Hopes and Dreams

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

President's Message

Greetings Illinois HD Families,

Happy Fall! Fall is in the air. The temperatures may not necessarily feel like it just yet, but it is coming, because… Pumpkins are everywhere!!

As we go into this season we are finishing up some of our fundraising events. A golf outing, Baggo Tournament, and two Team Hope Walks have happened since our last newsletter. Congratulations to all those events for helping raise money for HDSA and raising awareness in the fight against HD. Thank you to all of you for your support at all these events. The time and effort put into these events by all our volunteers is amazing. There is a lot of time and dedication that is put into the event that happens before the event. Committees meet months in advance, spend a lot of time working together, and gaining support of businesses, neighbors and friends. Each event comes with common themes.

Each event is full of excitement! The event itself has entertainment factors that may be a reason to why you attend an event. Maybe you really like walking, golfing, or playing bags. These events are more than just what they say on their advertisement. They are full of HOPE and TOGETHERNESS!

We have HOPE for one day finding the cure for HD! We hope that in all our research and advancements in medicine that we can stop this disease from hurting more of the people that we love and care about. The TOGETHERNESS that is at all these events helps find comfort in knowing that there is someone there with us. Together we can work to find that cure. Together we are not alone. Together we can make things happen. TOGETHER we have HOPE!

Know that you are not alone, and that there is always someone there for you. We have an amazing group of individuals on our board. Support networks are available everywhere. There is always someone there to help you.

We are in this together! Please let me know if you have any questions at all.

Have a great Fall,

Larry Haigh
President, HDSA Illinois Chapter

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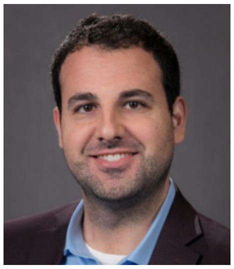
This newsletter attempts to report items of interest relating to the individuals with Huntington's Disease, their families, healthcare professionals, and interested friends and supporters. HDSA and the Illinois Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, 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.



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Caregiving for HD

By Danielle Marino, LCSW & Danny Bega, MD

HD is a family disease. If you are a family member or friend of someone with HD, caring for them is the greatest gift you can give. Caregiving can give us a sense of purpose, a chance to be needed and give back to a loved one, but it also can be draining. HD caregivers may themselves experience problems with mood, personal health, and quality of life.

We recently conducted a study at Northwestern where we surveyed HD caregivers in our clinic to learn more about their experience[1]. We learned that caregivers at our center exhibit a moderate degree of "burnout" related to their caregiving role and estimate an average of 42 hours per week (equivalent to a full-time job) in their caregiving role. Not surprisingly, those caring for loved ones with the most functional disability had the most burnout. Other factors relating to caregiver burden were less clear. We know that demands of caring for another person may be physical, financial, or emotional. As people require increasingly complex care, cognitive and behavioral changes may impact relationships, and we need to do a better job of addressing caregiver emotions over those changes in relationships. Importantly, identifying caregiver "burnout" early can introduce earlier interventions and support. Here are some suggestions to reducing caregiver burnout:

Build Community Now

In our clinic, we see that caregivers that are least burnt out are those that ask for help and spread the work of caregiving out among many. They aren't afraid to let their friends and family know of regular intervals they need help. Some even join and begin volunteering for communities such as local churches, temples, clubs, or senior centers years before they will need a community to pull from for support. Giving back to a community now could very well result in a community there to support you and your family later.

Use Technology

Families today are spread out and busier than ever. It's often hard to coordinate care among many family members. Those who have done it successfully use tools like Google Calendar to share upcoming doctor's appointments, vacations, and coverage needs. If family or friends ask, "how can I help?" add them to the Google Calendar where they can sign up to visit or stay with the person with HD. By allowing others to contribute their time, you reduce the burden on one caregiver and give many others the opportunity to help.

