

President's Message



Hello HD Families and Friends,

Reports from this year's National Convention in LA have been great and I know those who attended and listened in via the live streams have come away with renewed hope and energized. There is so much happening right now in the fight against HD and finding 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*! If you've not listened to the recorded sessions, go to this link: <http://illinois.hdsa.org/news/2018-national-convention-presentations>

UPCOMING CHAPTER EVENTS:

- Have you registered for the 2nd Annual Baggo Tournament? The 2nd annual Illinois Chapter Baggo Tournament will be held on September 8, 2018. Join us for a fun time and good company. Details can be found elsewhere in this newsletter.
- The inaugural Central Illinois Team Hope Walk in Bloomington, Illinois will be held on Sunday, September 16, 2018. This will be our second walk in Illinois, a much needed Walk for our central Illinois HD families. Contact Larry Haigh, Chair of the Central Illinois Team Hope Walk. LarryHaigh@gmail.com
- The chapter also provides an informative and educational one day conference each year. We are very excited that we will have an Education Day this fall in Peoria.

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

WE STILL NEED YOU!!!

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 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 meetings are held in person and three 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.

Have a safe summer everyone!

Susie Hodgson, President
HDSA Illinois Chapter
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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



FOR IMMEDIATE RELEASE

Contact: Christopher Cosentino, Director of Marketing & Communications
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HUNTINGTON'S DISEASE SOCIETY OF AMERICA HOSTS ITS 33RD ANNUAL CONVENTION IN LOS ANGELES WITH RECORD NUMBER OF ATTENDEES

New York, NY, June 13, 2018 -- The Huntington's Disease Society of America (HDSA) hosted its 33rd Annual Convention from June 7th – 9th at the Los Angeles Airport Marriott in California. With 1,046 attendees, this was the largest Convention in the 50 year history of the organization breaking the previous record of 1,001 in Minnesota back in 2011. The HDSA Convention is the world's largest conference for families affected by Huntington's disease (HD).

"On behalf of the HDSA Board of Trustees, staff and volunteers I would like to thank everyone who supported and attended the 33rd Annual HDSA Convention," said HDSA's President & CEO Louise Vetter. "Throughout the entire Convention, there was a clear message to follow in Marjorie Guthrie's footsteps to "do something" about this devastating disease. Fifty years ago Marjorie began her crusade against HD, and today we continue her legacy by bringing together the entire community to provide help and hope to all families affected by Huntington's disease."

This year's HDSA Convention kicked off on Thursday with its ceremonial Team Hope Walk and carnival-themed Welcome Reception. Guests were greeted by a surprise video greeting from actress Bryce Dallas Howard who donated four tickets to the LA premiere of her latest film, ***Jurassic World: Fallen Kingdom***. The excitement did not stop there, Bryce then introduced an HDSA Convention exclusive sneak peek and extended trailer of the film.

Friday morning's opening ceremony featured powerful keynotes from Anna Canoni and Bill Johnston, respectively. Anna, who is the granddaughter of Woody and Marjorie Guthrie, shared her family story on how the Guthries were impacted by HD and Marjorie's extraordinary determination to establish the Committee to Combat Huntington's Disease (now known as the Huntington's Disease Society of America) fifty years ago. San Diego Padres' executive and HD family advocate Bill Johnston then discussed his family's battle against this devastating brain disorder and encouraged families to follow in Marjorie's footsteps to get involved and "do something".

Immediately following the Opening Ceremony, the HDSA Convention featured workshops led by world-class researchers, caregivers, social workers, clinicians and other experts.

On Friday night at the annual HDSA National Youth Alliance (NYA) Talent Show attendees were entertained with magic, dance, stand-up comedy and singing. The show raised more than \$30,000 to support the NYA Convention Scholarship Fund which sends youth to Convention each year.

The much-anticipated Research Forum on Saturday featured a first-of-its-kind panel which presented the history of the discovery of the HD gene and how it has led to the development of a promising new potential therapy for HD using antisense oligonucleotides. The panel included Dr. Jim Gusella, Dr. Anne Smith, Dr. Holly Kordasiewicz, Dr. Robert Pacifici, Dr. Doug Macdonald, Dr. Ed Wild, Dr. Blair Leavitt, Erik Lundgren, Dr. George Yohrling and HD family advocate Amy Fedele. Dr. Jeff Carroll and Dr. Wild from HDBuzz.net also delivered an informative and highly entertaining update on HD research.

Saturday night's Awards Dinner and Gala closed out this memorable Convention with amazing food, entertainment and dancing. National awards were presented to Dr. Jim Gusella (Researcher of the Year), the Johnston Family (Marjorie Guthrie Award), HDSA's Greater New York Chapter (Chapter of the Year), HDSA's Central Maryland (Affiliate of the Year), Anna Lunsford (HDSA Youth Award), Frances Saldana (Woody Guthrie Advocacy Award), HDSA Center of Excellence Partner Kaiser Permanente of Northern California (Excellence in HD Care) and Jeannette Garcia (HDSA Person of the Year).

For the 20th year, Marie Nemec and Charlotte Reicks led a team of dedicated advocates who once again rode bicycles to the HDSA Convention while raising money for HDSA. To date, Bike for the Cure has raised more than \$730,000!

