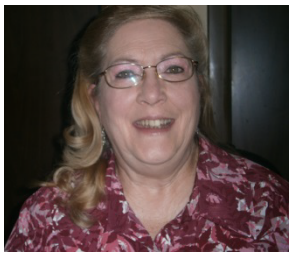
Hopes and Dreams
Huntington's Disease Society of America - Illinois Chapter Quarterly Newsletter

# Outgoing President's Message



Dear Friends,

Another year has come and is now almost gone. As we contemplate the New Year and all that it holds for us, it is also a time for reflection. This has been another outstanding year for the Illinois Chapter of HDSA. Without the help and support of all our families this would not have been possible.

As we look to the New Year our goal is a bigger and better year in 2019. In working towards our goal, we will continue to keep the mission and vision of our organization at the forefront of everything we do.

**MISSION:** To improve the life of everyone affected by Huntington's Disease.

**VISION:** A world free of Huntington's Disease.

The New Year will bring a few changes to your Chapter Board. I will be stepping off the board for a while so that I can spend more quality time with our son Bob. Our new Chapter President is Larry Haigh and I know that he will do an outstanding job helping the chapter to continue to move forward.

We also welcome 3 new board members, Ann Terry, Andy Hucker and Wayne Galasek. I am sure that we will be seeing and hearing many good things from these new additions.

In the coming year we will be seeing a few new events and the continuation of many of our standing events. 2019 will mark the 15th year for the Team Hope Walk on May 19. Our goal is to raise over $100,000 which will take us OVER 1 million dollars raised in 15 years. This great accomplishment could not have been done without all of you! We hope you will come out and be a part of this historic walk!

It has been my pleasure and honor to serve as your president. I will still be at and supporting our events and look forward to seeing many of you there.

Happy New Year and God's blessings on all of you and your loved ones.

With love and affection for you all,

Susie Hodgson
Outgoing President, HDSA Illinois Chapter

Huntington's Disease Society of America
Illinois CHAPTER

# SATURDAY, MARCH 30 2019

# HDSA IL Spring Fling

## DJ • DANCING • TEAM TRIVIA • SILENT AUCTION

VIENNA "PUPS" AND OTHER LATE-NIGHT BITES INCLUDED
CASH BAR • CASUAL ATTIRE

**7-11 PM**

Arlington Lakes Golf Club
1211 South New Wilke Road
Arlington Heights, IL 60005

***2-4 players per trivia team***

Register by February 28, 2019: **$40/Person**

Register on/after March 1, 2019: **$50/Person**

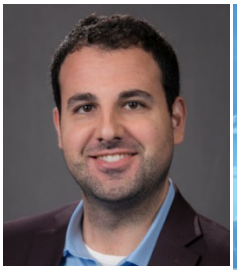
*Full registration price is 100% tax deductible*

## Sponsorship Opportunities Available

Questions? Contact Charlotte Rybarczyk at 847-259-3593 or charlotte82963@gmail.com
Return registration by March 23rd to: HDSA IL Chapter, PO Box 1883, Arlington Heights, IL 60006
OR register online at HDSA.org/IL
Checks should be made out to HDSA IL Chapter

---

Contact Name _____ Guest 1 _____
Address _____ Guest 2 _____
Phone Number _____ Guest 3 _____
E-Mail _____ Guest 4 _____




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

# HD Support Groups

By Danielle Marino, LCSW

"But I don't want to hear people cry!" is the most common response I get when I pitch the idea of a support group to those in the HD community. I'm here to tell you that support groups are not depressing but uplifting and a wealth of information, resources, and support.

**HD Support Groups: The Basics**
HDSA Support Groups are offered by HDSA chapters, affiliates, regions and Centers of Excellence. HDSA sponsors over 140 HD support groups nationwide. Support groups can be led by a professional or by a peer (other HD family member or friend). Every support group leader is provided training by HDSA and assigned a mentor who can serve as a resource and support to the support group leader.

*What actually happens at a group?*
Group facilitators usually begin the group by having attendees introduce themselves. They may then pose questions to help members focus on what's working in their lives and tips and tricks to managing HD. Those attending can choose to share as much or as little as they like. Sometimes people like to come and listen for a few groups before sharing. Often group members share tips on resources such as transportation support or home modifications that other attendees learn from. Over time, group members start to become bonded and we've seen families with HD come together to support one another outside of group.