Caregivers have also shared with us how helpful products like Amazon Echo Show allow them to use a call-in video system to their living room or kitchen to see and talk to their loved one. They place the console in the corner of a room and the family member with HD doesn't have to press any buttons to answer. The caregiver can be away from home and call in and video chat. Other families creatively use an old phone as a video monitoring system along with apps like AtHome Camera Security, so they can monitor how their loved one is doing using video on their phone.
https://apps.apple.com/us/app/athome-camera-security-app/id305567000

Stay Connected

There are no better experts on caregiving than other caregivers; joining a support group can mean tips and tricks that make your life easier. You don't even have to leave your home to join!

- HDSA has regular online HD Caregiver Support Groups you can sign up for here: https://hdsa.org/find-help/community-social-support/hdsa-support-groups/
- Caregiver Teleconnection (caregiverteleconnection.org) offers free one-hour conference calls where you can get expert advice, ask questions and talk to other caregivers.

We hope some of these suggestions are helpful to you and your loved ones! Don't forget to take the time to care for your own psychological and physical health needs because your loved one needs you to stay healthy. Remember that spreading out responsibility reduces caregiver burden. Caregivers who make time for themselves can give better care to their loved ones. Also, remember that your local social workers are also just a phone call away to provide support.

[1] *The study referenced is: Yu M, et al. Assessment of Caregiver Burden in Huntington's Disease. Journal of Huntington's Disease. 2019; 8:111-114.*

Huntington's Disease Society of America

The Huntington's Disease Society of America Illinois Chapter and the Great Lakes Region invite you to the 15th Annual

Celebration of Hope

Honoring Former
Chicago Blackhawks Player
Jake Dowell & His Family

Friday, November 8, 2019
Ivy Room, Chicago

Celebration of Hope

The Ivy Room ~ 12 East Ohio Street ~ Chicago

6:30 pm - Cocktails & Silent Auction
7:30 pm - Appetizer Buffet
8:00 pm - Honoree Presentation
8:30 pm - Live Auction
9:00 pm - Special Entertainment

Tickets $125 **Table of Eight $950**

Sponsorships available for more information
contact Deb Boyd at dboyd@hdsa.org or 269-629-5452

Buy Tickets or Donate Online at:
www.hdsa.org/coh-chicago

Cocktail Attire

All contributions are tax deductible to the extent provided by law. HDSA operates under section 501(c)(3) of the IRS code. We estimate the fair market value of one ticket to be $65. The charitable contribution per ticket is $60 HDSA EIN#: 13-3349872

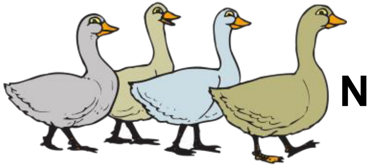
Huntington's Disease Society of America
Great Lakes REGION

HDSA is a top rated charity by

Huntington's Disease Society of America
Illinois CHAPTER

Huntington's Disease Society of America
Center of Excellence
OSF HealthCare-Illinois
Neurological Institute

Getting Your Ducks in Order



HDSA Central Illinois Symposium
November 9, 2019 ~ 9:00am to 3:15pm

OSF Healthcare Jump Trading Simulation & Education Center
1306 N. Berkeley Avenue, Peoria, IL 61603

AGENDA

9:00 - 9:25am	**Registration**	
9:25am	**Welcome**	
9:30 - 10:30am	**Research and Clinical Trials Update**	Dronacharya Lamichhane, MD
10:30 - 11:00am	**Advocacy**	Larry Haigh
11:00 - 11:15am	*Break*	
11:15 - 12:15pm	**Protecting Your Assets – Legal Documents, Trusts, Wills, etc.**	Tim Kirk
12:15 - 1:00pm	*Lunch*	
1:00 - 2:00pm	**Breakout Sessions (*Pick one*)** - Genetic Counseling and Reproductive Options (Jennifer Burton, MS, CGC) - Home Healthcare and Nursing Home Navigation for HD Patients (Emily Zivin, LCSW, MPA and Sheila Guither, MSN RN, CWOCN, COS-C)	
2:00 - 2:15pm	*Break*	
2:15 - 3:15pm	**Financial Planning –Medicare/Medicaid, Long Term Healthcare**	Tim Kirk
3:15pm	**Adjourn**	

This event is funded by the Huntington's Disease Society of America through an unrestricted educational grant from Genentech

Cost: $10/participant

Register Today

In an effort to keep cost down we ask that you register online at hdsa.org/il and select the link to HDSA Central Illinois Symposium

Day-of registration is available if needed

Northwestern Medicine®

Huntington’s Disease Patient and Family Symposium

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

Saturday, November 23, 2019

8:30 am to noon

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

Planned Topics
- HD Research Updates
- Personal Story
- Cognition in HD
- Testing & Pre-Symptomatic or Early HD
- Dealing with Advanced HD
- Question & Answer Panel
- Support Group

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

We provide FREE vouchers providing 6 hours of parking at 222 East Huron Street.

