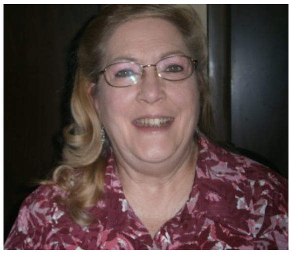
Hopes and Dreams

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

Huntington's Disease Society of America
Illinois CHAPTER

President's Message



Hello Illinois HDSA families and friends!

There is so much happening right now in the fight against HD and this gives us renewed hope for that all elusive treatment or cure. This is a fight that we do not fight alone, we fight it together because we are family and **Family is** *everything*

EXCITING HAPPENINGS:

- HDSA Partners with the ALS Association and TEVA Pharmaceuticals to identify Novel Therapeutic Targets for CNS Disorders. To further this mission to advance the development of new therapies to benefit patients in their respective disease areas, the ALS Association and HDSA are co-sponsoring the challenge with TEVA.
- HDSA has earned a Second Consecutive 4-Star rating from Charity Navigator. "On behalf of Charity Navigator, I wish to congratulate HDSA on attaining the coveted 4-Star rating for demonstrating strong financial health and commitment to accountability and transparency," said Michael Thatcher, Charity Navigators President and CEO.

EXCITING UPCOMING EVENTS:

- JUNE 7-9, 2018: If possible attend the 33rd ANNUAL HDSA NATIONAL CONVENTION in Los Angeles. Attending the National Convention offers many opportunities to learn about all aspects of Huntington's disease. Additionally, it offers a great opportunity to make new friends that will last a lifetime.
- On May 20, 2018, the Illinois Chapter will be hosting its 14th Annual TEAM HOPE WALK. This year's walk will be BIGGER than ever. Over the past 13 years, the HD families of Illinois have raised $800,000! This year the walk will feature an enhanced version of last year's popular Dunk Tank. Northwestern Medicine and Rush Medical Center have agreed to a Center of Excellence Dunk Off.
- Back in September of 2017, an outside group, the *Oak Park Invitational Charity Golf Tournament*, approached the Illinois Chapter. Each year they donate the net profits to a charity of their choice. Their 2018 charity of choice is the Illinois Chapter of HDSA. If you are a golfer and would like to participate, go to this link: **opigolf.com**.
- Did you attend last year's inaugural Baggo Tournament? The second annual Illinois Chapter Baggo Tournament will be held on September 8, 2018. Join us for a fun time and good company. Details will be provided in the Summer newsletter.
- Our last event of the year will be held sometime in October. If you live in Central Illinois join us for the inaugural Central Illinois Team Hope Walk in Bloomington, Illinois.

All of our events are designed to help support the mission of HDSA: To improve the lives of everyone affected by Huntington's Disease.

In addition to all of the above happenings, the chapter is very fortunate to have a Social Worker who works tirelessly to assist the families of Illinois. The chapter also provides an informative and educational one day conference each year.

- Did you know that the Illinois Chapter is over 50 years old, having been started by Molly Simon in 1968?
- Did you know that for the last 16 years your Chapter Board has been comprised of the same core group?

It is time for change and new beginnings! Don't worry, we "old ones" aren't going anywhere….BUT….

It is time for **NEW** faces and ideas on **YOUR** Chapter Board. Those of us that have been here for the long run may not be here tomorrow, then where will the Chapter be? **WE NEED YOU** to help keep the Illinois Chapter great.

You might be asking yourself, what can I do? You can join the Chapter Board. I hear you now, "I just don't have the time." You don't have 6 hours a YEAR to give to help in the fight against this disease that is destroying our families? Six (6) hours a year, that is what we are asking, and then, to help support our events, which many of you are doing already!

The Chapter Board meets 6 times a year. Three (3) meetings are held in person and 3 are held by phone conference. We try to keep our meetings to about an hour. There may be times it would be a little longer and times that it may be a little shorter. Again, you might be asking "what can I do?" YOU can VOLUNTEER to help with any of our events.

Simply, we NEED and WANT you! That is the only way we can guarantee that our chapter continues to grow, continues to stand out, and continues to be here to support our families. Remember…us "oldies" won't be around forever…then what????

