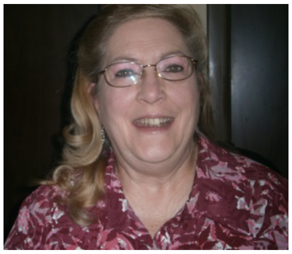
Hopes and Dreams
Huntington's Disease Society of America - Illinois Chapter Quarterly Newsletter

President's Message



Hello Illinois Families,

Wow!! Many of you were at the 32nd Annual HDSA National Convention held at the Renaissance Hotel in Schaumburg, and I hope that everyone came away as rejuvenated and filled with hope for the future as I did. From the opening ceremony and Keynote Speaker, Shana Verstegen and being HD STRONG, to the special Film Screening of Her Mother's Daughter, Friday ended with a BANG at the NYA Talent Show.

Saturday kicked off with the Research Forum and Keynote Speaker, Elena Cattaneo, PhD, Professor, University of Milan, Italy. The Research Forum continued with Speakers Ed Wild, MD, PhD, Scientist, University College of London, Institute of Neurology and Jeff Carroll, PhD, Assistant Professor, Western Washington University. After a brief break there was the Clinical Trials showcase & Luncheon. We heard from Jamie Levy, CDHI about **ENROLL-HD;** Paul Bolno, MD, *WAVE Life Sciences* about ***WAVE Life Sciences.*** We also heard from Neil Simon, PhD, *Azevan* about **STAIR** and George Yohrling, PhD, HDSA about **HD TrialFinder**.

Friday and Saturday were filled with break-out sessions that had something for everyone. Some of the sessions included were: Mental Health Awareness, Survivor's Guilt, Caregiver Huntington's Disease, Ask the Scientist, Navigating Psychiatric Admissions, Diagnosing JHD and Beyond, Managing Your Psychiatric Symptoms, Genome Editing: **CRISPR**, Drug Discovery: From Idea to Treatment. Many of these of these sessions were live streamed. If you missed them you can see them at hdsa.org/about-hdsa/annual-convention/2017-2/. Be sure to watch the "Welcome and Keynote Address", featuring Shana: #HDSTRONG.

There were also SUPPORT GROUPS for every phase of HD from Testing to Caregiving. One of the highlights was our own Emily Zivin, Social Worker for the Illinois Chapter, who facilitated the breakout, "Survivor's Guilt." There was even a breakout HD Activity Center for Persons with HD: The Sounds of Music: Music Therapy for Persons with HD.

I believe the highlight of the entire convention was Drs. Wild and Carroll's Research Forum news about IONIS Pharmaceuticals news about their "gene lowering" trial. In a significant update, the company has announced two important milestones: The trial is now fully recruited, and an 'open-label extension' will be activated for the volunteers in the current trial. For more information about this exciting news, go to HDBuzz.net.

Your Illinois Chapter was presented with 2 awards: **Best Use of Social Media** and **A Partnership Award** for helping to plan the National Convention. Saturday closed with the Gala Reception and the HDSA Awards Dinner and Gala. The Illinois Chapter Board would like to thank everyone who volunteered to help make this one of the very best conventions ever. I heard that this was the 2nd largest National Convention.

Mark your calendars now for the 33rd Annual HDSA Convention to be held in the city of stars-Los Angeles, California-at the Los Angeles Airport Marriott. June 7-9, 2018/Los Angeles, CA.

Susie Hodgson
President, HDSA Illinois Chapter
(**Illinois@hdsavolunteer.org**)

Family is *everything*

HDSA Collaborates with HealthWell Foundation to Launch Movement Disorders Fund to Provide Financial Assistance to Medicare Patients

Copayment and Premium Assistance Available for Individuals with Huntington's Disease

New York, NY (May 2, 2017) —The Huntington's Disease Society of America (HDSA) is proud to announce a valuable partnership with The HealthWell Foundation®, an independent non-profit that provides a financial lifeline for inadequately insured Americans, has launched a Movement Disorders Fund to provide copayment and premium assistance to eligible Medicare patients. Through the fund, HealthWell will provide up to $10,000 in copayment or premium assistance to individuals who have annual household incomes up to 500 percent of the federal poverty level. The new fund will assist patients in several different movement-related disease areas, including, but not limited to, Huntington's disease, Tourette syndrome, Parkinson's disease, Chorea, Tardive Dyskinesia and General Dyskinesia.