To reserve your seat, call 877.926.4664 or register online at classes.nmh.org.

This event is funded by the Huntington’s Disease Society of America through an unrestricted educational grant from Genentech.

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8 Free Phone Therapy Sessions for HD Families

Need support? Don't forget that the HDSA offers 8 free phone therapy sessions for families affected by HD. The sessions are provided by AmWell Telehealth and therapists have been educated on HD.
To learn more visit: https://hdsa.org/find-help/community-social-support/hdsa-telehealth/

Are you a jogger or serious runner? Come out for the 23rd Annual Edison Park Turkey Trot 5K fun run on November 28,2019. The 23rd Annual Edison Park Turkey Trot will be Thanksgiving morning and benefits two charities this year - Illinois Spina Bifida Association and Huntington's Disease Society of America - Illinois Chapter.

TIMES
Gobble Gallop (for ages 3-10): 8:30-9:00 a.m.
5K: 9:30 a.m.

PRICING
Early Bird Registration: August 19-September 30
$20.00 for online registration for 5K race
$12.00 for online registration for Gobble Gallop

General Registration: October 1-November 25
$25.00 for online registration for 5K race
$15.00 for online registration for Gobble Gallop

Week of Race Registration: November 26-November 28
$30.00 for online registration for the 5K race
$20.00 for online registration for the Gobble Gallop

For all the details, go to https://epturkeytrot.enmotive.com/events/register/2019-edison-park-turkey-trot

SEEKING VOLUNTEERS: We need volunteers to help pass out water bottles along the race path. If you can volunteer part of your Thanksgiving Day, please contact Dave Hodgson at dchodgson1946@gmail.com.

Just a reminder...
this is your last opportunity to support the chapter this year if you have not done so already!

Yes! Count me in!!

2019 Pledge Drive

Huntington's Disease Society of America
Illinois CHAPTER

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

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

Please complete the information below and return with your pledge:

THANK YOU

Your Name ______________________________

Email Address ______________________________

○ **Benefactor** ($500.00 donation) ○ **Patron** ($100.00 donation) ○ **Angel** ($75.00 donation) ○ **Supporter** ($50.00 donation)
○ **Member** ($25.00 donation) ○ **Friend** ($______ donation)

Make your check payable to
HDSA Illinois Chapter and mail to:
P.O. Box 1454, Lake Villa, IL 60046
*To make your pledge online go to HDSA.org/il, click DONATE and choose **pledge drive** on the drop-down menu for the solicit code*

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

2019 Golf for HD Inaugural Event

By Wayne Galasek

On Saturday, July 23, ***Golf for HD*** held its first annual golf outing on a beautiful summer day at Village Greens Golf Club in Woodridge! Registration/introductions began at 11 am, accompanied by goody bags for each golfer and hats for sale. Five (5) foursomes (20 golfers) teed off in a scramble (best ball system) starting at noon with temperatures in the low 80s. The golfers were treated to a sausage lunch after the 9th hole, while "closest to the pin" and "longest drive" challenges were presented at various holes.

During the tournament, the hard-working committee (Charlotte Rybarczyk, Holly Fraleigh and Judy Galasek) set up the awards/silent auction table, while Gretchen Galasek took lots of fab pictures of the venue as well as guests/golfers. As the finishing golfers arrived to the 19th hole, cold drinks, a cash bar and a dozen guests awaited them.

During the BBQ banquet, Charlotte made an impassioned overview of HD and the purpose of the tournament.
The golf "awards" ceremony preceded the silent auction and prizes were provided for the usual golfing skills (longest drive, closest to the pin, longest putt, lowest 4some score, etc.). However, most found the "fun" awards much more entertaining. We gave awards for the highest foursome score, Annette Funicello Beach Blanket (most sand traps hit), Captain Nemo (most water balls), Paul Bunyan (most trees hit), and Sartorial Splendor (best dressed)!