**Benefits of attending:**
Support groups can offer vital emotional support along the continuum of HD, valuable advice about community-based resources as well as guidance from other support group members about many of HD's most challenging situations. There are support groups that meet in person and those that communicate online. Support groups can meet monthly or quarterly depending upon the number of participants and wishes of the group.

**Illinois Groups:**
Illinois has many support groups to choose from. Most Illinois support groups are open to all affected by HD: at-risk, gene positive, currently have HD or are a family or friend of someone with HD. See the last page of this newsletter for a complete list. For example, at Northwestern Memorial Hospital's Huntington's Disease Center of Excellence we're excited to be able to offer a support group open to any person affected by HD.

**Other Options:**
Don't see a support group near you? Start one! If you would like to start a support group, contact Anne Leserman, HDSA Community Services Manager at aleserman@hdsa.org There are also online HDSA support groups (divided into caregiver groups, At-Risk/ not tested, 25-45 + but no symptoms, etc.): http://hdsa.org/osg/ Patients and family members have also found help through Facebook and other online HD groups. Find what level of support works for you.

Support groups can be a source of hope, connection, and resources. It can be a great relief to have the opportunity to share your feelings and experiences with people who have faced the same challenges. Check out the list of groups on the last page of this newsletter and commit to trying a few. You'll never know what you're missing until you try.

*"The support group meeting we attend monthly has kept me from becoming overly bitter and angry as a caregiver. I learned what to watch for in the future. I no longer feel alone."*

*HD Family Member*

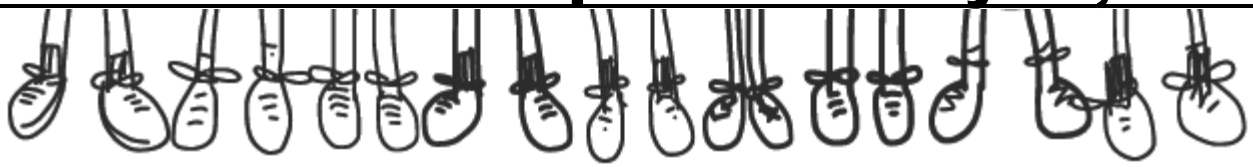
# 2019 HDSA Illinois Chapter State Conference

April 13, 2019
9:00am to 3:30pm

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


Save the Date

## 15th Annual Team Hope Walk – May 19, 2019



We have been making plans for our chapter's 15th Annual Team Hope Walk. Please mark off Sunday, May 19, 2019, as we again walk to help support the mission of HDSA! We hear that we might see a few very important people at our walk! Early pre-registration will begin mid-January. Watch for the Walk Brochure in your mail box. We hope you'll join us as we go over the one-million-dollar mark for 15 years of walking by the great HD Families of Illinois!

SAVE THE DATE

## 3rd Annual BAGGO Tournament
## August 24, 2019

## RG6042 GENERATION HD1 Study: Expected Sites in USA & Canada

**Status Update on December 19, 2018:**

- The observational HD Natural History study (Clinicaltrials.gov ID: NCT03664804) is open and currently recruiting. The planned sites in Canada, US, Germany and UK were announced in November. Information about the study, including individual site status, is posted on ClinicalTrials.gov.
- We are pleased to inform you on progress on the Phase III GENERATION HD1 study (Clinicaltrials.gov ID: NCT03761849). The first countries to open recruitment will be the USA and Canada. Below is a list of planned sites - it is important to note that these sites are not fully activated nor recruiting yet. We hope to complete the final steps as quickly as possible. The GENERATION HD1 study will run in approximately 15 countries; additional countries/sites will be announced on a progressive basis - as we obtain country approvals and when sites are nearly ready to enroll patients. For any clinical study, it is possible that an expected study site does not proceed to enroll participants. This can be for various reasons and we do not want to raise hopes or expectations.