To find out more on how you can make a difference, **PLEASE** contact any of our current board members or myself. All of our contact information can be found elsewhere in the newsletter.

Happy Spring!

Susie Hodgson, President
HDSA Illinois Chapter
Phone: 815-498-6092 or 815-508-2370
Email: susiehodgson53@gmail.com

Please pass this along. The Illinois Chapter has its own unique email address for contacting the chapter for problems, questions, and comments.

illinois@hdsavolunteer.org

Memorials and Tributes

In Memory of Glenn Arnett from the Grace M. Arnett Trust

In Memory of Keith Kowalewski Sr. from Mary Kowalewski and Family along with Keith's many loving and caring friends

In Loving Memory of Sharon Mooney Wiese, Cathleen Wiese Ulbrich & Linda Mooney Dietz from Clarence Wiese

In Honor of Scott McCallum from John Burchett

In Memory of Ronald Nunes from Ronald & Bonnie Nunes

In Memory of Ralph Short from Lois Short

In Honor of the Hodgson Family from H.V. Ted & Sara J.W. Larkin

IONIS-HTT Rx (RG6042) Top-Line Data Demonstrate Significant Reductions of Disease-Causing Mutant Huntingtin Protein in People with Huntington's Disease

Phase 1/2 study first to demonstrate disease-modifying potential up to ~60% reduction (mean ~40%) in the mutant huntingtin protein (mHTT) observed in the cerebral spinal fluid (CSF) of patients treated for three months with IONIS-HTT Rx (RG6042) at the two highest doses tested with mHTT levels continuing to decline at the last measurement. mHTT reductions of 40-60% in CSF correspond to an estimated 55%-85% reduction in the cortex of the brain, where mHTT is highly expressed, based on preclinical data. mHTT reductions observed in the Phase 1/2 study exceeded reductions that produced disease benefit in animal models of HD. Roche is working to quickly advance IONIS-HTT Rx (RG6042) to a pivotal study.

CARLSBAD, Calif., March 1, 2018 /PRNewswire/ -- Ionis Pharmaceuticals, Inc. (NASDAQ: IONS), a leader in antisense therapeutics, today announced the presentation of positive top-line data from a completed Phase 1/2 study of IONIS-HTT_{Rx} (RG6042) in people with early stage Huntington's disease (HD) at the 13^{th} Annual CHDI HD conference. The data demonstrate that IONIS-HTT_{Rx} (RG6042) is the first drug in development to lower the disease-causing protein in people with HD.

Ionis Pharmaceuticals (PRNewsFoto/Ionis Pharmaceuticals, Inc.)
HD is a rare, progressive, neurodegenerative disease caused by genetic mutation in the huntingtin gene, which results in the production of a toxic protein, the mutant huntingtin (mHTT) protein, which gradually destroys neurons in the brain resulting in deterioration in mental abilities and physical control. Ionis designed IONIS-HTT_{Rx} (RG6042), a Generation 2+ antisense drug, to specifically reduce the production of all forms of the huntingtin protein, including mHTT.

"For nearly twenty years, I have seen many families devastated from losses to this progressive neurodegenerative disease. With IONIS-HTT_{Rx} (RG6042), the HD community has new hope for a therapy that can reduce the cause of HD, and therefore, may slow the progression and potentially prevent the disease in future generations, which is truly groundbreaking," said Dr. Sarah Tabrizi, professor of clinical neurology, director of the University College London's Huntington's Disease Centre and the global lead investigator on the study. "I look forward to a longer-term, larger study that can establish the benefit of reducing the toxic mutant huntingtin protein in people with HD."