The 33rd Annual Huntington's Disease Society of America Convention was made possible by the generous support of its sponsors: Archcare, BioTek reMedys, Broda, Enroll-HD, Genentech, Huntington Study Group, Ionis Pharmaceuticals, Lundbeck, Mass Mutual, PTC Therapeutics, Tagi Pharma, Teva Pharmaceuticals, uniQure, Vaccinex, Voyager and WAVE Life Sciences.

Please visit HDSA.org and follow HDSA's social media channels for more information on recorded sessions and photos from this past year's Convention. Also, visit HDSA.org/convention in the coming months to learn more about the 34th Annual HDSA Convention in Boston on June 27th – 29th, 2019.

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*Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It 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 approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease. The symptoms of HD are described as having ALS, Parkinson's and Alzheimer's – **simultaneously**.*

The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by HD. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today and hope for tomorrow for people with HD and their families.

To learn more about Huntington's disease and the work of the Huntington's Disease Society of America, visit www.hdsa.org or call 1-800-345-HDSA.

volunteer
do good, feel good

Congratulations to the Illinois Chapter on the Outstanding Social Media Award!



From left to right: Louise Vetter (HDSA President and CEO), Bill Kline (National Field Staff Chair and Trustee of the Board), Deb Boyd (Great Lakes Region Development Director), Charlotte Rybarczk (Illinois Chapter Treasurer and National Field Staff Member), Larry Haigh (Illinois Chapter Vice President), Camille Colletti (Great Lake Region Development Manager), Dr. Arik Johnson (HDSA Board of Trustees Chairman), Nancy Rhodes (Director of Field Development & Operations), Peggy Cribbin (Great Lakes Region Development Director)

The 2018 HDSA Convention Research Forum

by Thomas Barr, HDSA Illinois Chapter

Over the years the Research Forum on Saturday morning has been the most anticipated program of the convention. This year the first disease altering treatment was discussed and the discussion ran into the HDBuzz presentation. I strongly recommend viewing this on the HDSA website if you have internet access. The presentation went into detail how we got here from the discovery of the CAG repeat in 1993 to the present with key researchers from each step presenting their contribution.

The status of the current Roche (IONIS) treatment which is injected into the spine once a month reduces the production of the normal and mutant Huntington protein and can be modulated based on the strength of the injection. So far a phase 1B and 2 clinical trials has been done with a group of 46 volunteers that are gene positive. This testing was somewhat streamlined from normal clinical trial procedures doing phase 1B and 2 at the same time including different dosage strengths along with some participants receiving a placebo. Testing has shown that the Huntington protein is reduced and the treatment is well tolerated with no difference in problems between those receiving the drug or placebo. The question now is will this be a disease altering treatment and are there any serious side effects. This testing lasted for four months and all original volunteers are now receiving the actual drug and are continuing to be followed.

It is planned to start recruitment for phase 3 trials late this year. Candidates need to meet certain criteria. Candidates need to be less than 65, been diagnosed positive with early physical onset. Phase 3 clinical trials will also include the use of a placebo and will include a few hundred volunteers. This study needs to be a longer than the original phase 1B/2 trials. No trial sites have been announced. Although no specific timetable was discussed, it seems that an approved treatment may still be 5 years away assuming things don't go really good or really bad. Because researchers don't want anything to go wrong, that might delay their work, compassionate use applications will not be considered.

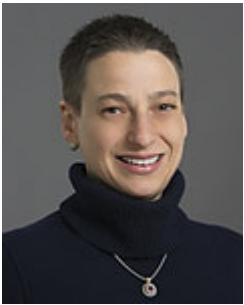
I also attended a number of other presentations to get a better understanding the research big picture. The treatment going into phase 3 trials reduces both the normal and mutant Huntington protein. Another company, Wave Life Sciences, has a procedure that only reduces the mutant Huntington protein and is looking to go into phase 1B/2 trials with initial data expected in the first half of 2019. They have two variants of the treatment that will be effective on 80% of those with the disease. Tests need to be done to determine if a gene positive person fits into one of the two treatment groups. Introduction of the treatment will be through the spine just as the Roche treatment is administered. This could address a problem with the Roche treatment; it is found that knocking down both forms of the Huntington protein causes a problem.

A third approach, by uniQure, to the Huntington protein reduction plan is also nearing phase 1B/2 clinical trials. This approach utilizes a virus that is surgically implanted into the brain that produces the RNA reduction component. Although this procedure is the most invasive, it should only need to be done once for lifetime of Huntington protein reduction. Initial trials will be at a low dosage because once introduced into the brain, the virus can't be removed.

There are a number of other treatments that are being developed that might have received more visibility if it were not for the Roche Huntington reduction treatment going into phase 3 trials. CHDI is again doing blanket testing of some possible disease altering drugs. More than 10 years ago over 3000 approved drugs were tested with nothing found that altered the disease. This time the feeling is a smaller collection of drugs are more promising. Another line of research is looking at gene repair issues in Huntington patients. Although the number of repeats someone may be tested as having might be 43, due to gene reproduction repair issues, some of the genes in the brain may have 80 or so repeats creating more problems than expected from the tested CAG repeat rate.

