



President's Message

Greetings Friends,

Happy Summer! I hope this newsletter finds you well. The start of the summer season is definitely an interesting one.

Just as the weather is changing, we are also seeing some of our restrictions lifted and we are changing into our "new normal". The Illinois Chapter of the HDSA is keeping up with these changes and still working hard to serve our families to the best of our abilities.

The National HDSA Convention was held virtually June 11th-13th. If you were unable to attend the sessions live, do not fear you will be able to view everything soon from www.HDSA.org, you will be able to see opening ceremonies, research updates, various sessions on tools to help navigate HD, and closing ceremonies. There is something available for everyone. Convention is a time to refresh and reset. Convention is also a time to reflect on the past year. 2020 was something that we necessarily may not want to look back on, but as a chapter we were able to take the year in stride. For our ability to pivot and manage to keep things going the Illinois Chapter of the Huntington's Disease Society of America was awarded the Chapter of the Year Award. This award does not go to just one person or a group of people, this is a team effort as a team we were able to pivot to provide the same assistance that we have offered for years. We were able to still host fundraisers whether it be the No-Baggio Fundraiser event, virtual walks, or a golf outing. Being able to pivot and keep providing support groups and services to the community is something that we can pride ourselves on. It takes a team to make everything possible. Congratulations once again to our Chapter! Mark your calendars now for the 2022 National HDSA Convention in Atlanta, Georgia June 9th-11th, 2022!

The month of May is Huntington's Disease awareness month. For our chapter that is also the start of our Team Hope Walks. In Naperville the committee was able to put on a hybrid event offering virtual and in person walking opportunities. As a Chapter we were also able to honor Dave and Susie Hodgson for their service to our chapter. They not only have serviced the chapter in various capacities as leaders, but they have been the hosts and chairs for the Team Hope Walk that is now in Naperville for 17 years and raising over one million dollars for HDSA. We will be forever grateful for their service and dedication to the mission of the Illinois Chapter. We wish them well into their retirement!

In this newsletter you will see the upcoming events for our Baggio Event, golf outing, and Team Hope Walk. We hope that we will be seeing you soon. Please keep your eyes open for our various educational events, and support group meetings as well that are coming up.

As always, thank you for your support. If there is anything that we can help you with do not hesitate to reach out. The chapter is made up of great leaders that are here to help. I appreciate the team that makes up our chapter.

Enjoy the rest of your summer,

Larry Haigh
President, Illinois Chapter HDSA



Save THE Date

Northwestern Medicine HDSA Center of Excellence Virtual Patient and Family Education Series 2021

July: Managing Difficult Behaviors

Date: July 31st, 1:00 PM (NOTE DATE CHANGE)

Speaker: Dr. Eric Gausche

Register in advance for this meeting:

<https://northwestern.zoom.us/meeting/register/tJcvfu6upj4vE9I8LrCRGkLDy7sdV4J9ThiK>

General support group after the presentation

November: HD Research Panel Discussion

Date: November 13th, 9:30 AM

Speaker: Dr. Bega and panel discussion with research participants.

NOTE: General HD Support Group to follow presentations.

Register in advance for this meeting:

https://northwestern.zoom.us/meeting/register/tJUoc-uuqDMrG9Xu-1NhX_f-HRPHcGorhUfR

General support group after presentation

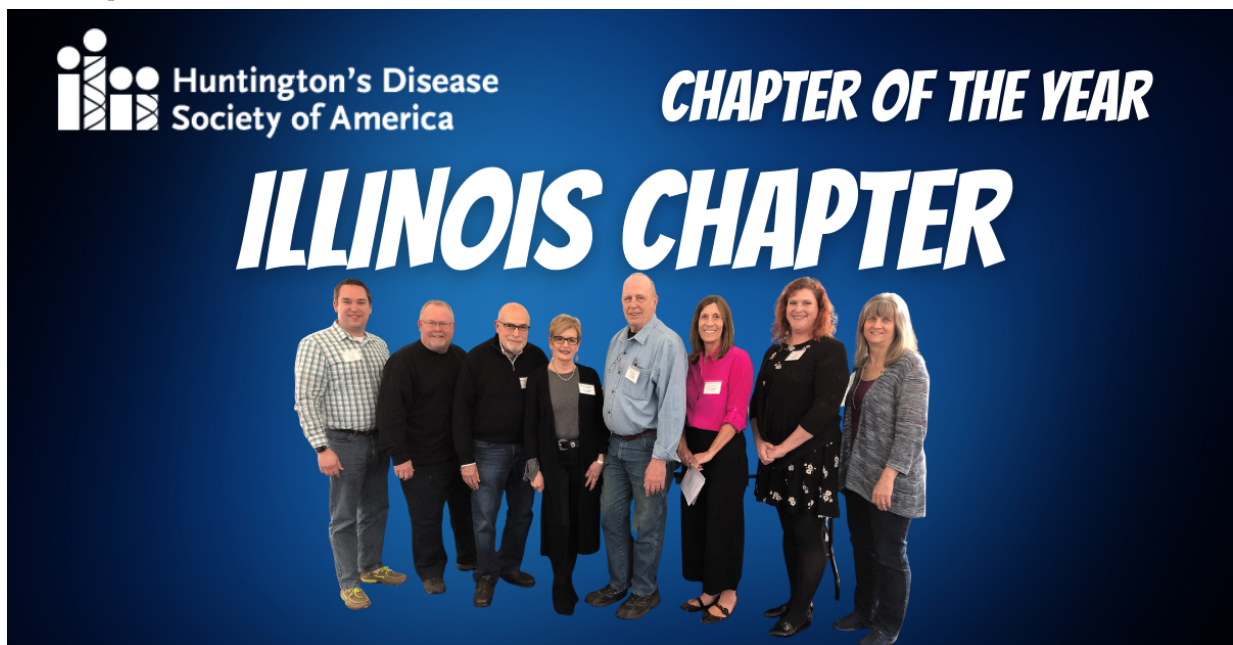
Questions: Please contact Emily Zivin: Emily.zivin@northwestern.edu