Phase 1/2 Study Results:

- 46 people with early stage Huntington's disease were treated for 13 weeks with four intrathecal injections of 10 mg, 30 mg, 60 mg, 90 mg or 120 mg of IONIS-HTT_{Rx} (RG6042) or placebo, administered monthly.
- Significant, dose-dependent reductions in mHTT were observed in CSF of treated participants with mHTT reductions of up to
- approximately 60% and mean reductions of approximately 40% in CSF observed at the two highest doses, 90 mg ($p<0.01$) and 120 mg ($p<0.01$).
- Based on a predictive model developed from data collected in rodents and non-human primates, a 40% to 60% reduction in CSF corresponds to an estimated 55% to 85% reduction in mHTT in the cortex and 20% to 50% in the caudate regions of the brain in humans.
- mHTT levels were continuing to decline at the last measurement with further decreases in mHTT anticipated; maximum reduction expected by approximately six months after first dose.
- No serious adverse events were reported in treated participants and most adverse events (AEs) were mild and considered to be unrelated to study drug. No participants discontinued from the study.
- An open-label extension (OLE) study for patients who participated in the Phase 1/2 study is ongoing.

Roche has been working closely with Ionis on this program since 2013 and is now leading the development of IONIS-HTT_{Rx} (RG6042) and collaborating with the HD community. Roche is currently planning a pivotal trial to determine the clinical efficacy and safety of IONIS-HTT_{Rx} (RG6042).

"We designed IONIS-HTT_{Rx} to treat all patients with HD. These important clinical results demonstrate that our approach of targeting the toxic mutant huntingtin protein can significantly reduce the underlying cause of this terrible disease. In this study, we were able to achieve mutant huntingtin protein reductions in study participants that were higher than those that produced disease benefit in preclinical models of HD," added Dr. C. Frank Bennett, senior vice president of research and franchise leader for the neurological programs at Ionis Pharmaceuticals. "We were pleased that this antisense approach, which targets all forms of the huntingtin protein, proved to be safe and well tolerated in this study. We look forward to working with Roche to quickly advance IONIS-HTT$_{Rx}$ (RG6042) into a pivotal study, which we hope will lead to marketing approval for this new drug for people with HD."

"IONIS-HTT$_{Rx}$ is the latest example of the innovation and productivity of our antisense technology," said Brett P. Monia, chief operating officer, senior vice president of antisense drug discovery and translational medicine at Ionis Pharmaceuticals. "Our efforts to develop antisense drugs for neurological diseases have already produced one commercial drug, SPINRAZA, another under review for marketing approval, inotersen, four drugs approaching definitive clinical studies, six preclinical-stage drugs, and more than 20 discovery-stage programs."

ABOUT IONIS-HTT$_{Rx}$ (RG6042)

IONIS-HTT$_{Rx}$ (RG6042) is an antisense drug designed to reduce the production of all forms of the huntingtin protein (HTT), including its mutated variant, mHTT, which is the driver of HD. IONIS-HTT$_{Rx}$ (RG6042) offers a unique approach to treat all patients with HD, irrespective of their individual HTT mutation. IONIS-HTT$_{Rx}$ (RG6042) has been granted orphan drug designation by the U.S. Food and Drug Administration (FDA) and by the European Medicines Agency (EMA) for the treatment of patients with HD.

ABOUT IONIS/ROCHE COLLABORATION

Roche and Ionis are collaborating to develop antisense drugs to treat HD. The alliance combines Ionis' antisense expertise with Roche's knowledge in clinical development of anti-neurodegenerative therapeutics. In December 2017, Roche licensed IONIS-HTT$_{Rx}$ from Ionis for $45 million and has renamed the investigational molecule RG6042. In total, Ionis has generated $100 million in up-front, milestone and license payments and is eligible to receive an additional $335 million in milestone payments as IONIS-HTT$_{Rx}$ (RG6042) progresses in development. If commercialized, Ionis is eligible to receive tiered double-digit royalties up to the mid-teens on sales of IONIS-HTT$_{Rx}$ (RG6042). Roche is responsible for all IONIS-HTT$_{Rx}$ (RG6042) development, regulatory and commercialization activities and costs.

ABOUT IONIS PHARMACEUTICALS, INC.