**Expected sites for GENERATION HD1 study in the United States of America**
Alabama, Birmingham - University of Alabama
Arizona, Phoenix - Barrow Neurological Clinic
California, Davis - University of California, Davis
California, Palo Alto - Stanford University
California, Pasadena - Arcadia Neurology Center
California, San Diego - University of California, San Diego
Colorado, Englewood - Rocky Mountain Movement Disorders Center
District of Columbia, Washington - Georgetown University
Florida, Tampa - University of South Florida
Illinois, Chicago - Northwestern University
Maryland, Baltimore - John Hopkins University
Massachusetts, Boston - Beth Israel Deaconess Medical Center
Missouri, St Louis - Washington University
New York, Amherst - Dent Institute
New York, New York - Columbia University
Pennsylvania, Pittsburgh - University of Pittsburgh Medical Center
Tennessee, Nashville - Vanderbilt University Medical Center
Texas, Houston - University of Texas Health Science Center
Utah, Salt Lake City - University of Utah
Washington, Kirkland - Evergreen Health

**Expected sites for GENERATION HD1 study in Canada**
Alberta, Edmonton - University of Alberta
British Columbia, Vancouver - University of British Columbia
Ontario, Ottawa - Ottawa Hospital
Ontario, Toronto - Centre for Movement Disorders
Nova Scotia, Halifax - Queen Elizabeth II Health Sciences Centre
Quebec, Montreal - Centre Hospitalier de l'Université de Montréal

***About the Phase III GENERATION HD1 Study***
*The GENERATION HD1 study will evaluate the efficacy and safety of RG6042 treatment given once per month or once every two months (bi-monthly) over a period of 25 months (approx. two years). This global study will enrol up to 660 patients with manifest HD at 80-90 sites in approximately 15 countries around the world. The study will begin at the end of 2018, with patients starting to enrol by early 2019.*

*GENERATION HD1 is designed to determine the effectiveness and safety of RG6042, and therefore includes a comparison to placebo. Participants will be randomized to one of three treatment study arms: RG6042 monthly, RG6042 bi-monthly or placebo monthly. This means for every two participants randomized to RG6042, one will receive placebo. The study is "double-blinded," meaning neither the participant nor his/her investigator or site staff will know which study arm the participant is assigned.*

*For all patients who complete the GENERATION HD1 study, an open-label extension study with the option of receiving RG6042 (no placebo control) is planned, pending eligibility, approval by Authorities and Ethics Committees/Institutional Review Boards and if data support the continued development of RG6042.*

Our Clinical Trial Information Support Line for the USA and Canada can be contacted at 1-888-662-6728. Also, information about the GENERATION HD1 study and sites will soon be posted on ClinicalTrials.gov, including individual site status.

Whether your HD clinic or centre is selected for participation or not, this is no reflection on the quality of the many outstanding HD clinics and dedicated care providers around the world. The need in HD is greater than the capacity of our development programme. We have designed the programme to provide the required data to Authorities so that the benefit-risk of RG6042 can be determined as quickly as possible. Our ultimate goal is that this investigational medicine can be approved by Health Authorities, and made accessible to the broader HD community.

The decision to join a clinical trial is personal and involves many factors. We encourage anyone interested in participating in any clinical research to discuss with his/her HD specialist about what may be best for his/her situation.


# 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

Huntington Disease affects everyone in a family. Children watch their loved ones' progress with HD and often become caregivers at an early age. Not all children are able to verbalize how they are feeling. It is important to keep the lines of communication open and offer support to children as they grow, and their emotional needs evolve.

HDSA provides significant support to children and young adults. The National Youth Alliance (NYA) is made up of young men and women between the ages of 9 and 29. They provide youth support, education at local education days, youth retreats and NYA Day at the National Convention. In addition, the NYA provides advocacy training, local NYA activities and connects youth affected by HD together. For more information about the National Youth Alliance: https://nya.hdsa.org.

The Huntington's Disease Youth Organization (HDYO) is an international, non-profit organization that provides information, education and support to young people impacted by HD. The have an interactive website that includes a great deal of resources for children and young adults. For more information about HDYO: https://en.hdyo.org,

There is a book available written by Dr. Bonnie L. Hennig-Trestman titled Talking to Kids About HD. This book is available to purchase at: http://www.talkingtokidsabouthd.com/book.html.

Individual and family therapy is also a great form of support. You might find yourself with a therapist you like who has no previous knowledge about Huntington's Disease. I am happy to reach out to your therapist to provide an HD overview and education.

