Hopes and Dreams

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

President's Message

Season's Greetings HD Families!

I hope the holiday season has treated you and your family well! This year has been a year of hope and inspiration. As I look back at my first year as President of the Illinois HDSA Chapter, I am proud of the accomplishments of the Chapter, Volunteers, and the many families of the HDSA Community.

2019 brought 3 new events for our Chapter. This year was the first year for our very successful new fundraiser the *Spring Fling* event. The event was a night of trivia, a silent auction, dancing, and a great time with friends and family. The chapter worked with a group in Galesburg to add a *third Team Hope Walk* to our event list. The walk had some rain, but it didn't drive away the crowd and it still was a successful event. The last event added to the list was the *Golf for HD* event. A warm day, but an event that helped in spreading awareness. Along with those events we had our other successful events to raise money for research and spread awareness of Huntington's disease. Our other events that the chapter hosted were the *Baggo Tournament*, the *Team Hope Walk in Bloomington*, and the *Team Hope Walk in Naperville*. The Team Hope Walk in Naperville celebrated 15 years, and in that 15 years they have raised one million dollars in working towards the HDSA Mission "To improve the lives of everyone affected by Huntington's Disease and their families." All these events will be back for 2020, and I am looking forward to seeing so many of you at these events.

Our Education day and symposiums help with spreading awareness and educating our families about resources available to them. In Illinois we have access to 3 Centers of Excellence, and they are all outstanding in providing the services for those with HD. The cooperation with the education provided by the Chapter, and the Centers helps in completing our Mission.

The Illinois HDSA Board is a group of individuals that have a passion to help those with HD. Our Board Members all have a story that connects them to Huntington's Disease just like all of you. They fight for finding that cure just like you. Our Board goes through changes every year, to help with preventing burn out everyone rotates on and off the board. In 2020 we have some former Board Members coming back, and a couple of new friends joining the Board. At the end of 2019 we had 2 Board Members that have served on our Board for many, many years at various capacities announced that they are stepping down from our Chapter Board. Barry and Marilyn Kahn have helped with many things, and their dedication to the Illinois Chapter and the HDSA community has been greatly appreciated.

Thank you everyone for a great and successful 2019, and I am looking forward to a fantastic 2020! If you ever have any questions at all please do not hesitate to reach out, help and support are always available for you.

Sincerely,

Larry Haigh
President, HDSA Illinois Chapter

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

NEW CHAPTER P.O. BOX

Make A Difference

Dronacharya Lamichhane, MD
Director of HD Clinic
OSF HealthCare Illinois – Neurological Institute
200 E. Pennsylvania Avenue
Peoria, IL 61603
309-624-4000 (main)
877-464-6806 (fax)
dronacharya.Lamichhane@osfhealthcare.org (email)

Huntington's disease: Hopeful Time Ahead

Discovering a disease-modifying treatment for neurological illness is inherently difficult, mostly because we still do not understand the basic underpinning of the disease processes very well. Unlike the organs outside the brain, the brain and spinal cord are not easily accessible, and of course, the central nervous system is perhaps the most complex organ system in the body. But, the scientific community seems to have made some headway into this difficult territory in the past couple decades.

One good example is Spinal Muscular Atrophy (SMA). It is one of the leading genetic causes of infant death. Although the severity can vary, infants born with this severe illness can have difficulty maintaining blood oxygen because of respiratory muscle weakness, can't feed, sit up, or even crawl before eventually succumbing to respiratory failure and death. The nerve cells that carry electrical impulses for the muscles to move originate in the spinal cord are called motor neurons. Because of mutation in the gene called SMN1 that produces vital protein for the survival of the nerve cells, motor neurons die. Humans also have another copy of the same gene called SMN2, but it doesn't produce nearly enough protein.

Guess what? The FDA has already approved two disease-modifying treatments for this otherwise fatal illness. One approach simply replaces the faulty gene, another, you might have heard, ASO, makes SMN2 gene make more of the same useful protein. Results so far have been remarkable. Some of these infants who otherwise would have died before crawling walked with this therapy.

One of the reasons this is a huge success not only for the affected patients, but for the whole neurological society, including patients, is because treatments using ASO (antisense-oligonucleotide) are undergoing testing for various diseases, including Huntington's disease (HD)~~.~~ One particular example is ASO treatment for HD led by Roche/GENENTECH.