Ionis is the leading company in RNA-targeted drug discovery and development focused on developing drugs for patients who have the highest unmet medical needs, such as those patients with severe and rare diseases. Using its proprietary antisense technology, Ionis has created a large pipeline of first-in-class or best- in-class drugs, with over three dozen drugs in development. SPINRAZA® (nusinersen) has been approved in global markets for the treatment of spinal muscular atrophy (SMA). Biogen is responsible for commercializing SPINRAZA. Drugs that have successfully completed Phase 3 studies include inotersen, an antisense drug Ionis is developing to treat patients with hereditary TTR amyloidosis (hATTR), and volanesorsen, an antisense drug discovered by Ionis and co-developed by Ionis and Akcea Therapeutics to treat patients with either familial chylomicronemia syndrome or familial partial lipodystrophy. Akcea, an affiliate of Ionis, is a biopharmaceutical company focused on developing and commercializing drugs to treat patients with serious cardiometabolic diseases caused by lipid disorders. If approved, volanesorsen will be commercialized through Ionis' affiliate, Akcea. Inotersen filings for marketing approval have been submitted in the U.S. and EU. Volanesorsen filings for marketing approval have been submitted in the U.S., EU, and Canada. Ionis' patents provide strong and extensive protection for its drugs and technology. Additional information about Ionis is available at www.ionispharma.com.

IONIS' FORWARD-LOOKING STATEMENT

This press release includes forward-looking statements regarding Ionis' alliance with Roche and the development, activity, therapeutic potential, commercial potential and safety of IONIS-HTT$_{Rx}$ (RG6042). Any statement describing Ionis' goals, expectations, financial or other projections, intentions or beliefs is a forward- looking statement and should be considered an at-risk statement. Such statements are subject to certain risks and uncertainties, particularly those inherent in the process of discovering, developing and commercializing drugs that are safe and effective for use as human therapeutics, and in the endeavor of building a business around such drugs. Ionis' forward-looking statements also involve assumptions that, if they never materialize or prove correct, could cause its results to differ materially from those expressed or implied by such forward-looking statements. Although Ionis' forward-looking statements reflect the good faith judgment of its management, these statements are based only on facts and factors currently known by Ionis. As a result, you are cautioned not to rely on these forward-looking statements. These and other risks concerning Ionis' programs are described in additional detail in Ionis' annual report on Form 10-K for the year ended December 31, 2017, and its most recent quarterly report on Form 10-Q, which are on file with the SEC. Copies of these and other documents are available from the Company.

Yes! Count me in!!

Huntington's Disease Society of America
Illinois CHAPTER

2018 Pledge Drive

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

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

Please complete the information below and return with your pledge:

Your Name ____________________

Email Address ____________________

○ **Benefactor**	$500.00 donation	○ **Supporter**	$ 50.00 donation
○ **Patron**	$100.00 donation	○ **Member**	$ 25.00 donation
○ **Angel**	$ 75.00 donation	○ **Friend**	$________ donation

Family is *everything*

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

Make your check payable to
HDSA Illinois Chapter and mail to:
P.O. Box 1883, Arlington Heights, IL 60006
*To make your pledge online go to HDSA.org/il – click DONATE and choose **pledge drive** on the drop down menu for the solicit code*

Recap of HDSA Illinois State Conference

Thanks to all who attended, presented and assisted on another successful conference. Nearly 150 people came together on March 17th at Harper College, Wojcik Conference Center in Palatine, IL to learn more about the Mind and Body as they relate to HD. Most in attendance agreed that the facility was very accommodating and the food was good! The presenters this year were exceptional and clearly care deeply about our community and we are grateful for their time, knowledge and compassion.

Topic's Presented	Presenter
Behavioral Challenges w/HD	Dr. Eric Gausche, Northwestern Medical Group
Physical Rehabiliation Sciences: Speech, Occupational and Physical Theraphy	Dr. Santiago Toledo, MD Shirley Ryan, Abilities Lab Medical Director of Orthopedic Rehab Program Amy Watt, Physical Therapist Joelle Johnson, Occupational Therapist Danielle Williams, SLP
Advocacy	Jennifer Simpson, HDSA Manager of Advocacy
Driving and HD	Anne Hegberg, OTR, CDRS
HD101	Dr. Jennifer Goldman, MD, MS, Rush University Center of Excellence Director
Mock Support Group	Emily Zivin, LCSW, MPA Barry and Marilyn Kahn
Clinical Research Update	Dr. Jennifer Goldman, MD, MS, Rush University Center of Excellence Dr. Danny Bega, MD, MSCI, Northwestern Memorial Hospital Feinburg School of Medicine Center of Excellence Director
Nursing Homes: How to navigate exploring, selecting and working with them	Andrea Donovan, President, Andrea Donovan Senior Living Advisers
Nutrition and Weight Management	Carrie Draney, MS, RD, LDN
At-Risk Support Group	Emily Zivin, LCSW, MPA Danielle Marino, LCSW
Current HealthCare Climate - Medicare and Medicaid	Mary Anne Ehlert, CFP

