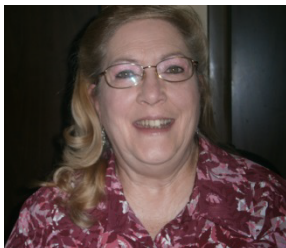


President's Message



What a year!! This has been an amazing year for our chapter. And now we are looking towards 2017 with hope and great expectations. June 22-24, the Illinois Chapter will be the host chapter for the HDSA 32nd Annual National Convention at the Renaissance Schaumburg Hotel and Convention Center in Schaumburg, Illinois. We will need volunteers to help with different aspects and at different times during the convention. We will need a committee to help stuff convention bags on Wednesday June 21. We will need a minimum of 20 to help at the Thursday Night, June 22, Kickoff Reception. We will need 20-30 people Friday and Saturday, June 23 & June 24, to help assist with the different tracks, assist people in finding their way around. We will also need people to sign up to help with the Chapter table in the exhibit hall. You can volunteer to help in more than one area and more than one time if you like.

- To volunteer to help at the Chapter Table please contact Charlotte Rybarczyk at charlotte82963@gmail.com
- To volunteer for the other areas of need contact me at sue_angels@softhome.net or Dave Hodgson at spiketdog@softhome.net

Stay tuned for updates about scholarship opportunities for Illinois residents who have never attended a HDSA National Convention.

Save the Date for our Annual Dinner Dance to be held January 28. The theme of the dinner dance this year is "Score for HD". Details can be found in this newsletter and also on our chapter website.

You will also want to save the date for our Annual State Conference, "Caring: Empowerment for Managing HD" on February 25. Details can be found in this newsletter and on our chapter website.

This past year was a banner year for our Team Hope Walk. Grossing over \$95,000, the HD families of Illinois have now raised close to \$700,000 in 12 years. Our walk in 2016 was the biggest Team Hope Walk in the nation. Our 2017 walk will be even bigger and better. Look for details elsewhere in this newsletter.

Remember, there is always a place for you to volunteer. We are always looking for new and creative ideas and events. Your idea may be our next ground-breaking success. For more information contact me at sue_angels@softhome.net.

As we look to 2017, it is with excitement and anticipation of great things to come. First and foremost as we move ahead, we are striving to keep the mission and vision of our organization at the forefront of everything we do.

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

VISION: A world free of Huntington's disease.

For us to succeed it takes ALL of us working together. We can't spell s_ccess without "U!"

Most sincerely,

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

Family is *everything*

We Can't Spell
S_CCESS
Without... U

Please pass this along to your support group members. The Illinois Chapter now has its own unique email address for contacting the chapter for problems, questions, and comments.

illinois@hdsavolunteer.org

While hdsailchapter@gmail.com is still active, it's no longer on our state webpage.

GET READY TO...

SCORE FOR HD

Tickets

\$75

\$25 is tax deductible

2 drink tickets included
vegetarian/gluten free
meals upon request

RSVP

by January 13

Sponsorship Opportunities
Donations
Questions

Visit Illinois.HDSA.org
-OR- Call Barry Kohn @ 847.975.2403

SATURDAY **28**
JANUARY 2017

6PM DRINKS AUCTION
7PM DINNER DANCE



Huntington's Disease
Society of America

Family is everything

Eaglewood Resort & Spa
1401 Nordic Road
Itasca, IL 60143

Discounted Rooms
\$109 plus amenity & fees

For directions and details visit Illinois.HDSA.org

REGISTRATION INFORMATION:

Visit our website at illinois.hdsa.org and under **EVENTS** click on *Score for HD* to register and pay with a credit card.

HDSA's HD TrialFinder Adds Live Call Center

In 2015, the Huntington's Disease Society of America launched HD TrialFinder (www.HDTrialFinder.org), an exciting and much needed new resource for HD community. HD TrialFinder is a free, easy-to-use clinical trial matching service that connects individuals with Huntington's disease, caregivers, healthy volunteers and physicians with current studies. Powered by Emerging Med, the continuously updated database includes - interventional, observational and biomarker studies being conducted at clinical trial sites across North America.