"The assistance that the HealthWell Foundation will be able to provide to individuals living with Huntington's disease through this fund addresses an unmet and critical need," said Louise Vetter, President and Chief Executive Officer, Huntington's Disease Society of America. "Huntington's disease (HD) is a devastating and debilitating disease for which there is no cure. Offering copayment and premium assistance as a resource to HD patients and their families will certainly go a long way in diminishing some of the financial obstacles they face in treating their disease."

Huntington's Disease Society of America + HealthWell Foundation®
When health insurance is not enough.®

HDSA COLLABORATES WITH THE HEALTHWELL FOUNDATION TO PROVIDE INSURANCE SUPPORT FOR HD FAMILIES

The Huntington's Disease Society of America (HDSA) announced a valuable partnership with the The HealthWell Foundation, an independent non-profit that provides a financial lifeline for inadequately insured Americans. The HealthWell Foundation has launched a Movement Disorders Fund to provide copayment and premium assistance to eligible Medicare patients.

Through the fund, HealthWell will provide up to $10,000 in copayment or premium assistance to individuals who have annual household incomes up to 500 percent of the federal poverty level.

To learn more about the fund and to determine eligibility and apply for financial assistance, visit HealthWell's Movement Disorders Fund page at https://www.healthwellfoundation.org/fund/movement-disorders-medicare-access/

Save the Date

November 11, 2017

8:30 a.m. – 12:00 p.m.

Northwestern Medicine

Hope Through Education: Huntington's Disease Patient and Family Symposium

**At risk support group from 12:30pm to 2:00pm*

Sponsored by the Northwestern Medicine Parkinson's Disease and

This symposium is complimentary and open to individuals, their family members and caregivers. Established patients, as well as newly diagnosed and at-risk individuals are encouraged to attend.

To register call 312.926.8400

CREDENTIALED HUNTINGTON RESEARCH SITE

Make **change** happen, **volunteer!**

HDSA Launches First-of-its-Kind
Free Telehealth Counseling for HD Families

Announcing free online therapy sessions to people affected by HD provided by **HDSA** and **American Well®**, a leading telehealth company. HDSA-trained licensed social workers and psychologists will be available to HD families in all 50 states.

To utilize HDSA's free telehealth portal, visit www.hdsa.amwell.com or download the free Amwell® app and use the codes **HDSA** or **HD** to access the Huntington's disease practice.

FUNDING FOR THIS PROGRAM IS PROVIDED BY A GENEROUS GRANT FROM TEVA PHARMACEUTICALS.

NEWS ALERT!!!

HUNTINGTON'S DISEASE SOCIETY OF AMERICA LAUNCHES FIRST-OF-ITS-KIND FREE TELEHEALTH COUNSELING FOR HD FAMILIES

New York, NY, June 21, 2017 – Today, the Huntington's Disease Society of America (HDSA) is launching a new technology partnership with leading telehealth company American Well® to offer free online therapy to people affected by Huntington's disease (HD). HDSA-trained licensed social workers and psychologists will be available on American Well's telehealth platform to families in all 50 states to help manage the emotional symptoms and burden of HD. Funding for this program is provided by a generous grant from Teva Pharmaceuticals.

Psychiatric and behavioral problems are highly prevalent in families affected by Huntington's disease, which is a rare, genetic disease that causes the progressive breakdown of nerve cells in the brain. Best estimates from mental health professionals indicate that approximately 50 percent of patients seen at HD clinics, such as HDSA Centers of Excellence, are referred to counseling for issues ranging from anxiety and depression to stress management and suicidal thoughts. Unfortunately, it is estimated that only between 15 and 25 percent of those referred for counseling actually seek treatment.

"By partnering with American Well, we are confident that we can greatly improve access to care for families impacted by the challenging mental health nature of HD," said Louise Vetter, President & CEO of the Huntington's Disease Society of America. "Thanks to the generous support from Teva we are able to provide free telehealth appointments with professionals who have HD expertise. This fills an urgent gap in care and removes the barriers of cost, geography and convenient scheduling that too often keep families from seeking the help they need."

Huntington's disease deteriorates a person's physical and mental abilities during their prime working years and has no cure. Each child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes HD. Today, there are more than 30,000 symptomatic Americans and an estimated 200,000 at-risk of inheriting the disease. The symptoms of HD are described as having ALS, Parkinson's and Alzheimer's – simultaneously.

The burden of care for families affected by HD is enormous. The need for multiple, expert care providers coupled with the physical, emotional and financial barriers makes following optimal clinical plans challenging. Finding clinicians skilled in HD, travelling to these providers and, for caregivers, finding coverage to care for their loved ones so they can take care of themselves, are all fundamental logistical barriers to HD care.