We will continue our effort to move the conference location around with the hopes that participants will more equitably share the burden of distance. Watch for our announcement this fall as to next year's location!

Holly Fraleigh, IL Chapter Board Member
Emily Zivin, LCSW, MPA

ON-LINE SUPPORT for Those At-Risk and Asymptomatic

The Illinois HDSA Chapter is now offering a closed, monitored (by the chapter social worker) Google group for individuals who are at-risk/asymptomatic. This is a private online group that allows individuals to ask questions, share ideas and support one another. All members of the group must be18 years and older. If you are interested in joining, please email ezivin@hdsa.org and ask to join the at-risk/asymptomatic Google group.

Emily Zivin, LCSW
Illinois Chapter Social Worker
Huntington’s Disease Society of America
(630-443-9876)

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hd@nm.org (email)
http://huntingtons.nm.org

Tips & Strategies for Cognitive/Behavioral Challenges in HD

HD is characterized by the triad of motor, cognitive, and behavioral disturbances. The cognitive disorder becomes more pronounced as the disease becomes more advanced, and is characterized by slower processing and difficulty organizing information, trouble with learning and memory, trouble recognizing emotions, impulsivity, and impaired insight. Changes in behavior often go along with these cognitive changes, and the root of many of the behavioral problems is frustration. The following are a few tips that caregivers, family members, and friends may consider using to help reduce some of the burden of these symptoms:

1. **Patience & Understanding:** Some people with HD need extra time. They may be capable of performing a certain task, but pressure makes it more challenging. Allow extra time for tasks to be completed whenever possible. This goes for conversation as well – allow additional time for responses to questions. For those with more impairment it is useful to use short sentences that convey no more than one or two pieces of information, and offer yes/no choices whenever possible. It is also important to remember that even if a person with HD is not speaking, they may understand what is being said. Finally, don't demand insight into every problem. Instead, focus on achieving behavioral goals rather than pushing a person with HD to see things the same way as you.

2. **Optimizing the Environment:** Multi-tasking poses an added challenge for people with cognitive impairment. Reducing distractions as much as possible when interacting with someone with cognitive problems can help set them up for success. Also, reduce physical obstacles in the house by keeping pathways clear and pad furniture wherever possible.

3. **Schedules & Routines:** Prevent irritability, confusion, and fear by introducing predictable daily schedules. Keep a structured environment that minimizes surprises. Routines make it easier for the person with HD to initiate tasks without guidance, and leads to less frustration. Finally, when decision-making leads to conflict, offer limited choices rather than forcing decisions or allowing open-ended options.

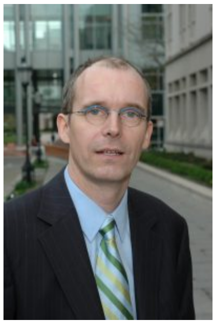
4. **Outbursts:** Some people with HD have sudden outbursts, or a "short fuse", that can be hard for them to control. Try not to react emotionally in response to the outburst. Although hurtful or embarrassing things may be said, try to remain calm knowing that in general, the person with HD is not doing this intentionally. Attempt to anticipate triggers that lead to frustration and outbursts and try to avoid them. If someone is having an outburst, try to avoid confrontation and try to redirect them away from the source of anger. Acknowledge the irritability as a symptom of frustration. Try not to take cruel words personally, and leave the area if there is a threat of violence or concern for your own safety.