Starting in 2016, HDSA added a live call center component to HD TrialFinder. Now, HD families can call 866-890-6612 between 9:00 a.m. and 5:00 p.m. eastern time and speak to

an HDSA-trained Clinical Trial Navigator. The Navigator is there to assist families with customer service needs related to the HD TrialFinder.org website as well as provide important clinical trial information to those who may not have access to a computer.

Currently, there are clinical research opportunities for every member of the Huntington's community to join, unlike other websites like clinical trials.gov, which are not HD patient focused, HD TrialFinder works closely with corporate and academic partners to provide information about all currently recruiting trials in lay language that is easy for HD families to understand.

How to use HD TrialFinder:

Step 1

Go to www.hdtrialfinder.org to create an account or log in if you already have a username and password or, dial 866-890-6612 between 9am and 5pm EDT to speak with an HD Clinical Trial Navigator.

Step 2

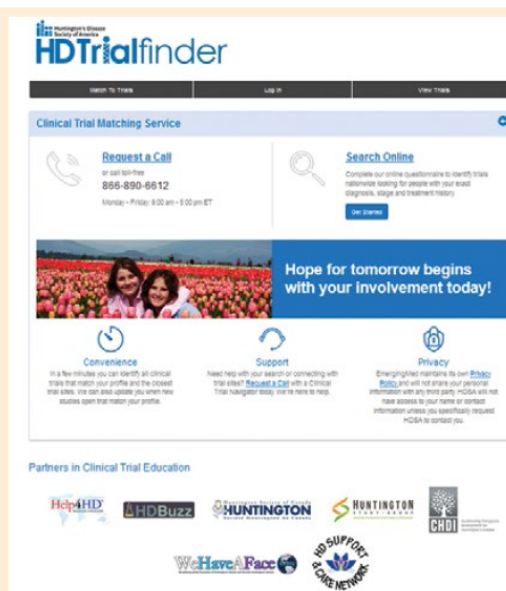
Complete a brief questionnaire about yourself or the HD impacted individual.

Step 3

Review your clinical trial match results. HD TrialFinder will compare your unique profile to its comprehensive, continually updated clinical trial database.

Step 4

Contact your nearest HD clinical center to speak with a study coordinator and get involved. As new clinical trial sites become active in your local area, HD TrialFinder will automatically notify you.



"Recent studies suggest that more than 80 percent of all clinical trials are delayed due to the inability to recruit participants in a timely manner," said George Yohrling, PhD., Senior Director, Mission and Scientific Affairs at HDSA. "Families have been waiting generations for the day when potential disease modifying therapies for HD would be developed. Well, that time is now upon us so we should do everything in our power to ensure no HD clinical trial is delayed."

HD TrialFinder was created to be a resource for the entire HD community. This is evident in the fact that numerous HD organizations such as CHDI Foundation, Huntington Study Group, Huntington Society of Canada, HD Buzz and Help4HD have all joined HDSA as partners in clinical trial awareness

and education by promoting use of HD TrialFinder among their constituents.

"HD TrialFinder is one of the most valuable tools the HD community has at its disposal", says Dr. Ed Wild (University College of London, Institute of Neurology). "As a researcher, and HDSA-supported communicator of HD research news via HDBuzz, I spend a lot of time and effort educating family members about all the cool research that's happening, and getting them motivated and excited to take part in clinical trials. HD TrialFinder brilliantly capitalizes on that motivation, supplying up-to-date, customized research opportunities and connecting patients to researchers in a few mouse clicks. It is a critical tool for recruiting the volunteers we need to help beat Huntington's disease."



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312-942-8007 (voice mail)

Driving and Huntington's disease (HD)

"Can I still drive, doc?" is a question frequently asked in the Huntington's disease (HD) clinic. Whether or not someone can safely drive can be a difficult conversation and a difficult decision, but is an important one. Talking about driving and HD should occur "early and often," a phrase that we in Illinois have often said!