ASOs are relatively small molecules made of the same building blocks that make RNA. Remember that RNA is translated into protein. ASOs are designed in a way that blocks the RNA from being translated into the protein. So, even if a person with the faulty HD gene kept making toxic huntington RNA, ASO would block this conversion. We already have proof that ASO does effectively decrease the huntington protein in the brain in a dose dependent manner. Decrease in this protein does improve symptoms in the animal model, but we are still waiting to see if it does the same in HD patients. This is what everyone hopes the final phase of testing by the Roche/Genentech currently underway will prove~~s~~. Fingers crossed!!

The good news is that there is more than one approach to lowering the huntington protein. Several other companies are working on this. As we understand more about the intricacies of the disease processes, we will find more ways to attack this illness.

At the same time, it is important that we aren't overly enthusiastic either, as experiences with other neurological diseases have taught us. Several well thought out clinical trials have failed to show benefits in late stages in Alzheimer's disease. If anything, the Alzheimer's community is a good example of how not give up no matter how many times you fall down.

Success in SMA treatment also teaches something about drug cost. One of its FDA approved medications (Zolgensma®) has price tag of $2.125 million per patient. It is the most expensive medicine in the world…… so far! Although drug-pricing is a big discussion these days, it does make us think how, we as HD community, can contribute to a healthy discussion about reasonable drug prices so nobody with the disease gets left out in the fight against HD.

All in all, there has never been more exciting time in the field of Huntington's disease. Every one of us can contribute whatever we can to carry this fight till the end.

Additional information and registration details will be available on our chapter website in the coming months.

HDSA Illinois State Conference
April 4, 2020
Harper College in Palatine, Illinois

8:30 – 9:00am	Registration
9:00 – 9:15am	Welcome
9:15 – 10:15am	Research and Clinical Trial Updates (Drs. Bega and Hall)
10:15 – 10:30am	BREAK
10:30 – 11:30am	Breakout Options • Planning for your financial future • PT/OT's role in treating someone with HD and how to get started
11:30 – 11:45am	BREAK
11:45 – 1:00pm	Lunch and Mingle – Breakout Options • Caregiver Support Group • At-Risk Support Group • HD Positive Support Group
1:00 – 1:15pm	BREAK
1:15 – 2:15pm	Advocacy and HDSA – What HDSA does, resources available to you and how you can get involved
2:15 – 2:30pm	BREAK
2:30 – 3:30pm	Breakout Options • Sharing a diagnosis with employer, friends and community members • Genetic testing and navigating testing within a family
3:30pm	Wrap-up and Adjourn

Huntington's Disease Society of America
Illinois CHAPTER

Presents:

SPRING FLING

DJ * DANCING * TEAM TRIVIA * SILENT AUCTION

Saturday, March 28th, 2020, 7-11 PM

2-4 Players per Trivia Team * Cash Bar * Casual Attire

Arlington Lakes Golf Club
1211 South New Wilke Road
Arlington Heights, IL 60005

Register by February 29, 2020:
$40/Person *($30 is tax deductible)*
Register on/after March 1, 2020:
$50/Person *($40 is tax deductible)*

Late-Night Bites Provided by:

GREAT FAMILY VALUES SINCE 1964
WAYNE'S PIZZA
ARLINGTON HEIGHTS
847·255·2441

Rep's PLACE

Vienna Beef

NOTHING bundt CAKES

Sponsorship Opportunities Available

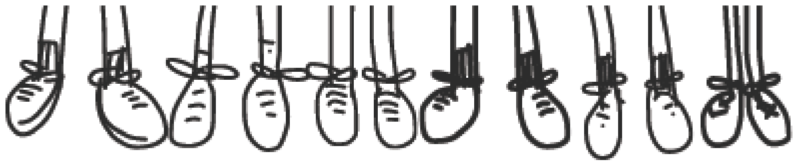
Questions? Contact Charlotte Rybarczyk at 847-259-3593 or **charlotte82963@gmail.com**
Return registration by March 23rd to:
Charlotte Rybarczyk, 3000 Owl Drive, Rolling Meadows, IL 60008
OR register online at HDSA.org/IL
Checks should be made out to HDSA IL Chapter

Contact Name ______________________________
Address ______________________________
____
Phone Number ______________________________
E-Mail ______________________________

Coming to the Spring Fling!
Guest 1 ______________________________
Guest 2 ______________________________
Guest 3 ______________________________
Guest 4 ______________________________

Save THE Date

16th Annual Team Hope Walk – May 17, 2020



Mark off Sunday, May 17, 2020, for the 16th Annual HDSA-Illinois Chapter's Team Hope Walk! Our 15th annual Team Hope Walk last year passed an important mile stone: we topped the one-million-dollar mark for donations to help support HDSA. This year's Walk continues the tradition of the HD Families of Illinois as we gather again to fight for a cure or treatment and advocate for awareness for Huntington's Disease that haunts all our families. Registration will open in mid to late January. Stay tuned for more information as we ramp up for the Illinois Chapter's biggest event AND home of the NOW FAMOUS Hot Dog Lunch! Look for your pledge sheet elsewhere in this newsletter.