Several studies have shown that cognitive impairments are a significant source of impaired function in HD and can create a greater burden on patients and families than the motor disorder. It is important to alert your physician to changes in cognitive processes, but family members can adopt strategies that help the person with HD optimize their functioning.

Huntington’s Disease Provides New Cancer Weapon

By Marla Paul on Feb 12, 2018

Scientists harness a super assassin gene for new cancer treatment



Marcus Peter, PhD, the Tom D. Spies Professor of Cancer Metabolism, was the senior author of the study that discovered why Huntington’s disease is toxic to cancer cells, a finding that may lead to new cancer therapies.

Patients with Huntington’s disease, a fatal genetic illness that causes the breakdown of nerve cells in the brain, have up to 80 percent less cancer than the general population.

Northwestern Medicine scientists have discovered why Huntington’s is so toxic to cancer cells and harnessed it for a novel approach to treat cancer, according to a new study published in the journal *EMBO Reports*.

Huntington’s is caused by an over-abundance of a certain type of repeating RNA sequences in one gene, huntingtin, present in every cell. The defect that causes the disease also is highly toxic to tumor cells. These repeating sequences – in the form of so-called small interfering RNAs — attack genes in the cell that are critical for survival. Nerve cells in the brain are vulnerable to this form of cell death, however, cancer cells appear to be much more susceptible.

“This molecule is a super assassin against all tumor cells,” said senior author Marcus Peter, PhD, the Tom D. Spies Professor of Cancer Metabolism and of Medicine in the Division of Hematology and Oncology. “We’ve never seen anything this powerful.” “We’ve never seen anything this powerful against cancer cells.”

Peter is also leader of the Translational Research in Solid Tumors Program at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University.

Huntington’s disease deteriorates a person’s physical and mental abilities during their prime working years and has no cure.

To test the super assassin molecule in a treatment situation, Peter collaborated with C. Shad Thaxton, ’04 MD, ’07 PhD, associate professor of Urology, to deliver the molecule in nanoparticles to mice with human ovarian cancer. The treatment significantly reduced the tumor growth with no toxicity to the mice, Peter said. Importantly, the tumors did not develop resistance to this form of cancer treatment.

Peter and Thaxton are now refining the delivery method to increase its efficacy in reaching the tumor. The other challenge for the scientists is figuring out how to stabilize the nanoparticles, so they can be stored.

First and co-corresponding author Andrea Murmann, PhD, research assistant professor of Medicine in the Division of Hematology and Oncology, also used the molecule to treat human and mouse ovarian, breast, prostate, liver, brain, lung, skin and colon cancer cell lines. The molecule killed all cancer cells in both species.

The Huntington’s cancer weapon was discovered by Murmann, who had worked with Peter on previous studies that identified an ancient kill-switch present in all cells that destroys cancer.

“I thought maybe there is a situation where this kill switch is overactive in certain people, and where it could cause loss of tissues,” Murmann said. “These patients would not only have a disease with an RNA component, but they also had to have less cancer.”

She started searching for diseases that have a lower rate of cancer and had a suspected contribution of RNA to disease pathology. Huntington’s was the most prominent.

When she looked at the repeating sequences in huntingtin, the gene that causes the disease, she saw a similar composition to the earlier kill switch Peter had found. Both were rich in the C and G nucleotides (molecules that form the building blocks of DNA and RNA).

“Toxicity goes together with C and G richness,” Murmann said. “Those similarities triggered our curiosity.”

In the case of people who have Huntington’s, the gene huntingtin has too many repeating sequences of the triplet sequence CAG. The longer the repeating sequence, the earlier they will develop the disease.

“We believe a short-term treatment cancer therapy for a few weeks might be possible, where we could treat a patient to kill the cancer cells without causing the neurological issues that Huntington’s patients suffer from,” Peter said. Huntington’s patients have a lifetime exposure to these toxic RNA sequences, but generally don’t develop symptoms of the disease until age 40, he noted.

Every child of a parent with Huntington’s has 50/50 chance of carrying the faulty gene. Today there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

The research was supported in part by funding from the National Institutes of Health/National Cancer Institute grant R35CA197450 and The Northwestern University Feinberg School of Medicine Developmental Therapeutic Institute.