"We are so pleased to partner with the HDSA and make mental health services available online to Huntington's disease patients, their caregivers and families," said Mary Modahl, Senior Vice President and Chief Marketing Officer, American Well. "We know from experience that many patients with chronic conditions often also bear the burden of mental health conditions such as depression and anxiety. The ability to receive counseling and support from experienced healthcare professionals through telehealth should ease that burden by making it easier and more convenient to get help."

To utilize HDSA's free telehealth portal, visit www.hdsa.amwell.com or download the free Amwell® app and use the codes **HDSA** or **HD** to access the Huntington's disease practice. On the site, patients can schedule personal appointments with social workers and psychologists licensed in their state. The session is free for families affected by HD, and no insurance is required.

Huntington's Disease Society of America
Illinois CHAPTER

HDSA IL BAGGO TOURNAMENT

Double Elimination

Saturday, August 26, 2017 at 1:00pm

Team Check in at 12:30pm

(rain date – August 27th)

The Home of Charlotte Rybarczyk

3000 Owl Drive, Rolling Meadows, IL 60008

SPLIT THE POT RAFFLES

32 TEAMS MAX!

Vienna Hot Dogs, Beef Sandwiches and Lemonade included

Purchase cups for Beer and Mudslides

Registration:	**Sponsorships:**
$60/Team	Cornhole/$250
$15/Spectator	Ace/$500

Your donation is 100% tax deductible

Winning team receives $100 plus both players choose one of our custom Baggo sets!

Questions? Contact Charlotte Rybarczyk at 847-259-3593 or charlotte82963@gmail.com

Return registration form and monies by August 10th to:
HDSA IL Chapter, PO Box 1883, Arlington Heights, IL 60006
Checks should be made payable to **HDSA IL Chapter**

TEAM NAME ______________________________

PLAYER 1 NAME ______________________________

PLAYER 2 NAME ______________________________

PHONE NUMBER ______________________________

E-MAIL ADDRESS ______________________________

SPECTATORS: Names ______________________ How many? __________

SPONSOR: Name ______________________ Amount __________

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Falls and Huntington's Disease

Introduction

Preventing falls is an essential objective for people living with Huntington's Disease (HD). Involuntary jerky movements (chorea) and walking and balance issues associated with HD can increase a person's risk of falling. Fall related injuries can lead to injuries and increased need for medical care, emergency room visits, or hospitalizations. Our goal is to reduce the risk of falls by providing education and strategies to help a person with HD to be safe.

Falls typically start to occur in the middle stages of HD. Falls can occur in many different situations, such as when trying to multi-task (e.g., walking and carrying on a conversation at the same time) or being distracted, stepping over obstacles on the floor or over a curb, turning quickly particularly when carrying items, or going up and down stairs. Some of the walking and balance issues seen in HD can increase one's risk of falls. People with HD can experience changes in their speed of walking and steps with slower gait; shorter, uneven or veering steps; and needed to have a wider stance (feet placed father apart). In addition, people with HD can sway when standing or walking which can lead to feeling or being off balance.

Benefits of Physical Therapy

A great place to start preventing falls or dealing with walking and balance trouble is with physical therapy (PT). Physical therapists are trained professionals that can teach exercises that are especially helpful for fall prevention.
You may be thinking "I haven't fallen yet. Do I need PT? When is the best time for me to start?"

Great question! The best time is actually before you ever fall. If you have been having any "near misses or near falls," or if you notice you have become more afraid of falling or cautious while walking, then PT could be ~~a~~ great addition to your treatment plan. Physical therapists can work with you on building physical strength and increasing coordination and balance to improve your walking. The training you do in PT sessions will provide you with knowledge to continue doing the PT exercises on your own. If it has been awhile since your last session of PT, you may want to talk to your neurologist or primary care physician about starting PT again to refresh and relearn. PT can be helpful throughout all stages of HD. However, the goals of PT and strategies used from early, to middle, to later stage HD and depending on a person's individual needs. For example, early on, the goals may be to have a regular exercise program and work on strength and balance to delay mobility issues. Later on, exercises may be needed for strengthening and balance, but also for range of motion, fall prevention, and enhancing function. Other goals may be to prevent complications of immobility and choose appropriate walking devices or seating systems.

"Fall" Proofing your Home

Many falls happen at home. It is important to look at the home environment to prevent falls. Remove any clutter from hallways or entryways. Move items such as magazine racks, child or pet toys, end tables, or coat racks from high traffic areas as these could be tripping hazards. Rugs can also be a potential hazard. Adding slip-resistant backing to rugs can be helpful. Another option is to remove rugs altogether from the household. Replace any loose carpeting or uneven floorboards.