The 2nd HDSA - OSF Symposium was held in Peoria on November 9th. Topics ranged from HD research and clinical trials, advocacy, must-have financial documents, genetic counseling and reproductive options, home healthcare and nursing home navigation, LT healthcare coverage, and Medicare/Medicaid planning. In 2019 OSF became the 3rd Center of Excellence in Illinois and is robustly building their support structure for HD families they serve. Look for the date of the 2020 OSF symposium at our HDSA.org/IL in the coming months.

CHAPTER OFFICERS

PRESIDENT – Larry Haigh
815-383-1877 ~ larryhaigh@gmail.com

VICE PRESIDENT – Dave Hodgson
630-386-3928 ~ dchodgson1946@gmail.com

TREASURER – Andy Hucker
224-715-0729 ~ ahucker1549@comcast.net

SECRETARY – Mary Bos
630-830-5329 ~ mary_bos@att.net

BOARD MEMBERS

Holly Fraleigh – holly.fraleigh@gmail.com
708-790-9618

Wayne Galasek – wgalasek@aol.com
708-289-1273

Erin Riley – erin.m.bentz@gmail.com
630-201-7396

Charlotte Rybarczyk –charlotte82963@gmail.com
847-259-3593

Arvind Shreedharan – avs2004@comcast.net
703-599-6000

Ann Terry – ann_terry5@yahoo.com
312-339-9356

OTHER CHAPTER MEMBERS

Emily Zivin –Social Worker
630-443-9876 ezivin@hdsa.org

Deb Boyd – Regional Director
dboyd@hdsa.org

Maryann Moynihan – Newsletter Editor
708-955-3080 shamrock1959@gmail.com

Hopes & Dreams
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P.O. Box 1454, Lake Villa, IL 60046
(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.

Memorials and Tributes

In Honor of St. Nicholas Day for Teressa & Craig Srajer from Catherine Evers

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
1			
2			
3			
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5			
6			
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8			
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11			
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16			
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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 ____________________

Yes! Count me in!!

2020 Pledge Drive

Huntington's Disease Society of America
Illinois CHAPTER

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

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

Please complete the information below and return with your pledge:

THANK YOU

Your Name ____

Email Address ____

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

Make your check payable to
<u>HDSA Illinois Chapter</u> and mail to:
P.O. Box 1454, Lake Villa, IL 60046

*To make your pledge online go to HDSA.org/il, click DONATE and choose **pledge drive** on the drop-down menu for the solicit code*

Family is *everything*

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

Huntington's Disease Society of America

35th ANNUAL HDSA CONVENTION

NEW ORLEANS

JUNE 4-6, 2020

HDBUZZ

Could molecular handcuffs lower the protein that causes Huntington's disease?

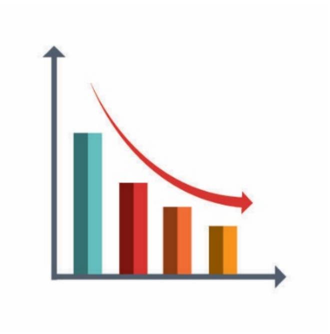
Researchers got surprisingly lucky when looking for drug molecules to pull mutant huntingtin protein into a cellular garbage disposal machine

By Dr. Tamara Maiuri, November 12, 2019 - Edited by Dr. Ed Wild

Several approaches are being taken to lower the amount of the toxic huntingtin protein as a way to treat Huntington's disease. Last week, a study reported a new strategy that helps target huntingtin for disposal by the cell. This approach is in its earliest stages and requires more testing, but the concept is sure to be investigated further.

Nipping the problem in the bud

The one good thing we can say about Huntington's disease is that, unlike many neurodegenerative diseases, we know the exact culprit: the huntingtin gene. Everyone has the huntingtin gene, but people with HD have an expansion in theirs.



Since we know the exact cause of HD, many treatment approaches aim to nip the problem in the bud: lower the amount of toxic mutant huntingtin protein.