To get a better understanding of the HD disease progression the data from the Enroll-HD, Registry, Track-HD/ON, and PREDICT-HD studies have been cleaned up, combined, and analyzed in a partnership between CHDI and IBM using Watson. This work took over a year, but is providing information to better track the effectiveness of disease altering treatments.

This is my 18th Convention in the last 20 years and each shows progress in the fight of this terrible disease. 20 years ago the cry was to make this the last generation of HD. Over those 20 years we have lost loved ones and seen others that we love fall under the influence of this disease. We are getting closer, but we are not there yet. We need to help the researchers help us. We need to participate in programs like Enroll-HD. We need to participate in clinical trials keeping in contact with our Centers of Excellence and keep looking at websites like HDTrialfinder.org. The fight is not over and even if we find a treatment we need to keep looking for better ones to make HD something we live with instead of something we die from.



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The Neuropsychological Evaluation in Huntington's Disease

Bryan Bernard, PhD and Sharlet Anderson, PhD
Rush University Medical Center HDSA Center of Excellence

People with Huntington's disease are often asked to have a neuropsychological evaluation. Sometimes, the reason for this evaluation may not always be immediately clear to the patient or their caregivers. The following information is provided to help patients and caregivers understand the role of the neuropsychologist in their care team.

What is neuropsychology? It is the study of the relationships between behaviors people have and the functions of the brain. Neuropsychology encompasses behavioral, emotional, and cognitive functioning.

Who are neuropsychologists? They are clinical psychologists who have a PhD or PsyD degree and specialized training in neuropsychology. They often see patients who have difficulty with cognitive functioning, which includes memory, thinking, and problem solving. Neuropsychologists conduct evaluations to assess these cognitive skills as well as emotional functioning in order to characterize changes that may be due to a neurological condition or injury.

What is a neuropsychological evaluation? A neuropsychological evaluation is an assessment of brain functioning. It usually involves an interview with the patient and their caregiver, several tests of cognitive, emotional, and behavioral functions, and possibly some questionnaires to fill out. The neuropsychologist analyzes and interprets the results to get a better understanding of the patient's cognitive and emotional changes or behavioral difficulties. Neuropsychological evaluations vary in length, but may take about an hour or more, depending on their level of complexity and detail.

Why would a person with a diagnosis of HD undergo neuropsychological evaluation? A neuropsychological evaluation is an important part of the clinical care provided for patients with HD. The brain changes of HD affect certain parts of the brain including the subcortical regions, basal ganglia, as well as the frontal lobes. We need our frontal lobes to plan and monitor behavior, to benefit from incorporating feedback into our decisions and behaviors, and to problem-solve. One of the most common cognitive changes in HD is executive dysfunction. This means there may be difficulty with attention, multitasking and problem-solving, which may affect the patient's ability to work or live independently. The information that comes from a neuropsychological evaluation helps the healthcare providers in treatment planning. It also helps the patient and their families make plans to optimize their quality of life.

The neuropsychological evaluation also assesses emotional functioning. The neuropsychologist interviews the patient, caregiver or other family members about possible psychological changes in the patient. Patients with HD may experience the spectrum of emotional changes associated with frontal lobe dysfunction, from depression to apathy to irritability to agitation. These changes may occur at different stages of HD too. However, there are many good medications which may be helpful in treating the various emotional changes in HD. Psychotherapy, including cognitive behavior therapy and supportive counseling, can help both patients and family members cope with the stress of dealing with a chronic illness such as HD.

In addition, people who are at risk for inheriting the HD gene, and are interested in obtaining pre-symptomatic genetic testing, will have a visit with the neuropsychologist as well as the neurologist and genetic counselor. The neuropsychologist assesses for psychological factors which may be important in helping the person when they receive the results of genetic testing.



Bryan Bernard, PhD and Sharlet Anderson, PhD are Neuropsychologists and Assistant Professors who work in the Department of Neurological Sciences, Section of Parkinson's Disease and Movement Disorders, HDSA Center of Excellence at Rush University Medical Center.

Maine South High School raises more than \$60,000 for Huntington's disease research

By Jennifer Johnson – Contact Reporter
Pioneer Press
Reprinted from Chicago Tribune

April 28, 2018 - Maine South High School's spectator gym was a sea of blue T-shirts on Thursday as students raised awareness for Huntington's disease research and celebrated the conclusion of another successful school-wide fundraiser.

Students, with help from local businesses and members of the community, raised a total of \$60,320 for Huntington's Disease Society of America — a new fundraising record for the Park Ridge, IL school.



Maine South reveals fundraiser total for Huntington's Disease research

The amount was revealed during the all-school spring assembly on April 26.

"It's absolutely amazing," said Maine South senior Maggie Etchingham, whose family inspired this year's fundraiser.

Four years ago, Maggie's father, Joe, a 1985 Maine South graduate, was diagnosed with Huntington's disease, a genetic disorder that causes physical and mental deterioration due to a breakdown of nerve cells in the brain.