Please note this important change of address for
Northwestern Medicine’s Center of Excellence
Lavin Pavilion
259 E. Erie Street, Suite 1900
Chicago, IL 60611

Additionally, the new Clinic Coordinator and Nurse at the Center is:
Christine M. Conrad BSN, RN (312-695-7950)

For complete Center of Excellence information, please visit
http://cts.vresp.com/c/?HDSAIllinois/f6d1af8f25/5d9306c9bd/3e2a08e149

We hope you can join us June 7-9 at the 33rd Annual HDSA Convention to Los Angeles, CA.

Please visit www.hdsa.org/convention to learn more, register online or download registration forms to attend this year’s Convention. Register by May 4, 2018 to receive the Early Bird Rate.

If you have any questions please contact Robert Coffey at rcoffey@hdsa.org or call us at 800-345-HDSA (4372).

14th Annual Team Hope Walk

Sunday, May 20, 2018

Mark Your Calendar NOW!

The Illinois Chapter of HDSA's 14th Annual Team Hope Walk will be held on Sunday, May 20, 2018, at the beautiful Grand Pavilion on the Naperville Riverwalk. Our award winning, nationally recognized, Team Hope Walk is one of the biggest fundraisers for HDSA in the nation! Over the past 13 years, the HD families and friends have raised approximately $800,000.00! The two mile walk along the DuPage River begins and ends at the Grand Pavilion.

This is a family friendly walk for everyone. Dogs on a leash are more than welcome to attend. Lunch is included in your registration fee ($20.00 per person if you pre-register, $25.00 if you pay the day of the walk). The **first 400 walkers who pre-register** are **guaranteed a correctly sized T-shirt**. The Dunk Tank will be back!

Fee:
Pre-register is $20/person

Day of the Walk is $25/person

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

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

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

TEAM HOPE - PLEDGE SHEET

Your challenge…have at least 10 FRIENDS sponsor you!

Huntington's Disease Society of America
TEAM HOPE

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

Team Hope – Walk for a Cure – 5K Walk

	NAME	ADDRESS	AMOUNT
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OFF TO A GOOD START

Getting Closer

You did it!

KEEP ON GOING

Name: ____

Address: ____

City: ___________________________ St: ________ Zip: __________

Email: ___________________________ Phone: __________________

This form may be reproduced.

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

Signature ____

REGISTER TODAY

For our next Chicago, IL Fundraising Event

Sip & Shop for HD

Sat. April 28th at the **Greenheart Shop in Old Town**

Spend this Spring Saturday Morning Supporting HDSA

Invite friends and family, visit the Lincoln Park Zoo (free admission), or take a walk on Lake Michigan after.

All within walking distance.

Enjoy the OPEN Bloody Mary and Mimosa Bars, coffee, & pastries

20% of SALES will go back to HDSA

to support HD Education, Research and Advocacy

For more information and to register,

https://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=1415

Contact Camille Colletti at ccolletti@hdsa.org or 847-849-0680

Congratulations to Teresa Srajer on her selection as an HDSA National Board Trustee.

Chapter Officers

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Hopes & Dreams
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(630) 443-9876 ~ www.hdsa.org/il

This newsletter attempts to report items of interest relating to the individuals with Huntington's Disease, their families, healthcare professionals, and interested friends and supporters. HDSA and the Illinois Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Illinois Chapter.

Together we make the difference

News from Our Illinois Chapter Social Worker

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An important area of medical research is aimed at understanding the human brain and what goes wrong for those living with Huntington's Disease. Research using donated brains following death has allowed scientists to answer important questions about Huntington's and other neurodegenerative diseases. One donated brain can provide tissue to hundreds of different research studies.

When considering brain donation, it is important to reach out to a brain bank. Brain banks are medical facilities that help acquire, store and distribute brain tissue for medical research. You do not need to live near a brain bank in order to make a donation. Brain banks will help coordinate all the logistics that come with making this type of donation.