The huntingtin gene acts as a recipe for the huntingtin protein, a molecular machine with many jobs in the cell. When a person inherits an expanded huntingtin gene, there's a corresponding expansion in their huntingtin protein. For reasons that are not entirely understood, this expanded, or 'mutant' protein is toxic to brain cells.

A new approach

A study published in the journal *Nature* last week reported a possible new way to lower mutant huntingtin levels.

Researchers turned to one of the cell's waste management systems, called 'autophagy'. Autophagy is an orderly way for cells to recycle unnecessary or damaged parts. The unwanted parts are swallowed up by big bags of digestive juices, and broken down, just like garbage bags left on the curb are thrown into a city garbage truck and hauled away.

Imagine if we had a set of molecular 'handcuffs' that could tether the mutant huntingtin protein to the garbage truck? Then it would always be cleaned up, with no chance to accumulate and cause problems in the cell. That's exactly what a research team from Shanghai set out to find.

Molecular handcuffs with the right fit

The team started their search with a list of existing drug candidates – things like FDA-approved drugs and natural remedies. This is called a drug library. They stamped each of the small molecules into tiny, clean-cut dots arranged in a grid on a glass dish.

Then they turned to a protein called LC3, which is in charge of capturing cargo destined for disposal in the cell. LC3 is like the garbage collector who hangs off the back of the truck, methodically picking up garbage bags around the neighborhood and dumping them into the compactor.

In the study, the LC3 protein was passed over the plate of small molecules in hopes that some of the small molecules would fit the shape of LC3, latch on, and stick LC3 onto the dish.

The same process was then done with mutant huntingtin, with some of the small molecules fitting its shape, latching on, and binding mutant huntingtin to the plate.

A fancy light-bouncing technique was then used to detect any dots on the plate that had captured both proteins – mutant huntingtin and LC3. The molecules in these dots were the first candidate molecular handcuffs that could link mutant huntingtin to the LC3 garbage collector.

To further refine the search, normal (non-expanded) huntingtin protein was also passed over the plate, with the purpose of *ruling out* any molecules that bound to normal huntingtin. The reason for this is that normal huntingtin has many important functions in the cell, so it makes sense to search for drugs that selectively lower the toxic mutant huntingtin, leaving normal huntingtin alone.

Although the research team started with a relatively short list of small molecules for a study of this type, they were apparently lucky enough to find not one, but two that stuck to both mutant huntingtin and LC3. Based on the chemical structures of these ‘hits’, they then came up with two more potential mutant huntingtin-LC3 handcuffs, for a total of four.

Do the handcuffs help get rid of huntingtin?

The candidate molecules were first tested in cells grown in a dish. From HD mouse model brain cells, to skin cells from HD patients, to HD patient cells that have been converted to neurons, the molecules appeared to lower the amount of mutant huntingtin while leaving normal huntingtin alone. The same was true in a fruit fly model of HD, and three of the four candidates even reduced mutant huntingtin when injected into the brains of HD model mice.

HD patient cells, grown in a dish and converted to neurons, usually die more easily than those from a person without HD. The candidate small molecules improved this somewhat, and also increased the lifespan and climbing ability of HD model fruit flies. In model mice, some HD-like symptoms were also improved.

Does this mean we have a treatment for HD?

“The handcuff molecules need to be tested by an independent team of researchers, to double check that they are as good as they sound, and to check for any potential downsides that the first team might have missed.*”*

As we have reiterated many times here at HDBuzz, mice are not people and so far, every potential drug that worked in mice has failed in humans. The excitement behind this study lies in the idea of tethering mutant huntingtin to the cellular waste disposal system, an idea that is sure to be followed up and refined as the research moves forward.

It is also an approach that could work really well in combination with others that are already being tested. Just as a bath will empty faster if you turn off the faucet *and* pull out the plug, so reducing the manufacture of huntingtin protein *and* speeding up its removal from cells could be a powerful combo.

One thing raising eyebrows among HD drug-hunters about this study is just how lucky the team was to find two molecules that did what they wanted, even though the library they started with wasn’t enormous. That doesn’t mean the results are untrue, but it could mean that the test of handcuff stickiness was easier to pass than they thought. If so, there might be unanticipated “off-target” effects if the molecules they found are generally sticky, and just happened to stick more to mutant huntingtin and LC3 than to healthy huntingtin.

All this calls for what one of our particularly smart friends called “orthogonal validation”. That means that the handcuff molecules need to be tested by an independent team of researchers, to double check that they are as good as they sound, and to check for any potential downsides that the first team might have missed.