In Illinois, we have several support groups that meet in person. This is also a good way to connect with other individuals and families. Wherever you fall within the HD community, support is available.

# Advances on many fronts in the battle against the protein that causes Huntington's disease

*This fall sees exciting announcements from several companies focused on novel Huntingtin Lowering technologies, including Wave, PTC and Voyager*

**By Dr Jeff Carroll - December 04, 2018**

We've had a run of exciting updates from Ionis and Roche/Genentech about their program to test a drug that lowers production of the huntingtin protein – but they're no longer the only game in town. Recently several other players - including Wave Life Sciences, PTC Therapeutics, and Voyager Therapeutics, have made big announcements about their own huntingtin-lowering programs. There's a lot happening, and HDBuzz is here to help untangle all these approaches.

**Huntingtin lowering**

The goal, for all these approaches, is to lower the amount of huntingtin protein in brain cells. The huntingtin protein is the little machine made by cells as they follow the blueprint found in the HD gene. It's the mutant huntingtin protein, not the mutation in the DNA, that most researchers believe causes the brain cell dysfunction that causes HD.


Which is the right approach to Huntingtin Lowering? Maybe all of them!

One quick reminder about how this process works is in order before we dive in. Cells follow instructions found in DNA, but they don't use it directly to make a protein: they copy the instructions found in DNA into a sort of scratch copy of the genetic information, made from a closely related chemical called RNA. Scientists call this scratch copy **messenger RNA** or mRNA for short.

So the instructions in the HD gene, in our DNA, are copied into messenger RNA, which is then interpreted by the cell to build the huntingtin protein. A bit confusing, but it works! If you only remember one thing, remember this: a break in the chain anywhere will stop cells from making the huntingtin protein. In animal studies, lowering huntingtin protein led to big improvements in HD-like symptoms.

This approach to HD therapy is called **huntingtin lowering** and it's behind the Ionis/Roche program and forthcoming large phase 3 trial. Recently though, at least three other companies have announced exciting advances in various huntingtin-lowering approaches.

**Wave's targeted approach**

"Wave's approach targets tiny genetic differences between the healthy and mutant HD genes, outside the disease-causing CAG stretch. These minor spelling differences are part of normal human genetic variation and appear to have no impact on HD symptoms. But the tiny spelling differences provide a target for an ASO that can discriminate between the normal HD message and the mutant one."

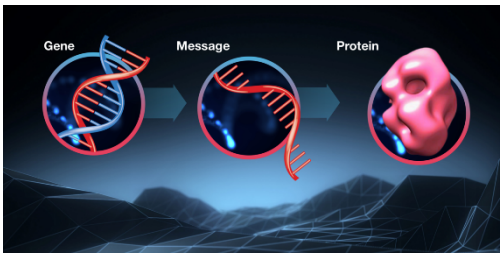
First up is not one, but two trials from Wave Life Sciences. We've written about Wave's approach here. Like the Ionis/Roche/Genentech drug currently being tested in HD patients, Wave's technology is based on antisense oligonucleotides (ASOs) - small, heavily modified bits of DNA that enter cells, find specific messenger RNAs and destroy them.

As in the Ionis/Roche trial, Wave is targeting the huntingtin message for destruction in hopes of improving HD symptoms. But Wave is taking a slightly different approach. Remember that virtually every HD patient has one mutant HD gene and one normal copy. The Ionis/Roche drug targets both copies, ultimately reducing levels of both the normal and the mutant Huntingtin protein in the brain.

Wave's approach targets tiny genetic differences between the healthy and mutant HD genes, outside the disease-causing CAG stretch. These minor spelling differences are part of normal human genetic variation and appear to have no impact on HD symptoms. But the tiny spelling differences provide a target for an ASO that can discriminate between the normal HD message and the mutant one.

In a perfect world, targeting only the mutant HD gene is obviously better. The normal HD gene has several important roles in cells, not all of which we understand perfectly. If it were just as easy to remove only the mutant copy, that's what we should do.

However, there's always a tradeoff. For huntingtin lowering, the tradeoff is that not every HD patient is eligible for the ASOs being developed by Wave. For their approach to work, a person must have inherited the HD mutation **and** one of the genetic spelling differences that the drugs home in on.