Wearing secure shoes, even while indoors, is encouraged. Check to make sure that shoelaces are tied and not dragging on the floor. Velcro straps can provide an easy substitute to shoelaces. Slippers, sandals, high-heels, and other non-secure footwear should not be worn as they can lead to a fall.

Check that stair railings are secure and hold on to them as you walk up and down staircases. Store essential items such as food, dishes, and clothing below your head height so you do not have to reach up or climb on a stepstool. In the kitchen, make sure to clean spills immediately so you don't slip.

Don't Forget the Bathroom!

The bathroom is another area of the household that can be a potential fall zone. Purchasing a non-slip mat for the bathtub or a shower seat can help you avoid a serious injury. Another option would be a hand-held shower head that can be used while seated. Sitting down to dry off after showering is also simple and effective strategy. Grab bars can be installed in the shower and near the toilet to help with balance. Remember, a towel rack is not a grab bar! It can be pulled off the wall with your body weight.

Before bed every night ensure there is a clear path from your bed to the bathroom for those middle of the night awakenings to urinate. A nightlight in your bathroom is also helpful. Bedside commodes or urinals can be helpful and save a trip to the bathroom.

Physical and occupational therapists are great resources who can evaluate your home environment and assist in making any changes needed to ensure your safety. Ask your healthcare professional if you qualify for a home visit with an occupational therapist.

Overall, there are many tips and tricks that can be easily used to decrease the risk of falling. We encourage you to discuss these options with your healthcare provider.
Stay safe and be well!

References

1. Grimbergen et al. (2008). Falls and gait disturbances in Huntington's disease. Movement Disorders, pages 970-976.
2. Mayo Clinic Staff. (2016). Falls Prevention: Simple tips to prevent falls. http://www.mayoclinic.org/healthy-lifestyle/healthy-aging/in-depth/fall-prevention/art-20047358?pg=1

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HDSA ILLINOIS CHAPTER

HDBuzz

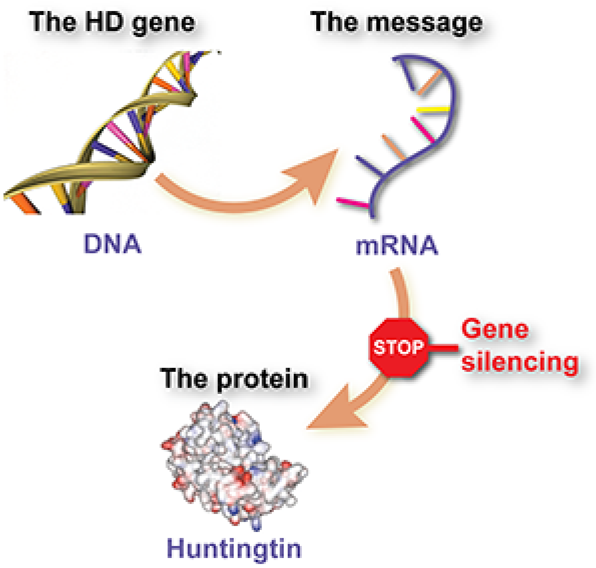
Update confirms Huntington's disease 'gene silencing' trial on track

By Dr Jeff Carroll on June 22, 2017; Edited by Dr Tamara Maiuri

Ionis Pharmaceuticals launched the first ever trial of a huntingtin-lowering drug – sometimes called a ‘gene silencing drug’ – in late 2015. In a significant update, the company has announced two important milestones: the trial is now fully recruited, and an ‘open-label extension’ will be activated for the volunteers in the current trial. While nothing is guaranteed, this bodes well for the future of this important program.

A quick recap on huntingtin lowering

The idea of ‘switching off’ the cause of Huntington’s disease was one of the first thoughts that popped into researchers' heads when the HD gene was discovered in 1993.



Huntingtin lowering drugs – previously called ‘gene silencing’ drugs – reduce levels of mutant huntingtin by telling cells to delete the ‘message molecule’ from the huntingtin gene

The first major progress in achieving this came around a decade ago, when several mouse studies reported success in reducing the activity of the gene. Doing that lowered levels of the protein for which the gene is a recipe: **mutant huntingtin**. In each case, lowering huntingtin improved symptoms of the disease in the HD mice.