The event concluded with all the high bidders taking their wonderful silent auction baskets/prizes/gifts home.
Contributions (collected at the event or sent directly to HDSA) exceeded $1600, while the tournament/silent auction netted around $1000.

Thanks to all who participated, but especially Holly, Charlotte, Judy, Gretchen and Robert Korecky, our creative web guy.

Central Illinois Team Hope Walk

By Larry Haigh

On Sunday, September 15th members of Central Illinois gathered for the 2nd Annual Team Hope Walk that was held at Tipton Park. The day started off a bit rainy and had us a bit nervous. The rain did not keep our walkers and supporters away though. We delayed the walk about 15 minutes, and shortened our walking path a little, but we still accomplished the goal of walking to raise awareness for HD. We had just over 100 walkers in attendance. The morning started off with the light rain, some doughnuts, and walking. As the walkers returned to the pavilion they were able to enjoy a hotdog lunch grilled by a few of our volunteers and have chips and cookies too. The day ended on a good note with smiles and everyone feeling part of a family. Thank you to all that helped and came out that day!

Huntington's Disease Society of America
TEAM HOPE

ANOTHER SUCCESSFUL BAGGO TOURNAMENT!

For the third year in a row, a super fun day of Baggo raised funds for the HDSA IL Chapter! Many thanks to all the sponsors, participants, and volunteers who helped to make our third annual HDSA Illinois Chapter Baggo tournament a success! On Saturday, August 24th in Rolling Meadows, 25 teams played in a double elimination bracket vying to win $100 plus their choice of custom Baggo games built by R&R Custom Cabinetmaking. Everyone enjoyed beautiful weather and an Italian Beef and hot dog lunch provided by Vienna Beef. This year the addition of home-made chili, prepared by Tom Bartik, was a huge hit! Winning for the second year in a row, Sully & John (AKA Team Freight Train), were once again undefeated for the day! And, best of all, over $8000 was raised for our HD families in Illinois! Mark your calendars as we look forward to next year's event to be held on August 29th, 2020!

A huge 'Thank You' to our Baggo Sponsors:

teva

fraleigh foundation

ARLINGTON Construction Services

R&R Custom Cabinetmaking

PREMIER LIGHTING
LANDSCAPE LIGHTING SPECIALISTS

Joe Rybarczyk

A ALFA PLUMBING & SEWER, INC

Fourth Lake Resort
BAR GRILL
LAKE VILLA, IL

Vienna Beef

Larry Haigh

YURAN LI

And special thanks to Mary Broderick and Sue Lerchbacker for the use of their back yards!

HDBUZZ

Exciting new Huntingtin lowering tool described

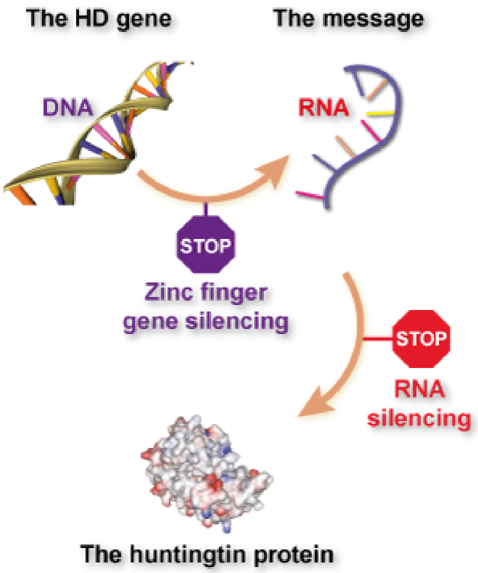
Exciting new Huntingtin Lowering work from @SangamoTx and @CHDIfoundation using "Zinc Fingers" to shut down expression of the mutant Huntingtin gene.

By: Dr Jeff Carroll August 05, 2019 Edited by Dr Tamara Maiuri

An exciting new tool in the fight against Huntington's disease has just been described. An international group of scientists have developed a new, targeted, way to lower levels of the mutant huntingtin protein.