October: Rush University HD Symposium

Date: October 30th

Participants can RSVP by emailing: movement_hd@rush.edu

**CONGRATULATIONS Illinois Chapter for being named
Chapter of the Year at the 36th Annual HDSA Convention!!!**



Please welcome the new additions to our HD team

Northwestern Medicine continues to offer comprehensive care and management of Huntington's Disease (HD) through our HDSA designated Center of Excellence. Starting August 2021, the HD clinic will expand and be offered more frequently, the 2nd, 3rd, 4th, & 5th Friday mornings of each month. New provider additions to the NM HD team include Dr. Danielle Larson, a Neurology-Board Certified Movement Disorders specialist, and Dr. Amy Corcoran, a Board-Certified Behavioral Neurologist & Neuropsychiatrist. These physicians will continue to collaborate with the center's genetics counselor, social workers, dedicated neurology nurses and rehabilitation therapy team to care for HD patients.



Dr. Danielle Larson completed medical school at Tufts University School of Medicine in Boston, MA prior to completing Neurology residency training at Northwestern. She is a Neurology-Board Certified Movement Disorders specialist, after completing Movement Disorders fellowship at Northwestern's Parkinson's Disease and Movement Disorders Center. Her clinic focus is seeing patients with Parkinson's disease, Huntington's disease, Tic Disorders and Tardive Dyskinesia as well as Essential Tremor and other types of tremor. Dr. Larson performs botulinum toxin injection treatments for Migraines, Blepharospasm, Hemifacial spasm, and Dystonia. In addition to her clinical work, she conducts Parkinson's disease and Huntington's disease research through involvement as an investigator on multicenter clinic trials, in community-engaged research for under-served Parkinson's disease populations, and on telemedicine utilization for Movement

Disorders, specifically Huntington's disease.



Dr. Amy Corcoran completed medical school and Psychiatry residency at the University of Illinois at Chicago. She completed a fellowship in Behavioral Neurology & Neuropsychiatry at Baylor University. She has been seeing Neuropsychiatric patients at Northwestern since 2017. She specializes in treating the cognitive, behavioral, and psychiatric sequelae of various neurologic illnesses like traumatic brain injury, Huntington's disease, Parkinson's disease, epilepsy, multiple sclerosis, COVID-19, strokes, autism spectrum disorders, intellectual disabilities, and developmental disorders.

GOLF for HD 2021!

Golfers and supporters will be hitting the links again for Huntington's Disease

Sunday, September 12

Old Orchard Country Club in Mt Prospect

This will be the second annual event sponsored by the Illinois Chapter, following a COVID restricted program in 2020 that raised almost \$10K for medical research, family support and public awareness. On September 12, golfers will tee off at noon in a shot-gun, best ball tournament, with prizes for all levels of skill. As last year, fun games on the course will provide the teams with extra opportunities for personal challenges and prizes. Post-golf we will be hosting a raffle/silent auction to further our fundraising goals. **Golfing fees:** \$140 single, \$275 for 2, \$410 for 3 and \$540 for a foursome. Direct donations and questions about raffle prize/golfer gifts can be addressed on our website (golfforhd.com). We are seeking golfers of all skill levels in addition to community/business support with in-kind donations for the raffle table, and volunteers who may want to help run the event. Other questions/concerns can be addressed to Wayne Galasek, wgalasek@aol.com. Thanks for your consideration - hope to see you there!

[Home | Golf for HD](#)

<https://illinois.hdsa.org>

[Huntington's Disease Society of America \(hdsa.org\)](https://hdsa.org)



17th Annual HDSA Illinois Chapter Team Hope Walk Recap

Sunday, May 16, 2021, the HD families of Illinois met for the 17th Annual Team Hope Walk on the Riverwalk in downtown Naperville. Approximately 250 walkers participated at our first “hybrid” walk and many more virtually.

By all accounts everyone had a great time.