There is no cure, according to Huntington's Disease Society of America, which helps to fund research and offers community services and education of the disease.

When her school was looking for charitable causes for the annual fundraiser, Etchingham suggested Huntington's disease research.

"When my dad was diagnosed, we had no really no idea what it was or how it would affect us," she said. "Over time, his ability to walk, talk and eat on his own [will be impacted]. He'll be unable to do anything. Our concentration now is being there for him."

Maggie's father was present for the school assembly, with service dog Echo in tow, as was her mother, Kristin. Both Maggie and Kristin said they would like to see the funds raised by Maine South go specifically toward research for a cure for Huntington's disease.

"Our goal, really, was to make people aware," Kristin Etchingham said. "Most people did not know about this disease. We didn't know about this disease when we found out Joe had it. We had never heard of it. Our mission is to spread awareness and raise money for research to find a cure."

That awareness campaign was evident at Maine South, where a number of students on April 26 wore blue T-shirts that read, "Hawks Fight Huntington's." And over the last few months, the cause has been at the forefront of students' minds as they participated in fundraiser after fundraiser led by the School-Wide Fundraiser Committee. There was Hawkfest, Pizza Wars, a color run, a day-long auction, partnerships with businesses around the community, and the



Junior class representatives participate in a tug-of-war during the Spring Assembly at Maine South High School on April 26. (Kevin Tanaka / Pioneer Press)

“miracle minute,” during which students stuffed envelopes with as much change as they could, among many others activities. One student even hosted a live comedy night to generate donations, Maggie Etchingham said.

Both Joe and Kristin Etchingham said they were “overwhelmed” by the outpouring.

“The love and support in this community, in this high school is so overwhelming and so humbling,” Kristin Etchingham said. “Our family feels so blessed to be a part of it.”

Principal Ben Collins also noted the school’s support and the care students have shown for a classmate and her family.

“Thank you so much for making this a special place,” he said.

Camille Colletti, development manager for the Great Lakes region of Huntington’s Disease Society of America, said the money and awareness raised by Maine South “really does make a difference.”

“HDSA’s vision is a world without HD — and we’re going to keep going until we find a cure,” she said.

jjohnson@chicagotribune.com

Twitter: @Jen_Tribune

— save the date —
SYMPOSIUM

Saturday, October 13, 2018

Half-Day HD Symposium in Peoria, IL

The HDSA Illinois Chapter in collaboration with OSF Healthcare will be hosting a half-day educational event on the OSF campus in Peoria. Details on the logistics, agenda, and registration will be posted soon on the HDSA Illinois Chapter website: HDSA.org/il.

— save the date —

Saturday, December 1, 2018

Celebration of Hope Chicago



Hosted at: Cubby Bear in Wrigleyville

Honoring Dr. Danny Bega from Northwestern University

Special Performance by comedian Tim Harmston

Registration and Sign-up to attend will be available soon at www.hdsa.org/coh-chicago



New collaboration seeks to speed Huntington's disease drug licensing

Critical Path Institute launches new initiative to get HD drugs licensed as quickly as possible

By Dr Jeff Carroll on May 10, 2018; Edited by Dr Ed Wild; Originally published on May 09, 2018

Recently the Critical Path Institute announced a new effort - the Huntington's Disease Regulatory Science Consortium, or HD-RSC. This collaboration with many international partners aims to speed the development of new HD treatments. What's all this about, and how could it help HD patients?

What is C-Path?

The Critical Path Institute is likely new to most Huntington's disease community members, but they're not new to the fight against human diseases.



Regulatory agencies like the FDA and EMA need very specific evidence before drugs will get licensed. The HD-RSC will work to speed up this process.

In 2004, the US Food and Drug Administration (FDA) launched an effort to modernize and speed the development of new therapies. As a result of that effort, in 2005, the FDA and partners founded and funded the Critical Path Institute (or C-Path) with a goal of speeding the development and reducing the costs of bringing new drugs to patients who need them.

To do its work, C-Path brings together teams of organizations that are working on a specific problem. These C-Path consortia work to streamline drug trials in their area of interest, as well as developing new tools to improve the quality of trials.

As an example, C-Path has a consortium focused on Alzheimer's Disease which they call Critical Path for Alzheimer's Disease, or CPAD. This consortium of regulatory agencies, drug companies, researchers and advocates focuses on developing new tools to accelerate the development of new therapies for Alzheimer's Disease.

What does C-Path do?

How do groups like CPAD work to improve or speed clinical trials? As an example, CPAD has developed a sophisticated computer model that tracks the progression of Alzheimer's Disease by compiling huge amounts of existing information about Alzheimer's Disease patients. Alzheimer's Disease clinical trials are done by a number of different individual organizations, and the data is not always shared between trials.

This is where C-Path comes in - they specialize at pulling together information about the disease stored with drug companies and academic researchers around the world. Based on real data from dozens of drug trials, C-Path's computer model allows organizations thinking of developing a new Alzheimer's Disease model to essentially do a practice run of their trial in a computer simulation.

This allows any organization with a new Alzheimer's Disease drug to plug in a few numbers about how well they think their drug will work, and get feedback about how likely a given trial design is to be successful. That can be enormously powerful for trying to figure out how many patients to enroll in a study, and how to divide the people in the study between the arms of the study.