These huntingtin-lowering drugs all act in similar ways – by ‘shooting the messenger’. A gene is a recipe for a protein, but in between gene and protein, a chemical messenger is made that is essentially a working copy of the gene. Getting rid of the messenger breaks the production line, so less of the protein is made.

Huntingtin-lowering drugs are made from molecules similar to DNA, the stuff that makes up our genes. These kinds of chemical have the special ability to stick to each other strongly, if the sequence of genetic ‘letters’ matches up properly. Drug-makers can build designer molecules with a sequence that will stick to the messenger molecule of the huntingtin gene, but not to other messengers.

When the cell sees that the messenger has a drug molecule stuck to it, it recognizes that something unusual has happened, and responds by deleting the message molecule. Eventually, this lowers the level of the protein.

The drug molecules themselves come in many different flavors. Some are made from RNA (the stuff the messenger is made from), while others are made from DNA (the stuff our genes are made from).

One quick word on terminology. Many people, including HDBuzz, have referred to these as ‘gene silencing’ drugs. That slightly suggests we’re trying to switch off the gene altogether, which is probably not possible or desirable. So, increasingly, you’ll hear us call them ‘huntingtin lowering’ drugs. We’ll still use the phrase ‘gene silencing’ from time to time, so that people can find the latest article if they Google the better-known term.

The current trial

When they started working on HD over a decade ago, the California-based company behind the current trial was called Isis Pharmaceuticals. A lot has changed since then, including the name of the company – since 2015 it’s been called Ionis.

Ionis' drug is an **antisense oligonucleotide**, or ASO. That means it’s a single strand of chemically modified DNA, designed to stick to the message molecule from the huntingtin gene.

Just to keep things exciting, the drug itself goes by two names. It was initially called **ISIS-443139**, but lately it's been going by IONIS-HTTRx or just **HTTRx** – a combination of *HTT*, the abbreviation scientists use for the huntingtin gene, and *Rx*, a symbol used in the pharmaceutical industry meaning a treatment or prescription.

"The open-label extension study will only be available to volunteers in the current trial."
(Fun fact: the origin of 'Rx' is unknown, but it may come from the Latin word 'recipe'.)

Ionis' trial, led in partnership with Prof Sarah Tabrizi of University College London, was the first time a targeted huntingtin-lowering drug had been tested in humans. As with the first trial of any new drug, the main focus of the trial is **safety**.

To reach the brain, ASO drugs like HTTRx have to be injected into the spinal fluid using a thin needle. This is called **intrathecal injection**. While this may sound gruesome, it is a commonly-used method for treating the brain in other conditions like cancer. A closely related procedure – lumbar puncture or spinal tap – is very widely used, and indeed many hundreds of volunteers from Huntington's disease families have undergone this procedure to donate valuable spinal fluid to help with HD research.

The current HTTRx safety trial involves patients with early symptoms of Huntington's disease. After extensive clinical evaluation, each volunteer receives four injections of the drug at monthly intervals, followed by a final spinal fluid collection.

Throughout the trial, a **placebo** arm has been used, to help distinguish drug effects from the effects of being in the trial, such as the injection procedure. The trial has a **dose escalation** design: very low doses were given at first, with later volunteers getting higher doses.

What's new

Today's press release from Ionis – the first official update since the trial began – brings cautiously optimistic news. It contains two important announcements. First, recruitment into the current trial is complete. And second, the company is launching an **open label extension** to the current trial.

Completion of recruitment is an important milestone for any trial, but for this one it's particularly significant. The trial involved a number of 'firsts' – the first ASO drug given to HD patients, the first time intrathecal injection had been used in HD – and each dose escalation brought both the hope of stronger benefits and a greater risk of unwanted effects.

Throughout a trial like this, an independent committee of experts regularly reviews all the safety data to look for any sign of danger or harm. News that the trial is fully recruited and the final patients are going through the procedures is a strong suggestion that even at the highest doses, the drug's safety looks good. Despite exhaustive safety testing before going into patients, any drug can produce unwanted effects, so that's really the best news we could be hoping to hear at this stage.

In the words of the press release: "The safety and tolerability profile of IONIS-HTTRx in the completed cohorts of the Phase 1/2a study supports its continued development". Thumbs up to that from us.

Developing a drug is like a relay race - it happens in stages and each one has to complete successfully for the next to start. This announcement is a good sign that the next stage – an efficacy trial to test whether HTTRx slows down Huntington's disease – may be round the corner.