Driving is a valued activity as it promotes independence and allows for convenient transport. Driving may be needed to get to the store, church, doctor's appointments, or friend's homes. Some people believe that driving is a personal right. However, driving is also a privilege and comes with responsibilities. Driving is a complex activity and requires healthy vision, hearing, cognitive, and motor abilities. When these abilities are impaired, there can be serious safety risks to the driver, passenger, and others. For this reason, drivers need periodic checks on vision, physical, and mental abilities for license renewals, with rules varying from state to state.

How does HD affect driving? Motor, cognitive, and behavioral features of HD can impact driving. This can be variable as people with HD are highly individual in their symptoms and course. Driving issues are more common as HD advances, but early issues can also arise. Involuntary or uncontrolled movements may make it hard to maneuver the steering wheel or to brake or accelerate properly. It can be difficult to coordinate multiple motor functions at once or to quickly respond to stimuli in the environment. Cognitive symptoms that affect attention, planning, multi-tasking, and memory can impact driving abilities. Altered visuospatial perception or sense of timing can lead to accidents such as bumping into curbs, parked cars, or the side of the garage. Sleepiness due to medications or other factors can impair one's attention and vigilance while driving. Behavioral symptoms such as anger, irritability, impulsivity, anxiety, or depression can also affect driving.

Talking about driving in HD is important. While some people with HD may be aware that they are having trouble with driving, not all people are. Therefore, it is better to start the conversation early and in an open, non-judgmental manner with regular check in's with the patient, their family and friends, and doctor. Safety is a primary concern. Moreover, in today's world, there is an ever-growing number of ways that people can be distracted in the car (e.g., radio, coffee or drinks in the car, cell phones, etc.). It is not just you the driver, but also the other drivers on the road and everything going on around you!

How can we assess driving? First steps include discussing any concerns with one's doctor and pursuing any necessary clinical or cognitive evaluations. Additionally, formal driving evaluations can assess driving abilities off and on the road. Driving evaluations are frequently part of Occupational Therapy programs, but may be run by private agencies or the Department of Motor Vehicles. People with HD may continue to drive until they have difficulty. If it is not clear if someone should stop driving, then a comprehensive driving evaluation is needed. Comprehensive driving evaluations include off-road and on-road assessments. The off-road assessment takes place in the clinic. Occupational therapists perform a vision screen; physical screen assessing movement, strength, sensation, and coordination; and cognitive screen evaluating judgment, memory, directional orientation, comprehension and knowledge of road rules and signs. The on-road assessment occurs in an actual car with an occupational therapist and a specially training driving instructor. Recommendations are then made - OK to drive without restrictions, drive with restrictions, or not allowed to drive. Driving restrictions may be for certain locations (local roads but not highways), times of day (daytime but not night-time), or conditions (no driving in rain or snow). Adaptive equipment (extended car mirror) or on-road training strategies may help someone continue driving. However, if a person is found to be unfit for driving, the doctor and family should insist that they stop. Some states require mandatory reporting.

How to deal with changes in driving? It is important to recognize that changes in driving abilities may affect not only a person's independence, but also their socialization and mood. Alternative means of transportation such as ride programs, public transportation, taxis, or volunteer drivers may be helpful. Deliveries or home visits may be useful. Even if someone reduces or stops driving, finding ways to continue regular socialization should be encouraged. The practical as well as social needs of driving are important aspects for caregivers, family, and friends to consider.

Stay safe and be well.

This article was written by:

Mary Ellen Stoykov, PhD, MS, OTR/L, Assistant Professor of Occupational Therapy, College of Health Sciences, Assistant Professor, Division of Health Sciences, Graduate College at Rush University Medical Center, Chicago, IL and Jennifer G. Goldman, MD, MS, Associate Professor of Neurological Sciences, Section of Parkinson Disease and Movement Disorders, Rush University Medical Center and Director of the Rush University HDSA Center of Excellence, Chicago, IL.



References:

1. Rebok et al. (1995). Automobile Driving in Huntington's Disease. Movement Disorders, pages 778-787.
2. Devos et al. (2012). Determinants of fitness to drive in Huntington disease. Neurology, pages 1975-1982.
3. Beglinger et al., (2012). Clinical predictors of driving status in Huntington disease. Movement Disorders, pages 1146-1152.
4. Baker et al. (2014). Fitness-to-drive decisions for acute care and ADHD. American Occupational Therapy Association OT Practice, pages 7-10.