Huntingtin genetics: from gene to protein

Huntington's disease (HD) is caused by a genetic change - or mutation - in the DNA of a specific gene. Scientists call the gene **huntingtin**. Like every other bit of DNA in our cells, the huntingtin gene is comprised of four chemical letters, which repeat in unique patterns that give them their unique functions.



Unlike ASOs and siRNA, which target RNA, ZFPs target DNA.

Those four DNA letters are referred to by abbreviations for their chemical names, 'A', 'C', 'T', and 'G'. Every case of HD is caused by a lengthening of a long stretch of the DNA letters 'C-A-G' very near the beginning of the huntingtin gene. In most people - the ones not destined to develop HD - that 'C-A-G' code is repeated around 20 times or so, for reasons we still don't totally understand.

HD arises when a person inherits a lengthened stretch of 'C-A-G', with the disease inevitably arising in people who inherit 40 or more 'C-A-G's. Note that everyone has two different copies of the huntingtin gene - one inherited from Mom and one from Dad. The vast majority of HD patients have a normal copy with a low number of 'C-A-G's, and the mutant copy in which they are longer.

Most genes, including the huntingtin gene, are used by cells as instruction manuals for building proteins - tiny molecular machines that help cells do their work. So, in the cells of people with the HD mutation, there's two different versions of the huntingtin gene, and those instructions tell the cell to make two different versions of the huntingtin protein.

Huntingtin Lowering

A major goal of the HD research world currently is to investigate whether "huntingtin lowering" strategies could be effective treatments for HD. The goal of huntingtin lowering treatments is to stop, or slow, the rate at which cells use the information in the huntingtin gene to make the huntingtin protein.

Animal studies suggest that if we can lower the amount of huntingtin protein made from the mutant huntingtin gene, we may have a hope of reducing the symptoms of HD. A number of drug companies are using a wide range of approaches to lower huntingtin as potentially new treatments for HD.

And now, ZFPs

The biotechnology company Sangamo Therapeutics has been working for a number of years on yet another way of lowering proteins: by controlling whether a gene gets turned on or activated. Their technology relies on little molecular machines called **zinc finger protein transcription factors**. That's kind of a mouthful, so we'll just call them **ZFPs** for short. Just like the other huntingtin lowering technologies we've described before, the goal for researchers using ZFPs in HD is to reduce huntingtin levels in cells.

While the basic idea is the same, ZFPs work in a quite unique way, compared to existing huntingtin lowering technologies. Existing huntingtin lowering drugs work by targeting an intermediate step between reading the huntingtin gene's information from DNA and making the huntingtin protein. The information in genes is first read from the DNA, copied into a closely related language called RNA and then translated into the language of proteins. This intermediate RNA message is the target of huntingtin lowering drugs currently in the clinic.

But ZFPs, like those developed by Sangamo and their collaborators, work in a very different way. Our cells contain a number of proteins that include tiny little pincers, which are shaped just right for grasping specific DNA sequences. (Nerd alert - the pincers are held together by a zinc atom, which explains the funny name).

"Unlike approaches that target the huntingtin RNA, cells treated with ZFPs never turn on their huntingtin gene in the first place.*"*

ZFPs for HD?

For many years, researchers have worked towards understanding naturally occurring ZFPs in the hopes that they could reprogram them to stick to new specific DNA sequences. Sangamo have been a leader in this field and developed a sort of tool kit of custom ZFPs that can target almost any DNA sequence.

Why do this, what's the point of making custom DNA-binding pincers? Well, it turns out that we can attach various payloads to these pincers, and some of them do very interesting things to the DNA where they attach. As an example, researchers know that they can fuse a sort of cellular stop sign to zinc fingers, to block the cell from activating the targeted gene.

A recent publication describes Sangamo's work developing ZFPs for use in HD, which was a large-scale collaboration with CHDI foundation and a number of HD researchers around the world. After a laborious screening effort, they were able to develop new ZFPs that stick to the huntingtin gene - in the DNA - and block its activation. So, unlike other approaches that target the huntingtin RNA, cells treated with these ZFPs **never turn on their huntingtin gene in the first place**.