C-Path's consortia have also worked on other critical roadblocks to rapidly completing trials. Several of their consortia have focused, for example, on helping researchers develop a new biomarker to simplify or shorten clinical trials.

There are a few kinds of biomarkers, but ultimately they are precise measurements that serve to tell us about how a disease is progressing in a human - say, a brain scan for HD. They can also report on how well a drug is doing based on changes that drug leads to in body chemistry or other measurements.

Because of their history and membership, C-Path understands how regulators, like the FDA and the European Medicines Agency (EMA), think about drug approval. This puts them in a great position to translate the science that researchers generate, into the measurements and outcomes that regulatory agencies need, to prove that drugs are safe and effective.

C-Path's Newest Consortium: HD-RSC

"This puts them in a great position to translate the science that researchers generate, into the measurements and outcomes that regulatory agencies need, to prove that drugs are safe and effective"

Recently, the official launch of C-Path's newest consortium was announced - the Huntington's Disease Regulatory Science Consortium, or HD-RSC. The consortium was launched in partnership with the CHDI foundation, a non-profit dedicated to rapidly developing meaningful treatments for HD.

The HD-RSC involves a huge range of players in the HD world beyond C-Path and CHDI, including drug companies (ten in fact, including Roche, Sanofi, Teva, Wave Life Sciences and others), regulatory agencies and patient advocacy organizations (including the HDSA, HSC and EHDN). These diverse organizations all have their own expertise and interests, but all of them are committed to developing new therapies for HD patients.

Last November, representatives from all these organizations came together in Silver Spring Maryland for a kickoff meeting. Your humble HDBuzz author attended to get a sense of what to expect from the HD-RSC. Over two days of meetings (program available at the link), dozens of participants talked about how best to speed clinical trials for HD.

Excitingly, the attendees included very high-ranking members of the FDA, including Eric Bastings (Deputy Director), and Billy Dunn (Division Director, Division of Neurology Products). These are the folks that are in charge of the review of new HD drugs being tested. Far from standing on the sidelines, the FDA attendees sat front and center in the first row, taking notes and asking a number of questions. It seems that these regulators get HD, and they're interested in trying to speed the safe development of new therapies for HD families. This consortium sums up the collaborative spirit of the HD community and our determination to make progress as quickly and efficiently as possible.

By the end of the meeting, the organizations comprising the HD-RSC had organized themselves into 5 working groups. Each of these smaller groups is focused on helping solve a specific problem - developing new biomarkers, for example.

Another exciting goal embraced by the HD-RSC is the problem of how to design trials of drugs for presymptomatic HD mutation carriers - meaning people who carry the HD mutation, but who don't yet have HD symptoms.

Stopping HD symptoms before they start is the goal for everyone working on HD, but it's complicated to understand how we would design a trial and monitor people who don't yet have any symptoms to measure. Excitingly, this working group suggests that some really savvy folks think this is an important problem and have agreed to spend time working on creative solutions.

Take home message for families

We're entering a new phase in the fight against HD. Incredible drugs, designed specifically for HD, have moved from labs around the world into the clinic. The feeling many in the community had that "no one cares about HD" is being replaced by the realization that HD is a very hard, but solvable, problem.

Groups like the HD-RSC are great news for us because they mean that smart people are working hard, that they're collaborating and most importantly - that all these organizations feel that HD drug development is an exciting place to work. Stay tuned for exciting new ideas from the HD-RSC.

HDSA Center of
Excellence at
Rush University
WELCOMES
New Social
Worker

Brian "Tucker" Eads, MA, LSW, is a Licensed Social Worker and has joined the *Rush University Medical Center Huntington's Disease clinic team*. Tucker has a background in mental health, including volunteering with the National Alliance on Mental Illness (NAMI), facilitating family education and support groups. In addition to working with the HD clinic at Rush, Tucker also provides outpatient care coordination and psychotherapy services. Tucker received a Master's in clinical social work from the University of Chicago School of Social Service Administration. He can be reached at 312-563-0042, brian_t_eads@rush.edu, and is located in the medical building at 710 S. Paulina, #316, Chicago, IL 60612.



HDSA IL Chapter Baggo Tournament

Double Elimination

When: Saturday, September 8, 2018 (rain date – September 9th)

Time: 1:00pm (Team Check in at 12:30pm)

Where: The Home of Charlotte Rybarczyk
3000 Owl Drive, Rolling Meadows, IL 60008

SPLIT THE POT



Registration Fee:

\$60/Team ~ \$15/Spectator

(Sponsorship Opportunities Available)

**Win a
Custom
Baggo
Set!**

****Vienna Hot Dogs, Beef Sandwiches and Lemonade included**
Your donation is 100% tax deductible**

Winning team receives \$100 plus each player chooses one of our custom Baggo sets!