With recruitment complete, Ionis is now in a position to set out a timetable for completion of the trial and the first release of its results. "Top line results" are expected **around the end of 2017**. In our experience, the results of a trial like this may not come out all at once. The safety data may come first, but information about whether treatment with HTTRx lowered the level of huntingtin protein in the spinal fluid – a much-anticipated 'biomarker' outcome – may take a little longer to materialize.

An open-label extension

The current HTTRx trial has a **blinded** design: some volunteers received four injections containing no active drug – and neither the patients nor the trial personnel knew who was receiving drug or placebo.

In an **open-label extension** trial, or **OLE**, the volunteers from a blinded trial are invited to come back for further doses, and every volunteer gets the active drug rather than some receiving drug and some the placebo – usually at the highest dose that was safely tried in the blinded trial.

Ionis had previously said that an open-label extension **may** be implemented if the data from the safety trial looked good. We don't want to read too much into a brief announcement, but running an OLE isn't cheap for a trial sponsor, so this announcement certainly gives us optimism about the whole HTTRx program.

The open-label extension study will only be available to volunteers in the current trial. That means it will run in the same study centers in the UK, Canada and Germany. The length and exact design of the OLE have not yet been announced, but it will provide a wealth of information that Ionis and its partner, Roche, can use to plan their next steps.

Thanking our heroes

An important upside of an open-label extension is that it rewards the volunteers who took part in the original study by giving them guaranteed access to the active drug. We're particularly pleased about this aspect of the announcement. The participants in this trial were all Huntington's disease family members who gave up significant time to receive spinal injections of a drug that, at the start of the trial, had never been given to humans before. Those enrolling later were given higher doses than anyone had previously received.

Whatever the outcome, these volunteers accepted personal risk, and in most cases did so to help others rather than themselves. Our whole community owes these heroes a debt of gratitude for their bravery and service. Please join us in saluting them on Social Media using the hashtag #HDResearchHeroes.

What's next?

"Ionis said: "the next step for this program will be to conduct a study to investigate if decreasing mutant huntingtin protein with IONIS-HTTRx can slow the progression of this terrible disease." "

The open-label extension will begin soon, likely in the next few months. Volunteers in the safety trial will be contacted by the study sites, with information about how and when they can enroll for the OLE. Meanwhile those participants still in the blinded trial will need to finish their involvement before rolling over into the open-label extension.

If you weren't in the blinded safety trial, you will not be able to sign up for the open-label extension. **Please do not contact study sites unless you were in the original trial.**

Towards the end of 2017, we can expect to hear an official announcement about the results of the blinded trial. Don't be disappointed if that is confined to safety data in the first instance. "Safe and well tolerated" should be music to the ears of HD family members after a trial of this kind!

Later, maybe in early 2018, there may be a separate announcement about some of the more experimental results of the safety trial - things like whether HTTRx lowered the huntingtin level in the spinal fluid.

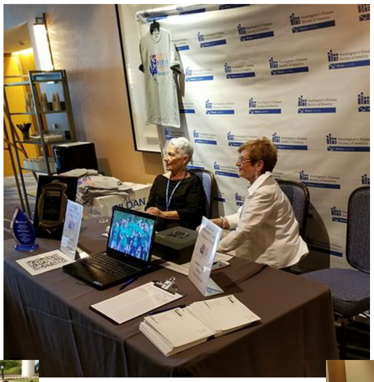
The next big news, if all continues to go well, may be an announcement of an efficacy trial, testing whether HTTRx for long enough so determine whether it slows progression of the disease. Roche now has the right to opt in, take over development of the drug and run such a trial based on its own decision-making process. With a bit of luck, we may hear about that in the coming months too.

Emphasizing their desire to move the drug forward, in a separate announcement made directly to the HD community, Ionis said "Upon study completion, the next step for this program will be to conduct a study to investigate if decreasing mutant huntingtin protein with IONIS-HTTRx can slow the progression of this terrible disease."

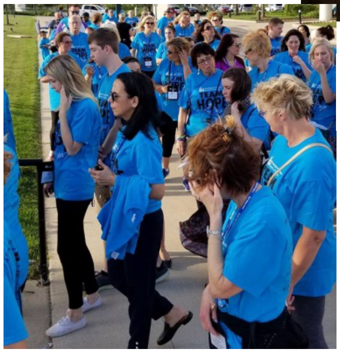
As yet, we have no idea when the next big study will start, but our best guess would be late 2018 or early 2019. As to when, and how many patients, and what countries and sites – it is just too early to be sure, but Ionis says "Future studies for the program will be conducted globally **and will include US study sites**". As to the rest, you can be sure you'll read about it first on HDBuzz.