Even better, the team was able to develop ZFPs that can shut off expression of only the mutant copy of the huntingtin gene, while leaving the normal copy entirely alone. Sangamo tested their ability to discriminate between one of the lowest CAG sizes that cause HD in humans (38 CAG repeats), while leaving the normal copy of huntingtin alone.

Promising results in mice

Having proved in cells that their new ZFPs could shut off mutant huntingtin specifically, the team next did a number of very well-conducted animal studies to see if their tool might be useful in the brains of animals that have HD-like mutations. To be comprehensive, they tested two different animal models of HD - one with very rapidly progressing symptoms, and another with more subtle long-term changes.

In both cases, ZFP delivery to the brains of mice led to reductions of the huntingtin protein. It also helped some of the symptoms these mice experience, which look a bit like things we observe in HD patients.

It's reasonably easy to test experimental drugs like this in mice. Researchers are able to collect brain tissue from animals and study it intensively, but similar studies are impossible in human HD patients, who get quite grumpy if you take pieces of their brain. Because translating mouse studies into humans is so difficult, the team did another set of experiments to determine whether ZFP treatment improved things in a way that we can also measure in people.

In fact, using sophisticated brain scanning techniques, the team was able to observe benefits of ZFP treatment in HD mice. These well-established techniques also work in humans, so if we want to test ZFPs in human studies we can hope to look for improvements without the need for removing tissue.

Researchers can fuse a sort of cellular stop sign to zinc fingers, to block the cell from turning on a gene.

What are the risks and benefits of ZFPs?

As with every other potential treatment for HD, there are benefits and disadvantages to the use of ZFPs. In theory, it's a much better approach to shut off the protein production from a mutant gene entirely, rather than trying to clean up the RNA and protein afterwards. We don't completely understand which RNA and protein species have toxic effects in cells, so shutting it off at the tap seems like the best approach.

Moreover, the data presented by Sangamo and their collaborators shows a very nice ability to discriminate between the normal copy of the huntingtin gene and the mutant copy. Silencing just the mutant copy of the huntingtin gene and sparing the other copy is, in theory, preferable, since we still don't know every risk associated with reducing the normal copy.

On the downside, the ZFPs developed by Sangamo and their collaborators are genes themselves, encoded in DNA, that must be delivered to every cell we want to treat. Using delivery of genes to treat a disease is generally known as **gene therapy**. To be an effective treatment for HD, ZFP gene therapy will require certain interventions. The DNA encoding the ZFPs needs to be packaged up into a virus and injected into the brain.

Like any drug, the ZFPs developed by Sangamo and their collaborators could have unexpected consequences. In this case, the simplest concern about ZFPs might be that they accidentally target other genes - besides huntingtin - for lowering. The team conducted quite detailed investigations of this possibility in cells, but of course in the brain things could be more complicated.

The best way to determine whether these ZFPs are as useful as we would hope is to run human studies. To support this, Sangamo has established a partnership with Japanese drug giant Takeda, who certainly have the expertise and resources to run such studies. Stay tuned to HDBuzz for any announcements about future studies with ZFPs in HD patients.

Take home

This exciting new study provides another arrow in our quiver as we tackle huntingtin lowering in the clinic. The study was very well-conducted and leaves us well-poised to consider testing ZFPs in human clinical studies. It's very exciting to see that brilliant scientists around the world continue to develop new approaches to treating HD.

These new ZFPs seem likely to provide exciting benefits compared to other Huntingtin lowering approaches that we look forward to seeing tested in HD patients. Stay tuned to HDBuzz for more coverage of huntingtin lowering therapies!

Memorials and Tributes

In Memory of John David Hodgson from The Wiedemann Sisters: Barbara Ruppel, Carla Wiedemann, Ann Deborah Reed & Sara Jo Larkin, Hugh & Sara Larkin, Craig Duy & Marilyn Bulson, Daniel Born, Betty Tucker, Holly & Jon Fraleigh, The Stecyk & Bos Families, Judy Nebel, Chris Wiedemann, Megan Wiedemann, Sister Ann Goggin

Galesburg Inaugural Team Hope Walk a Great Success!