Any questions, contact Charlotte Rybarczyk at 847-259-3593 or charlotte82963@gmail.com

**Return registration form and check made payable to HDSA IL Chapter by September 1st to:
HDSA IL Chapter, P.O. Box 1883, Arlington Heights, IL 60006**

TEAM NAME: _____

Player #1 Name: _____

Player #2 Name: _____

Phone Number: _____

Email Address: _____

Spectators: Name _____ How many? _____

Baggo Tournament Sponsorship

The Huntington's Disease Society of America (HDSA) invites your company to become a local sponsor for the 2nd Annual Illinois Chapter Baggo Tournament being held on Saturday, September 8, 2018, in Rolling Meadows, Illinois. Events such as this are a way to show how local communities of inspired individuals can join together to make a difference.

Huntington's disease (HD) is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities during their prime working years and has no cure. HD is known as the quintessential family disease because every child of a parent with HD has a 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. Many describe the symptoms of HD as having ALS, Parkinson's and Alzheimer's – simultaneously.

A local sponsorship of the Illinois Baggo Tournament for **\$250.00 or more** is an excellent opportunity for your company to support a great cause and to take advantage of a wonderful marketing opportunity. As a local sponsor, your company will be increasing your brand recognition and visibility, demonstrating your commitment to the local community your employees and customers live and work in.

Proceeds from the Baggo Tournament support the mission and programs of HDSA, the largest voluntary health agency dedicated to finding a cure and providing assistance to those individuals living daily with HD. **Any donation at or above \$250** will qualify your company's logo to be placed on sponsor signage at the tournament and will include one team as well as food and beverages for the team.

YOUR DONATION IS 100% TAX DEDUCTIBLE!

COMPANY NAME: _____

Phone Number: _____

Email Address: _____

Team Name: _____
(one team participation included with sponsorship)

Player #1 Name: _____

Player #2 Name: _____

PLEASE RETURN FORM WITH YOUR CHECK PAYABLE TO HDSA IL CHAPTER AND MAIL TO:
HDSA IL CHAPTER PO BOX 1883, ARLINGTON HEIGHTS, IL 60006-1883

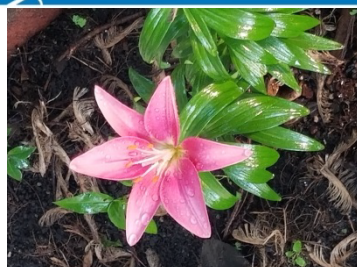
PO Box 1883, Arlington Heights, IL 60006 | T. 630 443-9876 | www.hdsa.org/il



HDSA meets all Standards of Excellence of the
Better Business Bureau Wise Giving Alliance,
National Health Council and the American Institute
of Philanthropy



Federal employee?
Support HDSA through the
Combined Federal Campaign
Designate #0526



Planting for HD

Do you have a **green thumb**? Do you have a spot in your home garden to plant a lily bulb? Join our new fundraising event and spread both awareness for HD and beauty and fun for you and your family!

Simple Rules:

1. Buy a lily bulb or bulbs of your choice and color.
2. Plant the bulb(s) in the Fall.
3. When it blooms the following June or July, take a picture of it. Please make sure YOU are in the picture. Any photos sent in without you in the picture with your blooming lily will automatically be disqualified.
4. Submit the picture along with a **\$20.00 by check made payable to:**
Illinois Chapter-HDSA and mail to:
Planting for HD
75 Birch Drive
Sandwich, IL 60548
5. All pictures will be judged by a certified AIFD florist.
6. The winner receives 5 new lily bulbs to plant for next year's contest.
7. You may enter as many pictures of **different lilies** you have planted, but each entry must be accompanied by a \$20.00 entry fee.

All pictures will be posted to the HDSA Illinois Chapter Facebook page along with your name. There are no restrictions on the age of the participants. What a great way to have some family fun as well as **spread some awareness for Huntington's Disease!**

Please submit your entries using the form below

Name _____

Street Address _____

City _____

State _____ Zip _____

Email address _____

Phone _____

Name of Lily _____

Questions? Contact Dave Hodgson at dchodgson1946@gmail.com

We are a 501(c)(3) non-profit charity (EIN 13-3349872)
Illinois Chapter-HDSA, PO Box 1883, Arlington Heights, Illinois 60006

14TH Annual Team Hope Walk – SUCCESS!!

By Dave Hodgson



On Sunday, May 20, 2018, 624 walkers and a few dogs braved the cold weather to walk in the 14th Annual Team Hope Walk along the beautiful Riverwalk in downtown Naperville, Illinois. According to all the weather pros, we were expecting rain and cold weather. They got the cold weather right, but the rain held off almost all day long.

This year's walk again broke a record for the most donations turned in by the HD families and friends of Illinois.

Early morning walkers were treated to coffee and bagels from Einstein Bagels of Naperville, and donuts provided by Eric Anderson and friend from the Woodstock Dunkin' Donuts store.

After a few opening remarks by Dave Hodgson and a welcome from TEVA Neuroscience, Chapter President Susie Hodgson cut the ribbon, and the walk stepped off at 10:30 A.M.



Post walk activities included the famous Hot Dog Lunch, the Carnival Bag Raffle, and the Dunk-Off Challenge between Rush Medical Center and Northwestern Medicine, our two Centers of Excellence.