Nothing happens quickly enough for people whose families are impacted by HD – but this is a moment to pause and be glad that, for this important huntingtin lowering program, the news so far is all good.

32nd Annual HDSA National Convention in Schaumburg, IL attended by 987 people!!


IL Board Member, Marilyn Kahn and friend Doris, at the IL Chapter Table selling Convention t-shirts

The HDSA National Convention held in Schaumburg, IL, June 22 – 24, gathered 987 people from around the country to hear about the latest developments in efforts to cure HD. Caregivers, family members at risk, our wonderful young people of the National Youth Alliance, and individuals with HD also learned how to live more fully while coping with the disease today.


A Team Hope Walk around the hotel kicked off on Thursday Night. HD Blue was represented!!

Huntington's Disease Society of America
HDSA
32ND ANNUAL CONVENTION
SCHAUMBURG, IL
JUNE 22-24, 2017


IL Chapter volunteers on Wednesday night filling the Convention tote bags that were distributed to all attendees

The convention kicked-off with a Team Hope 'Walk around the Hotel' on Thursday night followed by a Welcome Reception complete with deep-dish pizza and funnel cakes and many sports-themed inflatable games of chance culminating with a free raffle drawing with over 50 prizes donated by Teva Pharmaceuticals.

Friday and Saturday were full of sessions on topics such as driving issues, survivor's guilt, research updates, diagnosing JHD, drug discovery and even individual support group sessions geared toward caregivers, persons with HD, at risk and youth. Recordings of MANY of the sessions are now available at **HDSA.org/2017 Convention**. PowerPoint presentations of the tracks will be coming soon to www.hdsa.org.


IL Chapter President, Susie Hodgson and IL Chapter Newsletter Editor, Maryann Moynihan

The Illinois Chapter received the award for '**Outstanding Social Media Outreach Activity'** which honors an outstanding Chapter who promotes their fundraising and community highlights through the use of Social Media. A few highlights of how the Illinois Chapter achieves this are we coordinate the use of our chapter page (http://www.hdsa.org/il) with our Facebook page (http://www.facebook.com/hdsaillinoischapter), with our Chapter Newsletter, Hopes & Dreams, and distributed on line (or through using U.S. Mail if the families do not have an online account.

Members of the National Youth Alliance presented a 'Talent Show' on Friday night which was fabulous!! What amazing young people we have who are affected in some way by Huntington's disease. They are our future, and we could not be prouder.

The weekend ended with a moving candlelight ceremony at the Saturday Gala followed by an evening of fellowship, dancing and celebrating who we are and how far we've come! Looking forward to seeing everyone next year in Los Angeles, June 7 – 9, 2018.


IL Chapter President, Susie Hodgson during the candlelight ceremony at the Saturday night Gala

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

Support groups are a great way to connect to other individuals and families who struggle with Huntington's Disease. These groups are formed when a group of individuals meet on a regular scheduled bases and share common health concerns and/or interest. The goals of a support group are for members to share experiences and provide encouragement in a safe and supportive environment.

Support groups bring people together and help create communities. The benefits of participating in support group include, feeling less lonely, improving coping skills, reducing distress/depression, gaining a sense of empowerment, developing a clearer understand of situations and getting practical advice. Because our HD community is spread out throughout the state, support groups have been beneficial to bring people together and provide and extra level of encouragement and friendship.

When joining a support group, one should know that they are designed to be a safe space for individuals and families who have similar experiences. Sharing experiences help people engage with one other another in a supportive setting. Meeting individuals and families who share the same struggles allows participants to realize that they are not alone and gives them the opportunity to gain new knowledge.

The Illinois HDSA chapter offers several support groups within the state.
Please follow **http://illinois.hdsa.org/about/support-groups** for more detailed information.

Support Group at Northwestern Memorial Hospital

The HD living positive group for at-risk and asymptomatic individuals and families is led by Dr. Danny Bega and Emily Zivin, LCSW. The group is held at Northwestern Memorial Hospital and meets bimonthly. Remainder of 2017 dates and locations are listed below and also available at: **http://illinois.hdsa.org/about/support-groups**.
For more information contact Emily Zivin, ezivin@hdsa.org or 630-443-9876.