Since the molecular handcuffs identified in this study are already available to HD researchers everywhere, you can bet they will be added to laboratory tool sets around the world.

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

Traveling can be very stressful for individuals diagnosed with Huntington's Disease and their families. The American with Disabilities Act guarantees that travelers with disabilities receive equal treatment. Unfortunately, travel is difficult and not all airports, restaurants and facilities are prepared to meet the required accommodations.

The following tips and resources will help individuals with disabilities and their travel companions anticipate some of the barriers and access to travel:

Travel Tips

1. Call ahead. Service providers are required by law to accommodate travelers with special needs. However, many need time to make arrangements. Contact your hotels, car rental, etc. 24-48 hours prior to your arrival to confirm that accommodations have been made.
2. Be clear and specific when you are describing Huntington's disease. Give them as many details about what you need. Let them know the specific accommodations you are requesting.
3. Consult your physician before you plan your travel and see how he/she can help. Your doctor can prescribe medications that might help on the trip. If you are traveling for a long time, it is also important to have all required medication organized and prepared.
4. Take a doctor's note and phone number. Travel with a statement from your doctor, preferably on letterhead, covering HD, medications, potential complications, special needs and other pertinent information.
5. Bring extra medication. Organize all medications and other necessary medical supplies in your carry-on bag.
6. Identify physician availability at your travel destination.
7. Carry medical information about Huntington's disease (wallet card, necklace, etc.).
8. Consider traveling to destinations that are accessible via car or one flight.
9. If you are flying, allow plenty of time before your flight.
10. Before your plane lands, check in with your flight attendant about an exit strategy.
11. Don't forget about transportation to and from the airport. If you have a wheelchair, make arrangements in advance to have an accessible vehicle pick you up at your destination.
12. Bring spare parts and tools. Wheelchairs can take tremendous abuse while traveling; assemble a small kit of spare parts and tools for emergency repairs.
13. Make sure all the sites you are visiting are handicapped accessible. You can call ahead to museums, restaurants, etc.
14. Have fun!

SUPPORT groups

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

CENTRAL ILLINOIS

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

2020 Meetings: 2/9, 4/13, 6/14, 8/9, 10/11 (no Dec. meeting)

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

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

ROCKFORD

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

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

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

GENEVA

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

2020 Meetings: 1/19, 3/29, 5/17 (no mtg), 7/19, 9/20, 11/15

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

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

LAKE COUNTY

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

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

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

(Call for additional information and directions)

MUNSTER, IN

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

2020 Meetings: 2/11, 4/14, 6/9, 8/11, 10/13, 12/8

Southside Christian Church, 1000 Broadmoor Avenue

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

CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL

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

2020 Meetings: 1/18, 3/7, 5/16, July, Sept, Nov. TBD

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

Contact: Emily Zivin (630-443-9876); emily.zivin@northwestern.edu

CHICAGO – RUSH UNIVERSITY MEDICAL CENTER

3rd Saturday of Every Month (10:00am – 12:00pm)

2020 Meetings: 1/18, 2/15, 3/21, 4/18, 5/16, 6/20, 7/18, 8/15, 9/19, 10/17, 11/21, 12/19

Rush Oak Park Hospital, 520 S. Maple, Oak Park, IL 60304
Conference Room 1B
Parking is Free; Refreshments will be provided
Each group will have a short presentation from a professional (dietician, therapist, etc.)

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

SOUTH SUBURBAN

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

2020 Meetings: 1/14, 3/10, 5/12, 7/14, 9/8, 11/10

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

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

Caring for the Caregiver

Caregiver Support Group

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

2020 Meetings: 2/19, 4/15, June, August, October, December TBD

Northfield Branch Library, 1785 Orchard Lane, Northfield, IL 60093
Meeting will be held in the Community Room
Contact: Emily Zivin (630-443-9876); ezivin@hdsa.org

NEW LOCATION

☑ SAVE THIS DATE!

March 28, 2020	HDSA IL Chapter Spring Fling – Arlington Heights, IL
April 4, 2020	HDSA IL Chapter State Conference – Palatine, IL
May 17, 2020	HDSA IL Chapter Team Hope Walk – Naperville, IL
August 29, 2020	HDSA IL Chapter Baggo Tournament – Rolling Meadows, IL

https://hdsa.org/il

<u>NOTE NEW P.O. BOX:</u>

HDSA/Illinois Chapter, P.O. Box 1454

WINTER 2020