The link between DNA, RNA and Protein - everything you need to know about molecular biology.

Wave has conducted studies in HD clinics, and shown that up to about two thirds of HD patients may be suitable for treatment with one of the two ASOs they've developed. Each of these targets a different genetic variation and having two drugs allows them to use their approach on a larger share of the HD population.

They're testing the safety of these first two mutant Huntingtin lowering ASOs in HD patients in Canada, Europe and the US. Like the first Ionis/Roche trial, the goal of these studies is to determine whether these drugs are safe. If so, they would be subsequently tested for their ability to improve HD symptoms in larger studies.

We've also recently heard from Wave that they're working behind the scenes on another ASO, targeting yet another variation in the HD gene. This third drug is not yet being tested in humans but provides additional hope for folks who aren't eligible for either of the existing Wave drugs. In 2019 we hope to hear preliminary updates about the human safety studies from the first two Wave trials, as well as more details on their program developing a third ASO.

**What's the P-T-C?**
It's not just ASOs in the huntingtin-lowering world. At the European Huntington's Disease Network meeting in Vienna this fall, Anu Bhattacharyya, of PTC Therapeutics, updated the EHDN audience about exciting progress at her firm, which is also interested in Huntingtin lowering as a treatment for HD.

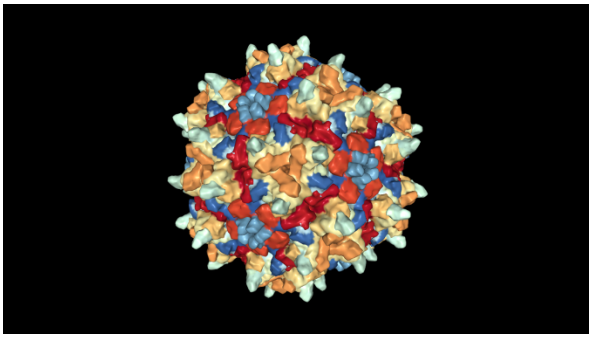
"PTC is developing what researchers call a **small molecule**, meaning a drug that can hopefully be taken as a pill, to lower levels of the Huntingtin messenger RNA. A few years ago, this would have seemed like science fiction, but several companies have described experimental drugs where this approach appears to work."

The approach taken by PTC is totally different than the ASO approach taken by Wave and Ionis/Roche. All the other programs involve injections into the brain or spinal column - worthwhile if they work, but much more invasive than we'd ultimately like to see. PTC is developing what researchers call a **small molecule**, meaning a drug that can hopefully be taken as a pill, to lower levels of the Huntingtin messenger RNA. A few years ago, this would have seemed like science fiction, but several companies have described experimental drugs where this approach appears to work.

PTC is at the forefront of companies developing this new approach to interfering with specific messenger RNAs, and they have their eyes set on HD. They've developed a drug that reduces levels of the Huntingtin protein in cells. For the first time, at EHDN, Bhattacharyya revealed that these drugs also work in the brains of living mice - suggesting the drugs get from the stomach into the brain, which is a huge accomplishment.

What's especially cool about this is that even if a drug taken as a pill reduces huntingtin in the brain by a smaller amount than an injected drug, it could still be useful. A huntingtin-lowering pill could mean spinal injections of a more powerful drug could be needed every six or twelve months, say, instead of every one or two months.

PTC's program is at an earlier phase than the Ionis/Roche and Wave programs, as it's still being tested in animals. But it's a genuinely exciting approach that might offer real benefits if it's proven safe and effective in future trials. And PTC appears to be planning for the future - Bhattacharyya told the audience at EHDN that PTC had a goal of beginning safety studies in humans in 2020. Excitingly, PTC has a track record of success, with two approved oral medications for muscular dystrophy, another genetic neurological disease.



**Voyager**
Viruses, like the one used by Voyager, are beautiful machines tuned by evolution to be great at breaking into cells.

At another conference this fall – the Congress of the European Society of Gene and Cell Therapy – we got another exciting huntingtin-lowering update from Voyager Therapeutics. Voyager is a biotechnology company focused on using **gene therapy** to treat brain diseases, including Huntington's.