Planning for a brain donation can be a difficult conversation. This can be arranged prior to or immediately following death. An optimal time to start planning for a brain donation is when your loved one enters hospice. This way, the medical center receiving the brain can be prepared to accept the donation. There is a significant amount of paperwork and planning that is associated with brain donation. It is helpful to be prepared ahead of time.

Generally speaking, brain donations are free of costs. However, it is important to make sure that the funeral home is "organ donation friendly". If not, there might be costs associated with finding another funeral home and/or additional transportation needs.

If you are looking for additional information about brain donations throughout the country. Here are some helpful resources:

The NIH neurobiobank website: https://neurobiobank.nih.gov
Harvard Brain Tissue Resource Center: http://www.brainbank.mclean.org
Rush University Medical Center: Contact number: 312 563-2848

At HDSA, we know it's hard to find time for appointments or even find a local Huntington's disease specialized counselor. HDSA's FREE Telehealth Program, powered by Amwell, makes it easy for you to talk to mental health therapists from the comfort of your home.

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

Announcing free online therapy sessions for 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.

Huntington's Disease Society of America

amwell

TEVA

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

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 appointments with social workers and psychologists licensed in their state. The session is free for families affected by HD, and no insurance is required.

What is Telehealth?
Simply put, it is connecting healthcare professionals with the populations most in need of the services offered but who cannot travel to a medical center for a variety of reasons including time, cost, distance and insurance.

What services are provided?
An internet based program that brings qualified HD knowledgeable licensed social workers and psychologists to the HD community. By bringing these services directly to those most in need, HDSA and American Well can bridge that gap for those who find traditional on-site counseling inconvenient.

How many times can I receive counseling?
Over the course of a year, you may schedule up to 8 visits with an HD knowledgeable licensed social worker or psychologist through HDSA's free program.

Can only one member of the family use the service?
No, every member of your family can receive counseling with up to 8 telehealth visits per year.

Will it be the same counselor each time?
That depends. You can request the same person or another counselor may be more readily available at the time you are requesting.

What are the hours for appointments?
Specific hours will vary from state to state depending upon the number of therapists available. While American Well is building its network of mental health providers, coverage may vary from state to state. We encourage you to check the site often if you find limited access in your state.

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	**2018 Meetings:** 2/11, 4/8, 8/12, 10/14 (No meeting in June because of Natl Convention)	Dave or Susie Hodgson (815) 498-6092 dchodgson1946@gmail.com
GENEVA		
3rd or 4th Sunday of **odd numbered months** (see dates in next column) TIME: 2:00 to 3:30pm LOCATION: Northwestern Medicine - Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot) * Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome.	Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left. **2018 Meetings:** 1/21, 3/11, 5/6, 7/15, 9/16, 11/11	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	**2018 Meetings:** 1/9, 3/13, 5/8, 7/10, 9/11, 11/13	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
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. **2018 Meetings:** Please call for specific dates	For more info, contact Sarah Mitchell Chen, LSW (312) 942-6445 Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD
CHICAGO – NORTHWESTERN MEDICINE		
LOCATION: Logan Square Library, 3030 W. Fullerton Ave., Chicago, IL – Room: Meeting Room TIME: 10:00am – 11:30am *****Please note, the March 17th support group will run as a break out session at the HDSA Illinois State Conference at Harper College, Wojcik Conference Center, 1200 W. Algonquin Road, Palatine, IL 60067. 2-3PM**	For Asymptomatic/at-risk patients and family members. **2018 Meetings:** 1/20, 3/17*, 5/5, 7/7, 9/22, 11/3	Emily Zivin (630) 443-9876 ezivin@hdsa.org
MUNSTER, INDIANA		
2nd Tuesday of **even months** TIME: 7:00 – 8:30pm LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	**2018 Meetings:** 2/13, 4/10, 6/12, 8/14, 10/9, 12/11	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!

May 20, 2018	HDSA IL Chapter Annual Team Hope Walk – Naperville, IL
June 7 – 9, 2018	HDSA National Convention – Los Angeles, CA
September 8, 2018	HDSA IL Chapter 2nd Annual Baggo Tournament
October 2018	HDSA Team Hope Walk – Bloomington, IL

https://hdsa.org/il

SPRING 2018