet parking is available in front of 1620 W. Harrison. Parking at both venues will be validated in full. 2019 Meetings: 2/26, 4/23, 6/25, 8/27, 10/22	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
CHICAGO – NORTHWESTERN MEDICINE		
<u>TIME:</u> 10:00am – 11:30am <u>LOCATION:</u> Logan Square Library, 3030 W. Fullerton Ave., Chicago, IL – Room: First Meeting Room (Free ground-level parking lot)	Now open to ALL members of the HD community: family members, friends, and patients—with and without symptoms. 2019 Meetings: 1/26, 3/16, 5/18, 7/20, 9/14, Nov date to be determined	Emily Zivin (630) 443-9876 ezivin@hdsa.org A group to build connection and support to those affected by HD.
MUNSTER, INDIANA		
2nd Tuesday of even months <u>TIME:</u> 7:00 – 8:30pm <u>LOCATION:</u> Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	2019 Meetings: 2/13, 4/10, 6/12, 8/14, 10/9, 12/11	Cindy Rogers (219) 836-2369 clrogers111@comcast.net



April 13, 2019	HDSA IL Chapter State Conference – Palos Hills, IL
May 19, 2019	HDSA IL Chapter Annual Team Hope Walk – Naperville, IL
June 27 - 29, 2019	HDSA National Convention – Boston, MA
July 13, 2019	Golf Outing benefiting the HDSA IL Chapter – Woodridge, IL
August 24, 2019	HDSA IL Chapter Baggo Tournament – Rolling Meadows, IL
November 9, 2019	HDSA IL Chapter Education Symposium – Peoria, IL
https://hdsa.org/il	

SPRING 2019

Happy Spring!