The Illinois Chapter and Tara Guidinger hosted the Galesburg Inaugural Team Hope Walk on September 8, 2019. Over 70 people were in attendance as we walked to create advocacy and hope for those affected by Huntington's Disease. This is our third Team Hope Walk in Illinois, and the folks in Galesburg are already planning for the 2nd Annual Galesburg Team Hope Walk.

Rush Center of Excellence Half Day Symposium

Date: October 12, 2019

Location: Searle Conference Center, Rush Professional Building
1725 W. Harrison St., Chicago, IL 60612
Time: 8:30 A.M – 12:30 P.M.
RSVP: by October 1, 2019

The free to attend event will include our featured guest speaker, **Dr. Kathleen Shannon**, updates on research, and a question and answer panel. For additional questions please call 312-563-3796 or email: movement_hd@rush.edu.

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

The national office at HDSA offers support services to individuals and families. You can now get help from the comfort of your own home which includes:

Telehealth

Eight free online counseling sessions annually with a therapist who is familiar with Huntington's Disease. This is an internet-based program that brings licensed psychologists and social workers to the HD community. To utilize HDSA's free Telehealth portal, visit www.hdsa.amwell.com or download the free Amwell® app and use the **Service Key HDSA** to access the Huntington's disease practice. Individuals can schedule appointments with social workers and psychologists licensed in their state.

Online Support Groups

You can access these groups from your own home and connect to individuals across the country. HDSA offers online support groups that are led by social workers for the following groups:

- Caregivers
- at-risk
- parent caregivers
- 24-45 (gene +, asymptomatic)
- HD positive, early symptoms

For more information and to register for groups:
https://www.supportgroupscentral.com/groups_detail.cfm?cid=27&CFID=780632&CFTOKEN=e8cc0c63f0fc2013-A5281720-078A-0981-AE222644646D124E

Disability Resources

Allison Bartlett works at the national office as the Manager of disability programs. She is a licensed attorney who spent the last 4 years working as a disability attorney. Her role at HDSA includes:

- Educating health professionals, social workers, and HD families on the disability process.
- Facilitating a better understanding of the disability process specific to the HD community to ensure that more HD families are approved for disability.
- Creating a database of easily accessible disability resources for the HD Community.
- Providing consultation on disability cases.

HDSA recently launched disability chat webinars that can be located here:
https://hdsa.org/find-help/healthcare-and-future-planning/disability-chat/

"Hiccup" in HD Gene Contributes to Age of HD Onset

The age that Huntington's disease symptoms appear can vary a lot from person to person. For decades, scientists have been exploring the reasons behind this, and an important new finding has recently emerged. The vast majority of people with HD have a certain type of genetic "hiccup" near the end of their CAG repeat – one CAA. This doesn't actually change the huntingtin protein, so we didn't know it was important until now. Very rarely, this CAA hiccup occurs twice (for about 1 in 100 people with HD). In these individuals, symptoms tend to occur later in life. Even more rarely, the CAA hiccup is absent (for about 1 in 300 people with HD). For these individuals, symptoms tend to occur earlier. This discovery was made simultaneously by two separate research groups working with data from more than 9,000 individuals with HD, and formally published this month.

This is not something that a doctor could test for – such spelling differences in the HD gene are extremely rare, so today's genetic tests are not designed to pick it up. However, to many HD researchers, this discovery about the CAA hiccup feels like fitting in a missing puzzle piece. HDBuzz explained in detail back in March. A few years ago, there was a major HD discovery suggesting that the body's ability to repair damaged DNA could contribute to age of onset, and this finding helps to confirm that hypothesis.