Memorials and Tributes

In Memory of Sharon Mooney Wiese and Cathleen Wiese Ulbrich from Clarence Wiese

In Memory of Laura C Smith from Leonard & Lucy Kelley, Terry & Linette Brown, Cliff Armstrong, Russel & Carol Miller, Richard & Carolyn Smith, James & Barbara Ely, Richard & Mary Foulkes, Kaywin & Ann Lindsay, Brian & Janet Pavlons, Bonnie Grizzle, Warren & Violet Bates, Larry Hankins, Thomas & Shirley Boward, Carlton & Sandra Jenkins, Lawrence & Arlene Pennie, Fred & Marcia Giese, Charles Stewart, Brian & Nicholas Hitch, Gerald & Karen La Voie, Cooksville Grain Co

In Memory of Ralph Short from Lois Short

In Memory of Peter Gavras from Mildred Gavras

In Honor of Jennifer, Michael and Richie Bliven from Zachary Bliven

In Tribute to Craig Srajer from Catherine Evers

In Tribute to the Etchingham Family from Sheila M. Stephani, Michael R Mizwicki & Kristen Pugliani Mizwicki, The Children's Surgical Foundation, Inc, John & Lori Power



The National Youth Alliance (NYA) of HDSA just completed a fund raiser, "The 12 Days of NYA," during the holiday season to raise funds for NYA scholarships to the National Convention this June in Schaumburg, Illinois. Their goal was to raise \$2500 in 12 days and they were successful! The Illinois Chapter was able to donate \$500 to their scholarship fund to help them meet their goal. The NYA represents those young people, ages 9 to 29, affected by HD and helps to send young people to the NYA Day at the convention each year. We are proud to help the NYA as they will be our future leaders.

Annual Convention Coming to ILLINOIS in 2017!



Save the Date!

Join us for the 32ND Annual HDSA Convention right outside of Chicago at the elegant Renaissance Schaumburg Hotel & Convention Center.

June 22-24, 2017 / Schaumburg, IL

Stay tuned for more details at HDSA.org



Caring: Empowerment for Managing HD 2017 HDSA Illinois State Conference Saturday, February 25, 2017

Northwestern Memorial Hospital, Feinberg Pavilion, 3rd Floor – Room A
251 E Huron Street, Chicago, IL 60611

Registration is \$10.00/person, includes continental breakfast and lunch

We encourage you to register online at illinois.hdsa.org

Click on the Conference link, Events or News tabs

Join us for a day packed full of empowering information for managing HD. Our keynote speaker, Claudia Cook from LivHome, will be bringing us up to date on technologies that assist and, in many cases, improve caregiving for our loved ones. Dr Danny Bega from Northwestern Memorial Hospital will be sharing insights into current Research and trials to be aware of. A panel of caregivers will share their experiences and insights into the vital role they play, and more.

Agenda

- 8:15 am **Registration, Breakfast and Community**
- 9:00 am **Welcome & Introductions** – Susie Hodgson, LPN, HDSA IL Chapter President
- 9:15 am **Technology for Caregiving** – Claudia Cook, AM, LivHome
- 10:00 am **Break**
- 10:15 am **Morning Breakout Sessions**
 - Estate and Asset Protection, Rick Law
 - Government Benefits and Finding Long Term Care Facilities, Gina Salamone
 - Advocacy for HD, Jennifer Simpson, HDSA
- 11:15 am **Break**
- 11:30 am **Research and Clinical Trials Update**, Dr. Danny Bega, MD, MSCI Northwestern Memorial Hospital Feinberg School of Medicine
- 12:15 pm **Lunch**
- 1:15 pm **Caregiving Panel Discussion**, moderated by Emily Zivin, LCSW, MPA, HDSA Illinois Chapter Social Worker, Dave Hodgson, Medina Kazimi, Sandra Morris
Option for Youth - Community Building
- 2:15 pm **Break**
- 2:30 pm **Afternoon Breakout Sessions**
 - HD 101 - Dr. Danny Bega, MD, MSCI Northwestern Memorial Hospital
 - Physical Therapy's Role in all Stages of HD, Melissa Layher, PT, DPT, CFMT and Sarah Mikesell, PT, DPT
 - Nutrition for all Stages of HD, Kristin Gustashaw, MS, RDN, LDN, CSG
 - Genetics and Reproduction Options, Sara Cherny, MS, CGC
 - Learning about the National Youth Alliance, Miranda Spencer, BSN, RN, NYA board member
- 3:30 pm **Closing and Adjourn**

This event is supported by the Huntington's Disease Society of America through an unrestricted educational grant from Teva.