Gene therapy works very differently from ASOs or small-molecule drugs. Gene therapy relies on tiny, harmless, viruses to deliver new genetic information to cells - in this case brain cells. Viruses are very good at sneaking into cells, so clever researchers have figured out how to trick them into delivering beneficial things into different cells of the body.

In this case, Voyager's team of researchers has built custom viruses that deliver instructions that tell brain cells how to make a special piece of RNA that seeks out the Huntingtin mRNA and destroys it. In effect, the virus reprograms cells to become factories to make a daily supply of a drug that works like the ASOs we discussed above.

This approach has a huge benefit, which is that the treatment only needs to be delivered one time. Once treated, the brain cell will theoretically produce the huntingtin-lowering molecule indefinitely. If safe and effective, this would obviously be better than getting monthly injections into the spinal fluid, or even taking a pill every day.

However, there are a few potential downsides to this approach. First - it might turn out to be unsafe in some way that we can't foresee at this stage. And because the treatment isn't reversible, we must take extra caution with safety for gene therapy trials. Secondly, while it's pretty easy to get these hacked viruses into most of the cells in a tiny mouse brain, it's much trickier to do this to the 86 billion neurons in the human brain.

"Voyager's team of researchers has built custom viruses that deliver instructions that tell brain cells how to make a special piece of RNA that seeks out the Huntingtin mRNA and destroys it. In effect, the virus reprograms cells to become factories to make a daily supply of a drug that works like the ASOs we discussed above."

That's what makes this update from Voyager scientists particularly interesting. They've reported on experiments conducted in monkeys, which have large complex brains that are much closer to our own. Voyager has developed surgical techniques that help the virus spread over very large portions of the monkey brain, both deep brain structures and the cortex - the wrinkly outer bit of the brain.

This is an especially important advance, because the deep brain structures targeted by Voyager are relatively poorly reached by ASO drugs, but play a key role in HD. Voyager's experiments also reveal very good suppression of the monkey huntingtin gene – reductions of about two-thirds in deep brain structures, and about one third in the outer, cortical, brain cells. These are decent reductions, and one might hope that achieving similar results in human HD patients could provide some real benefits.

Like the Ionis/Roche trial, the path envisioned by Voyager is to reduce both the mutant and the normal copies of the HD gene. Given this, and the fact that their therapy can't be shut off after it's delivered, this approach demands a super-cautious approach, which they appear to be taking with all these monkey studies.

**Take home**

There is a lot of justified excitement in the HD community about the ongoing Ionis/Roche/Genentech study. Everyone, including HDBuzz, is pulling for this study and has high hopes that it will provide some benefit to HD patients. But, as these recent advances show, it's not the only game in town. There are other approaches to Huntingtin lowering that are not quite as far along but offer large potential benefits.

So to recap: there are two ongoing trial programs with huntingtin-lowering ASOs in patients. One targets both copies of the HD gene (Roche/Genentech), has passed the safety test, and will soon be tested for efficacy. The other targets only the mutant gene (Wave) and is currently being tested for safety. Behind that, we have single-shot gene therapy trials undergoing extensive safety studies in preparation for human trials (Voyager and others), and a novel small molecule approach (PTC).

Supporting multiple shots on goal doesn't just increase the chance that one will succeed - it also offers the chance that **more than one** might work. That offers a tantalizing future where combinations of drugs might be used to produce the maximum benefit for the lowest possible risk. Combination approaches have proven successful for other diseases like HIV, cancer and diabetes. When it comes to drugs in development, and drugs that work, more is more.

# Memorials and Tributes

**In Memory of Kathleen Talenco** from Catherine Evers

**In Memory of Ralph Short** from Lois Short

**In Memory of Arthur Thomas Hradek** from Read & Cherie Boeckel, Toby & Bonnie Duckett, Lynn Ferino, Ingo Kempfe & Suzy Alfano, John & Marie Kurczab, Dirk & Adrianna Ollech, Jim & Tricia Smith, Bill & Patty Ward

**In Honor of Craig Srajer on his birthday** from Catherine Evers

**In Honor of Jack & Kay Talenco** from Catherine Evers

# Caregiver's Corner on HDSA Website

**Caregiver's Corner** is designed to provide information, resources and support for caregivers, so they are better able to face the daily challenges of living with HD.