Thank you to all of our major sponsors including TEVA, Steiner Electric, Seating Matters, and Chiro-One. This year's Team Hope Walk put us over the \$900,000.00 mark for 14 years of walking to support the mission of HDSA. Don't miss next year's Walk when we will go over the \$1,000,000.00 mark. Mark your calendar: Sunday, May 19, 2019!



This year, the HDSA-Illinois Team Hope Walk Committee honored the Stecyk/Bos family for their years of support to the Team Hope Walk program. Mary Bos, current member of the Illinois Chapter Board, and George Stecyk, former member of the Illinois Chapter Board, have remained steadfast and resilient in helping to find a cure for HD as well as supporting the mission of HDSA.

Congratulations!!



Photo's Courtesy of Tom Barr



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

Driving is a very important part of our independence. For people living with Huntington's disease, the ability to drive changes as the disease progresses. In the early stages of HD it is important to implement driving tools to reduce risks. As the disease progresses, there will be a time when a person living with Huntington's disease must give up his/her keys. When a person can no longer drive, it is important to identify alternative methods of transportation.

Individuals living with HD progress differently, so there is no strict cutoff as to when someone should stop driving. Once a person becomes symptomatic, it is important to have a conversation about driving, to create a plan and set rules about the future. In addition, neurologists can be great partners for this discussion. Your treating physician can provide feedback as to when is an appropriate time to stop driving.

In general, there are many distractions that come with driving. While a person with HD is still using a car, it is important for him/her to learn how to drive defensively. There are tools which can be helpful to keep someone focused on the road, which include:

- Program your phone to do not disturb while driving
- No music or audio programming in the car
- Drive only during daylight hours
- Do not drive in bad weather
- Plan routes ahead of time, so that you are comfortable with the roads

Deciding to stop driving is a difficult decision. For a person living with HD, it is important to know and understand limitations. If a family member or loved one becomes uncomfortable driving with an individual living with HD, it is important to discuss these concerns. There are certified driver rehabilitation specialist and occupational therapists that can perform professional evaluations. It can be helpful to get feedback from a neutral third party. Below is a list of driving evaluation sites in Illinois:

Chicago Lighthouse Driving Rehabilitation Program
1850 W. Roosevelt Road, Chicago, Illinois 60608 (312-447-3433)
Link: <http://chicagolighthouse.org/program/driving-rehabilitation-program/>

Loyola University Medical Center
1219 W. Roosevelt Road, Maywood, Illinois 60153 (888-584-7888)
Link: <https://www.loyolamedicine.org/rehabilitative-services>

Marianjoy Rehabilitation Hospital
Wheaton Campus, 26W171 Roosevelt Road, Wheaton, Illinois 60187 (630-909-6080)
Link: <http://www.marianjoy.org/MARTI/DriversInfoletterupdated2016.pdf#search=>

Northshore University Health System
Evanston Medical Office Building, 1000 Central Street, Ste. 101, Evanston, IL 60201 (847.570.2060)
Link: <https://www.northshore.org/physical-medicine-rehabilitation/our-programs/driving/>

Rush University Medical Center Driving Rehab Program
1725 W. Harrison St., Suite 440, Chicago, Illinois 60612 (312-563-2454)
Link: <https://www.rush.edu/services-conditions/occupational-therapy-ot/driving-rehabilitation-programs-and-services>

Additional Driving Resources:

UberAssist: Uber service that provides additional assistance for people with disabilities: <https://www.uber.com/en-SG/drive/resources/uberassist/>

Go Go Grandparents: A services that helps arrange for ride services: <https://gogograndparent.com>

Local Senior Centers: Follow up with your local senior center as they frequently have discounted taxi service for people living with disabilities.

Pace Paratransit Service: Chicagoland bus system. Passengers reserve a ride in advance.
<http://pacebus.com/sub/paratransit/default.asp>

Memorials and Tributes

In Memory of Michael Bliven from Marilyn Maiers, Keith & Debbie Fleero & Family, Larry & Tamara Ficher, Ronald & Ann Kookan, Jeremy & Shelley Arns, Marty & Diane Ward, Annette L. Newquist, Deena & Gregory Kroeger, Nicole Carson, Ange & Steven Heming, Deborah & Bruce Tritsch, Stephanie Hoener, Donna Walbring & Randy, Jerry & Betty Ulrich, Karen Bliven, Deborah Rueb, Steven & Carol Hamann, Brad & Crystal Bliven, Bill & Glenda Todd, Jack & Carol Gustson & Family, Kaitlen Edwards & Mark Hoffman, Laurie & Thomas Gilbert, Chad & Melissa Hoener, Kathy & Carl Edwards, John & Patricia Hubbard, Richard & Carol Hillbrenner, Emily Decker, Roger & Peggy Schoenekase, Bill & Linda Vandiver, Judy & Bud Bushaus, Louis & Theresa Quinyero, James & Linda Bliven, Kent & Linda Rodemich, Bill & Carol Chaplin, Trudy Hill, Charles & Carolyn Briddle, Clifton & Karen Weisinger, Richard & Joan Klimstra, Michael & Judith Graham, Richard Reis, Mont & Martha Robertson, Thomas & Susan Reeder, Curtis & Kathryn Fauble, Doug & Pam Wiewel, Charlie & Judy Bach, Quincy Tennis Assoc., Caroline & Lester Kewney