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

Applying for government benefits can often be a difficult task. The application process requires a lot of financial and medical information. In the fall newsletter, there was information about various government benefits. If you feel overwhelmed starting this process or are in the process of appealing a decision, there are people and organizations that are available to help.

Caring Voices Coalition is an organization that provides comprehensive outreach programs to patients who live with life-threatening chronic illnesses. The services they provide include financial, emotional and educational

support. One of the very important services Caring Voice Coalition offers is free assistance applying for SSI/SSDI. Please take a look at their website to see all the great services available to you and your families: www.caringvoice.org.

Elder law attorneys are also a good resource for long term and financial planning. Attorneys with experience in aging and disability law have a great deal of knowledge about long term health planning. They can help guide you through this very difficult process. Eldercare lawyers are aware of the mental and physical difficulties that often face Huntington's Disease clients. They have a broad knowledge base and are able to help with all the planning needs for you and your families.

Acquiring legal services can be a very expensive endeavor. There are several legal services offered within Illinois that have reduced or no fees. Some of the local non-profits include:

- 1) Chicago Legal Clinic
- 2) Legal Council for Health Justice

There is a lot to consider when planning for your future. There are services available to make the process of applying for benefits and planning for your future easier. Please contact me if you would like any additional information on how to apply for benefits. ezivin@hdsa.org or (630) 443-9876.

Emily Zivin, LCSW will be GUEST SPEAKER at the January 15th

HD Rockford Support Group Meeting

OSF Medical Center, 5666 E. State Street, Rockford, IL

St. Francis Room

TIME: 2:00pm

(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. St. Francis room is straight ahead)



13TH ANNUAL - Team Hope Walk

SUNDAY, MAY 21, 2017

NAPERVILLE RIVERWALK (RAIN OR SHINE)

REGISTRATION: 9:30AM ~ WALK BEGINS: 10:30AM



The Illinois Chapter invites everyone to join us for the 13th Annual Team Hope Walk which will be held on Sunday, May 21, 2017, at the beautiful Grand Pavilion of the Naperville Riverwalk in Naperville, IL. To register, please visit our webpage at: <http://www.hdsa.org/thwnaperville>. As in past years, registration will begin at 9:30 AM and we will walk at 10:30 A.M. After the Walk, stick around for the now famous HOT DOG LUNCH! Also, as in past years, The Carnival Bag Raffle promises bigger auction items than ever. Additionally, we will have some surprises for the kids and adults. Pre-registration through the above link guarantees you the correct t-shirt size. Pre-registration is \$20 and will save you \$5 over walk-in registration fee of \$25 the day of the event. We can only guarantee the first 400 who pre-register will have a correctly sized t-shirt. We anticipate that the 2017 Team Hope Walk will surpass the record setting 2016 Team Hope Walk, the biggest walk in HDSA history! Did you know that the 12 annual Team Hope Walks have grossed nearly \$700,000.00? Let's set another record this year! If you have any questions, please contact Dave Hodgson by phone at 815-498-6092 or by email at spiketdog@softhome.net. We look forward to seeing you there!

The Riverwalk is very people friendly with park benches, along the way. It is wheelchair, wagon, and stroller friendly! Dogs are welcomed as long as they are on a leash. Please be sure to bring your lawn chairs and plenty of your own non-alcoholic drinks for everyone walking in your group. Don't forget water for your dog too!

Fundraising

Team Hope Walks aim to raise as much money possible in the local community to support the mission and services of the Huntington's Disease Society of America. There are many different fundraising strategies you may use to have a successful fundraising campaign, and HDSA suggests you use all of them! Please go to the walk website and download the Team Hope Walk Participant Packet and check out the Team Hope website's Fundraising Tips & Tools (including some fundraising webinars!) and Participant Resources sections.