*Please note that webinars are recorded and posted online approximately a week after live viewing. To view recorded webinars please click on the links.*

http://hdsa.org/living-with-hd/caregivers-corner-webinars/

A sample of webinar topics online for viewing are:

- Advocacy
- Care Management
  - HD & Nutrition
  - Gait & Balance
  - Physical and Occupational Therapy
  - Managing Psychiatric Symptoms
  - Long Term Care & HD
  - Planning for Incapacity
- Family Issues
  - Safety in the Home
  - Talking with Kids about HD
- Finance
  - Applying for Disability
  - Estate Planning & HD
  - Financial Planning & HD
- Juvenile Onset HD
  - Diagnosing JHD
- Social Issues
  - Spirituality & HD
  - Living Positively
  - Law Enforcement Toolkit: Caregivers
  - Driving Cessation & HD

## 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


# SUPPORT groups


| Date/Time | Additional Information | Contact Information |
|---|---|---|
| **CENTRAL ILLINOIS** | | |
| 2nd Sunday of **even months**<br>TIME: 2:30 to 4:30pm<br>LOCATION: Grace Church, 1311 W. Hovey, Normal, IL 61761 | **2019 Meeting Notes:** No Meeting in December | Larry Haigh<br>(815) 383-1877<br>larryhaigh@gmail.com |
| **GENEVA** | | |
| 3rd or 4th Sunday of **odd numbered months** (see dates in next column)<br>TIME: 2:00 to 3:30pm<br>LOCATION: 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.<br><br>**2019 Meetings:** 1/20, 3/24, 5/26, 7/21, 9/15, 11/17 | Joe Wiedemann<br>(847) 505-3933<br>joseph.wiedemann@gmail.com<br><br>* 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**<br>TIME: 7:00 – 8:30pm<br>LOCATION: Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville, IL | Call for additional information and directions. | Marilyn and Barry Kahn<br>(847) 975-2403<br>marilynkahn1@gmail.com |
| **ROCKFORD** | | |
| 2nd Sunday of **every month**<br>TIME: 2:00 – 4:00pm<br>LOCATION: OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room, Rockford, IL<br>* 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<br>(815) 498-6092<br>dchodgson1946@gmail.com |
| **SOUTH SUBURBAN** | | |
| 2nd Tuesday of **odd months**<br>TIME: 7:00 – 8:30pm<br>LOCATION: 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<br>(708) 955-3080<br>shamrock1959@att.net<br>TCHF Office (877) 687-8243 |
| **CHICAGO – RUSH UNIVERSITY MEDICAL CENTER** | | |
| 4th Tuesday of **even months**<br>TIME: 7:00 to 8:30pm<br>LOCATION: Rush University Medical Center, 1620 W. Harrison Street, Tower Resource Center, Tower, 4th Floor, Suite 04527, Chicago, IL<br>* 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.<br><br>**2019 Meetings:** 2/26, 4/23, 6/25, 8/27, 10/22 | For more info, contact Sarah Mitchell Chen, LSW (312) 942-6445<br><br>Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD |
| **CHICAGO – NORTHWESTERN MEDICINE** | | |
| TIME: 10:00am – 11:30am<br>LOCATION: Logan Square Library, 3030 W. Fullerton Ave., Chicago, IL – Room: First Meeting Room<br>**(Free ground-level parking lot)** | ***Now open to ALL members of the HD community: family members, friends, and patients—with and without symptoms.***<br><br>**2019 Meetings:** 1/26, 3/16, 5/18, 7/20, 9/14, Nov date to be determined | Emily Zivin<br>(630) 443-9876<br>ezivin@hdsa.org<br><br>A group to build connection and support to those affected by HD. |
| **MUNSTER, INDIANA** | | |
| 2nd Tuesday of **even months**<br>TIME: 7:00 – 8:30pm<br>LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN | **2019 Meetings:** 2/13, 4/10, 6/12, 8/14, 10/9, 12/11 | Cindy Rogers<br>(219) 836-2369<br>clrogers111@comcast.net |


| | |
|---|---|
| March 30, 2019 | HDSA IL Spring Fling – Arlington Heights, IL |
| 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 |
| August 24, 2019 | HDSA IL Chapter Baggo Tournament |

**https://hdsa.org/il**


**2019**