SUPPORT groups

*****Whether you have HD, are at-risk, a caregiver, friend or just someone who wants to know more about HD, you are welcome!*****

CENTRAL ILLINOIS

2nd Sunday of Even Months (2:30 – 4:30pm)

2019 Meetings: 2/10, 4/14, 6/9, 8/11, 10/13 (no Dec. meeting)

OSF PromptCare Fort Jesse, 2200 Fort Jesse Road, Normal, IL

Contact: Larry Haigh (815-383-1877); larryhaigh@gmail.com

ROCKFORD

2nd Sunday of Every Month (2:00 – 4:00pm)

OSF St. Anthony Medical Center, 5666 E. State Street, St. Anthony Room (Use main entrance – second one back from parking lot entrance. As you enter building, you'll see a counter staffed by volunteers. Turn right, before you reach the counter. St. Anthony room is straight ahead)

Contact: Dave or Susie Hodgson (630-386-3928); dchodgson1946@gmail.com

GENEVA

3rd or 4th Sunday of Odd Months (2:00 – 3:30pm)

2019 Meetings: 1/20, 3/24, 5/26, 7/21, 9/15, 11/17

Northwestern Medicine – Delnor Hospital, 300 Randall Road Conf. Room #4, Medical Office Building 351 (park near the south entrance to the hospital and enter at the southeast corner of the building. Turn left, go past the gift shop and cafeteria, then follow the sign for Building 351. Conference Room #4 is a short ways down the hall on the right)

Contact: Joe Wiedemann (847-505-3933); joseph.wiedemann@gmail.com

LAKE COUNTY

2nd Monday of Every Month (7:00 – 8:30pm)

Advocate Condell Medical Center, 801 Milwaukee Avenue, West Tower, Libertyville, IL

Contact: Marilyn & Barry Kahn (847-975-2403); marilynkahn1@gmail.com

(Call for additional information and directions)

MUNSTER, IN

2nd Tuesday of Even Months (7:00 – 8:30pm)

2019 Meetings: 2/13, 4/10, 6/12, 8/14, 10/9, 12/11

Southside Christian Church, 1000 Broadmoor Avenue

Contact: Cindy Rogers (219-836-2369); clrogers111@comcast.net

CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL

Saturdays (see dates below) (10:00 – 11:30am)

2019 Meetings: 1/26, 3/16, 5/18, 7/20, 9/7, November group will take place downtown right after HD Family Symposium

Logan Square Library, 3030 W. Fullerton Avenue, Conference Room (Free ground-level parking available; building is handicap-accessible)

Contact: Emily Zivin (630-443-9876); ezivin@hdsa.org

CHICAGO – RUSH UNIVERSITY MEDICAL CENTER

2019 Meetings: 10/26, 12/14 **(10:00 – 11:30am)**

2020 Meetings (every 3rd Saturday (Feb, Apr, Jun, Aug, Oct, Dec)

Rush University Medical Center, 1653 W. Congress Pkwy., Tower Resource Center, 4th Floor, Chicago, IL (Parking available at Rush garage on the southeast corner of Paulina and Harrison. From the 4th floor, follow signs to Tower. Valet parking available in front of 1620 W. Harrison)

Contact: Samantha Lunde, AM, LSW (312-942-2163) or Samantha_R_Lunde@rush.edu

SOUTH SUBURBAN

2nd Tuesday of Odd Months (7:00 – 8:30pm)

2019 Meetings: 1/8, 3/12, 5/14, 7/9, 9/10, 11/12

Thomas Cellini Huntington's Foundation, 3019 East End Ave. South Chicago Heights, IL

Contact: Maryann Moynihan (708-955-3080); shamrock1959@att.net OR TCHF Office (877-687-8243)

Caring for the Caregiver

Caregiver Support Group

Wednesdays (see dates below) (7:00 – 8:30pm)

2019 Meetings: 10/16, 12/4

Winnetka Library, 768 Oak Street, Winnetka, IL; Community Room

Contact: Emily Zivin (630-443-9876); ezivin@hdsa.org

☑ SAVE THIS DATE!

October 12, 2019	Half Day Symposium – Rush Center of Excellence, Chicago, IL
November 8, 2019	HDSA IL Chapter & Great Lakes Region Celebration of Hope – Chicago, IL
November 9, 2019	HDSA IL Chapter Education Symposium – Peoria, IL
November 23, 2019	HD Patient and Family Symposium – Northwestern Medicine, Chicago, IL
November 28, 2019	Edison Park Turkey Trot supporting HD – Chicago, IL

https://hdsa.org/il

NOTE NEW P.O. BOX:

HDSA/Illinois Chapter, P.O. Box 1454, Lake Villa, IL 60046

AUTUMN 2019