Sponsorship

We invite all local companies and small businesses to sponsor this Team Hope Walk. We depend on the generosity of sponsors, and by sponsoring a walk, your company will be supporting a great cause as well as engaging in an exciting marketing opportunity within the local community. If your company or a company you know is interested in sponsoring the walk, please email teamhope@hdsa.org!

Proceeds support HDSA's fight to improve the lives of people affected by HD and their families. As in past Walks, memorial and business signs are available for a \$100 donation and will be displayed near the Walk. We hope all of our families affected by HD will join us and make this year's Walk our most successful one!

If you have any questions, please contact Dave Hodgson at 815-498-6092 or email at spiketdog@softhome.net.

NATIONAL SPONSOR

TEVA

Neuroscience

LOCAL SPONSOR



This year's challenge: Have 10 FRIENDS sponsor you!

PLEDGE SHEET

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 all 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.



Family is everything



13th ANNUAL TEAM HOPE WALK

	NAME	ADDRESS	AMOUNT	
1.				Good Start
2.				
3.				
4.				
5.				Getting Closer
6.				
7.				
8.				
9.				
10.				You Did It!
11.				
12.				
13.				
14.				Keep Going!
15.				
16.				

Name: _____
 Address: _____
 City: _____ St: _____ Zip: _____

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: _____

Pfizer Amaryllis trial ends in disappointment: no improvement in Huntington's disease symptoms

Pfizer announces the 'Amaryllis' trial of a PDE-10 inhibitor drug failed to improve symptoms of HD



By Dr. Ed Wild on December 16, 2016 Edited by Dr. Jeff Carroll

Pfizer has announced that the first-pass analysis of its 'Amaryllis' trial, testing a PDE-10 inhibitor drug, shows the drug did not meet its target of improving Huntington's disease symptoms. As a result, the open-label extension study will be stopped. This is not the news we'd been hoping for, but we've learned a lot about HD along the way.

No improvement in symptoms

In a call with investigators, drug company Pfizer yesterday announced negative results from the first-pass analysis of its **Amaryllis** trial. Unfortunately, the trial drug failed to show significant improvement in the main symptom it was targeting – movement function – or any of the other symptoms it might have helped with – thinking ability, behavioral problems and activities of daily life.

The amaryllis is the emblem of the global HD community. Despite this negative trial result, we remain determined to fight on.

As a result, the company has decided to terminate the still-running open-label extension study that many participants in the Amaryllis trial had been entered into.

The Amaryllis trial was testing an experimental drug code-named **PF-02545920**, which acts on signaling chemicals inside brain cells. It had been hoped that it would improve the communication between neurons, which is one of the things that goes wrong in HD brains. PF-02545920 reduces the activity of a molecular recycling machine called phosphodiesterase 10, so it is known as a **PDE10-inhibitor**.

The trial included 271 people with Huntington's disease in five countries. At the end of the trial, participants were invited to participate in the **open-label extension** study, in which everyone receives the active study drug at the highest dose they could tolerate. Participants in that extension study will now be contacted to be informed of the negative outcome of the trial, and instructed on how to reduce and stop the study drug. **Participants should wait to be contacted, or get in touch with the study site, but should not just stop the drug immediately.**

Why didn't it work?

Testing experimental drugs in people is really hard, especially for a disease as difficult to treat as Huntington's disease. Sometimes, a trial drug turns out to be unsafe, causing some kind of unexpected harm to patients taking it. It's very important to note that as far as we know now, this was **not** the case with the Amaryllis trial: there were no major safety issues with the trial.

The other risk is that an experimental drug just might not work as well as hoped. Despite our best efforts to test only HD drugs that look promising, the brain is a complicated thing. A brain with HD is extra-complicated, because it's changing all the time. However good the science that precedes a trial, we can never perfectly predict whether an experimental drug will actually do what we hope, when it's given to patients.

"Despite the negative outcome, we've learned a great deal about Huntington's disease and PDE10."