In Memory of Ralph Short from Lois Short

In Honor of Teresa Srajer on her Birthday from Catherine Evers

In Memory of Jennifer Bliven from Richard & Joan Klimstra, John & Wanda Cosgrove, Bill & Glenda Todd, Trudy Hill, Karen Koehn, Trudy & Mark Johnson, Deborah & Bruce Tritsch, Kenny & Pat Hermann, Wendy & Richard McCartney, Byron & Donna Wittler, Larry & Kathie Clark, Caroline & Lester Kewney, James & Linda Bliven, Betty Reddick, Wayne & Jane Wittmer, Mike & Bev Bliven, Mark Hoffman & Katie Edwards, Mont & Martha Robertson, Jill & Alan Rurvis, Marilyn Maiers, Daniel & Diana Reis, Ruth Hill, David & Susan Hill, Susan Meyer, Louis & Theresa Quintero, Patrick Humphrey, John & Patricia Hubbard, Deborah Rueb, Mel Ward, Marty & Diane Ward, Victoria Nieders, Bob & Janice Shupe, Chad & Melissa Hoener, Ronald & Ann Kookan, Nicole Carson, Clifton & Karen Weisinger, Kathy & Carl Edwards, Stephanie Hoener, Randy & Sandy Rieger, Judy Nastasi, Gary Wittkopf, Janet Wittkopf, Debbie & Keith Fleer, Karen Bliven, Steven & Carolyn Hamann, Kaz & Nayer Attai, Anne Ward, Jack & Carol Gustison, Dawn Stanley, Brad & Crystal Bliven, Deena & Greg Kroeger, Mary Hoener, Ann Reis

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Hopes & Dreams

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P.O. Box 1883, Arlington Heights, IL 60006-1883
(630) 443-9876 ~ www.hdsa.org/il

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



Reminder about HDSA's **on-line support groups**! We realize that many do not have access to an in person support group, so join us for an hour-long group to receive support, information, and the necessary resources for those affected by HD.

Please visit www.supportgroupscentral.com/hdsa for the most up to date schedule.

In order to participate you must be pre-registered. To register please visit www.supportgroupscentral.com/hdsa and select Join Now. Please note that there are a limited number of spots available so we encourage early registration. (Image below is the main page of you will see when you visit the site.)

Powered By **SupportGroupsCentral** *Live Online Peer Support for Life's Challenges*

SGC Home **How SGC Works** **About SGC** **Contact SGC**

Help for Today. Hope for Tomorrow.

The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by HD. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today and hope for tomorrow for people with HD and their families.

To learn more about Huntington's disease and the work of the Huntington's Disease Society of America, visit www.hdsa.org or call 1(800)345-HDSA.

Our Meeting Calendar

Dates/Times displaying in: **Eastern Time (ET)**

Meeting	Date	Time	Group Leader
HDSA Caregiver Support Group	Thursday June 28, 2018	7:00 PM ET	Lisa Mooney
HDSA Caregiver Support Group	Monday July 9, 2018	5:00 PM ET	Emily Zivin
HDSA Caregiver Support Group	Tuesday July 10, 2018	7:00 PM ET	Courtney Treharn
HDSA Caregiver Support Group	Thursday July 12, 2018	2:00 PM ET	Natasha Boissier
Closed Support Group	Wednesday July 18, 2018	7:30 PM ET	Lisa Mooney
At Risk / Not Tested Support Group	Thursday July 19, 2018	7:00 PM ET	Courtney Treharn
HDSA Caregiver Support Group	Tuesday July 24, 2018	7:00 PM ET	Lisa Mooney

Member Login

To register for and attend a meeting, please log into your member account.

Email

Password

LOG IN
TO YOUR MEMBER ACCOUNT

☐ Remember Me [Forgot Password?](#)

Not Yet a Member?

Membership is Free!

By joining today, you will become a member of Support Groups Central and Huntington's Disease Society of America will become one of your groups.

How Support Groups Central Works

JOIN NOW
SETUP A FREE ACCOUNT

Volunteer. Educate. Advocate. Donate.
HDSA.org (800)345-HDSA

Together we can make a Difference



Yes! Count me in!!

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



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		
3 rd or 4 th 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		
2 nd 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		
2 nd 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		
2 nd 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		
4 th Tuesday of even months TIME: 7:00 to 8:30pm LOCATION: Rush University Medical Center, 1620 W. Harrison Street, Tower Resource Center, Tower, 4 th Floor, Suite 04527, Chicago, IL * Parking is available at the Rush garage on the southeast corner of Paulina and Harrison Streets. From the 4 th 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 HDIA 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		
2 nd 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



September 8, 2018	HDSA IL Chapter 2 nd Annual Baggo Tournament
September 16, 2018	HDSA Team Hope Walk – Bloomington, IL
October 13, 2018	HDSA IL Chapter Half-Day Symposium – Peoria, IL
December 1, 2018	HDSA Celebration of Hope – Chicago, IL

<https://hdsa.org/il>



SUMMER 2018