Date: 7/8/2017 10:00 AM - 11:30 AM
Northwestern Memorial Hospital Feinberg Pavilion ~ Room: Feinberg NM Acd-2-715 (Near Chapel)

Date: 9/9/2017 10:00 AM - 11:30 AM
Northwestern Memorial Hospital Feinberg Pavilion ~ Room: Feinberg NM Acd-2-715 (Near Chapel)

Date: 11/11/2017 12:30 PM – 2:00 PM
(After Northwestern HD Symposium (see Save the Date below)
Northwestern Memorial Hospital Feinberg Pavilion ~ Room: B

13TH Annual Team Hope Walk – SUCCESS!!

By Dave Hodgson

On Sunday, May 21, 2017, the Illinois Chapter of the Huntington's Disease Society of America held its 13th Annual Team Hope Walk at the Grand Pavilion on the Naperville Riverwalk.

Over 640 people and several family pets helped to raise over $93,000.00 to help support the mission of HDSA which is to improve the lives of everyone affected by Huntington's Disease. Once again we were blessed with beautiful weather, THE Famous Hot Dog Lunch, music, and some new fun with a dunk tank. Thank you to those who braved the cold water!

TEVA Neuroscience and TAGI Pharmaceuticals, our two national sponsors, were on hand to talk about their latest offerings. Thank you for helping to underwrite the Team Hope Walk events throughout the nation! If you missed the Walk this year, we've posted several pictures on our Facebook page. ***Search for HDSA Illinois Chapter***. Be sure to mark your calendar for next year's walk on Sunday, May 20, 2018!

Thank you to those that braved the cold water in the Dunk Tank!

Oldest and Youngest at the Event!!

Mary Bos with George and Peter

Team Echingham

Memorials and Tributes

In Memory of In Memory of John Allen Lynch from Phillip Begole

In Memory of Leona May Hajost from Robert & Grace Pascolini, Carolyn Hajost, James & Cynthia Hajost, Donald & Mary Ann Spooner, Gary & Marika Neuhardt, James Hajost

In Memory of Katherine Milbratz from Janet Pomillo

In Honor of Lucinda Pasley from Gary & Vallie Gould

SUPPORT groups

Date/Time	Additional Information	Contact Information
CENTRAL ILLINOIS		
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, Bloomington, IL	**2017 Meetings:** 2/12, 4/9, 6/11, 8/13, 10/8 (No meeting in Dec.)	Dave or Susie Hodgson (815) 498-6092 dchodgson1946@gmail.com
GENEVA		
3rd or 4th Sunday of **odd numbered months** (see dates in next column) TIME: 2:00 to 3:30pm LOCATION: Cadence 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. **2017 Meetings:** 1/29, 3/26, 5/28, 7/23, 9/17, 11/12	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
LAKE COUNTY		
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 marilynkahn1@gmail.com
ROCKFORD		
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
SOUTH SUBURBAN		
2nd Tuesday of **odd months** TIME: 7:00 – 8:30pm LOCATION: Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	**2017 Meetings:** 1/10, 3/14, 5/9, 7/11, 9/12, 11/14	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH UNIVERSITY MEDICAL CENTER		
4th Tuesday of **even months** TIME: 7:00 to 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.	Valet parking is available in front of 1620 W. Harrison. Parking at both of these venues will be validated in full. **2017 Meetings:** 7/25, 8/28, 10/24, 12/12	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 MEMORIAL HOSPITAL		
Meeting Date: 7/8/2017, TIME: 10:00 - 11:30am Northwestern Memorial Hospital Feinberg Pavilion Room: Feinberg NM Acd-2-715 (Near Chapel) **Meeting Date: 9/9/2017**, TIME: 10:00 - 11:30am Northwestern Memorial Hospital Feinberg Pavilion Room: Feinberg NM Acd-2-715 (Near Chapel) **Meeting Date: 11/11/2017**, TIME: 12:30 - 2:00pm Northwestern Memorial Hospital Feinberg Pavilion – Room B (After Northwestern HD Symposium)	For At Risk (non-symptomatic) patients and family members.	Emily Zivin (630) 443-9876 ezivin@hdsa.org **Parking Passes Available**
MUNSTER, INDIANA		
2nd Tuesday of **even months** TIME: 7:00 – 8:30pm LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	**2017 Meetings:** 2/14, 4/11, 6/13, 8/8, 10/10, 12/12	Cindy Rogers (219) 836-2369 clrogers111@comcast.net

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

☑ SAVE THIS DATE!

August 26, 2017	HDSA IL Chapter Baggo Tournament – Rolling Meadows, IL
May 20, 2018	HDSA IL Chapter Annual Team Hope Walk – Naperville, IL
June 7 – 9, 2018	HDSA National Convention – Los Angeles, CA

https://hdsa.org/il

SUMMER 2017