A negative trial, not a failed trial

This is undoubtedly sad news. We had been enthusiastic about the drug and the trial and Pfizer had done a great job of working with the HD scientific and family community

Marielle Delnomdedieu, who led the Amaryllis study for Pfizer, told us "We're all very disappointed that the study drug didn't meet its primary endpoint of improving movements in HD, or any of the secondary endpoints looking at other features of the disease. But despite the negative outcome, we've learned a great deal about Huntington's disease and PDE10. The trial data will be a rich resource for HD research. We're pleased with the way the trial was planned and run, and immensely grateful to the patients and their relatives involved in the trial."

We couldn't agree more. All that work by researchers and HD family members has not been wasted. Thanks to Pfizer and its collaborators, we now have a much better understanding of how HD progresses, and the role of the PDE10 enzyme in the disease. Scientists will continue to comb through the data generated in the trial to try to figure out why the drug didn't improve symptoms as had been hoped. Others will continue to study PDE10 and try to come up with new ways of improving communication in the Huntington's disease brain.

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Hopes & Dreams

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



Date/Time	Additional Information	Contact Information
CENTRAL ILLINOIS		
2nd Sunday of even months TIME: 2:00 to 4:00pm LOCATION: St. Joseph Medical Center, Bus. Conf. Center – Room 2, 2200 E. Washington Street, Bloomington, IL	2017 Meetings: 2/12, 4/9, 6/11, 8/13, 10/8 (No meeting in Dec.)	Dave or Susie Hodgson (815) 498-6092 spiketdog@softhome.net
GENEVA		
3 rd or 4 th Sunday of odd numbered months (see dates in next column) TIME: 2:00 to 3:30pm LOCATION: Cadence Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot) * Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome.	Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left. 2017 Meetings: 1/29, 3/26, 5/28, 7/23, 9/17, 11/12	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
LAKE COUNTY		
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	2017 Meetings: 1/10, 3/14, 5/9, 7/11, 9/12, 11/14	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH UNIVERSITY MEDICAL CENTER		
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.	Dr. Steve Clinger (847) 778-2881 sclinger@cookcountyhhsorg Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD
CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL		
Meeting Date: 1/28/2017 , TIME: 10:00 - 11:30am Northwestern Memorial Hospital Feinberg Pavilion Room: Feinberg NM Acd-2-715 Meeting Date: 3/18/2017 , TIME: 10:00 - 11:30am Northwestern Memorial Hospital Feinberg Pavilion Room: Feinberg NM Acd-2-715 Meeting Date: 5/13/2017 , TIME: 10:00 - 11:30am Northwestern Memorial Hospital Galter Pavilion Room: Galter 8-234 675 North St. Clair	For At Risk (non-symptomatic) patients and family members.	Emily Zivin (630) 443-9876 ezivin@hdsa.org Parking Passes Available
MUNSTER, INDIANA		
2 nd Tuesday of even months TIME: 7:00 – 8:30pm LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	2017 Meetings: 2/14, 4/11, 6/13, 8/8, 10/10, 12/12	Cindy Rogers (219) 836-2369 clrogers111@comcast.net

Sadie Foster, M.A., L.C.P.C., has a telephone Information & support call service for HD families. This call is held the fourth Sunday of every month at 7pm. To participate dial 630-300-6276 and when asked, enter code 702087#. You do not need to identify yourself on the call.

For additional support you may call:

Sadie Foster, MA, LCPC, at the College of Medicine Huntington's Disease
Clinic Tel: 815-271-7101 or E-mail: sadie@sfoster.com

Sarah Mitchell, Rush University Medical Center Social Worker
Tel: 312-942-6445 or E-mail: sarah_mitchell@rush.edu

 **SAVE THIS DATE!**

January 28, 2017	HDSA IL Chapter Score for HD Dinner/Dance – Itasca, IL
February 25, 2017	HDSA IL Chapter State Conference – Northwestern Memorial Hsp. – Chicago
May 21, 2017	HDSA IL Chapter Team Hope Walk for a Cure – Naperville, IL
June 22-24, 2017	HDSA 32 nd Annual Convention – Schaumburg, IL

<https://hdsa.org/il>



WINTER 2017