It appears that the Illinois Chapter of the Huntington’s Disease Society of America (HDSA) will reach its goal of \$70,000 in support of the mission of HDSA. Thank you to everyone who took part in this year’s walk. This year’s top team was **Team Stecyk and Friends** followed by **Team Skewes** and **Wally’s Warriors**. Top individuals included *Jan Skewes*, *Matt Haydock*, and *David Emmons*. Matt Haydock won the crocheted Team Hope Lap Throw.

Mark the date for next year’s walk on **Sunday, May 15, 2022!** If you’d like to join the committee that plans next year’s walk, contact Chapter President, Larry Haigh.



As this is their last year chairing this awesome fundraiser, this bench was presented by the HDSA Illinois Chapter Board to Dave & Susie Hodgson to thank them for the 17 years of being our Team Hope Walk Superheroes!





HDSA IL Chapter Baggo Tournament

Double Elimination

When: **Saturday, August 28, 2021** (rain date – August 29th)

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

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



Registration Fee:
\$60/Team ~ \$20/Spectator
(Sponsorship Opportunities Available)

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

Link for registration and donations: <https://illinois.hdsa.org/baggo>



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 August 21st to:
Charlotte Rybarczyk, 3000 Owl Drive, Rolling Meadows, IL 60008

TEAM NAME: _____

Player #1 Name: _____

Player #2 Name: _____

Phone Number: _____

Email Address: _____

Spectators: Name(s) _____ How many? _____

MEDICAL RESEARCH CORNER

**Study recruitment is impacted by Covid-19
and will resume as soon as possible.



NORTHWESTERN MEDICINE HDSA CENTER OF EXCELLENCE

Kinect-HD Study for Chorea

Northwestern Medicine is recruiting for a study of a treatment for chorea associated with Huntington's disease. The study is of a medication called Valbenazine to treat chorea and is being conducted by the Huntington Study Group and Neurocrine Biosciences. The study involves 9 visits and will last 18 weeks. There is the opportunity to stay on the drug after the first part of the study is over. Participants will be randomly selected to receive the drug or placebo at first. If you or someone you know is interested in taking part in KINECT-HD, please contact our study coordinator ZsaZsa Brown at 312-503-4121 or email zsazsa.brown@northwestern.edu.

Kinect-HD 2 Study

Northwestern Medicine is recruiting for an open-label extension study of Kinect-HD. The purpose of this study is to continue to gather safety and efficacy data on Valbenazine for the treatment of Huntington's chorea, while also providing study subjects who participated in Kinect-HD continued access to the study drug. In this open label study, all subjects are given Valbenazine, even if they received placebo during Kinect-HD. Kinect-HD 2 is open to research subjects who completed participation in Kinect-HD. For more information on Kinect-HD 2 contact ZsaZsa Brown at 312-503-4121 or zsazsabrown@northwestern.edu

PROOF-HD Study

Northwestern is recruiting for the PROOF-HD Study. This is a phase 3, randomized, placebo-controlled study evaluating the efficacy and safety of an oral drug called Pridopidine in patients with early stage Huntington's disease. The objective is to see if Pridopidine can slow down functional decline in Huntington's disease when compared to a placebo pill. If you are interested in learning more about the study and how to get involved, please reach out to study coordinator ZsaZsa Brown at 312-503-4121.

Telemedicine for Huntington's Clinical Care

Individuals with Huntington's disease are invited to participate in the study "TeleHD" to determine the feasibility and value of telemedicine visits for HD patients and their care partners. This research study is conducted by Dr. Danielle Larson and Dr. Danny Bega. Please e-mail research study assistant Robert Modiest at robert.jr3@northwestern.edu or call 312-503-5645 to let him know your interest, or if you have any questions.

HDSA CENTER OF EXCELLENCE AT RUSH UNIVERSITY

Uniqure, a gene therapy study for Huntington's disease

Rush University Medical Center is excited to be participating in a new gene therapy trial for Huntington's disease, sponsored by Uniqure. The therapy is called AMT-130 and will hopefully slow the progression of HD by lowering the level of huntingtin protein in the brain. "Gene therapy" works by targeting genetic abnormalities that contribute to us getting sick. Administration of the therapy involves a small incision in the skull through which AMT-130 is delivered to the brain. Researchers are looking for people aged 25 to 65, with at least 40 CAG repeats in their huntingtin gene, and specific brain structure that will be assessed by MRI. Eligible participants will be randomized to receive the real treatment or a "sham" surgery involving a small mark made on the skin without making an actual incision. Study duration is approximately 5 years, during which time participants will complete physical assessments, treatment dosing, lumbar punctures, blood draws, and MRIs. Assessments and treatment will be completed across multiple sites. If you or someone you know would like to take part in the Uniqure study, please reach out to Jacob Hawkins at 312-563-5563, or email Jacob_Hawkins@rush.edu. We anticipate being ready to enroll patients in the next few months.

KINECT-HD, a phase three drug trial of Valbenazine for Huntington's chorea

Rush University Medical Center is recruiting participants for a clinical trial evaluating a drug called Valbenazine for the treatment of chorea. Valbenazine is already an FDA approved medication for another type of movement disorder that causes involuntary movements called tardive dyskinesia. The study is sponsored by the Huntington Study Group and Neurocrine

Bioscience. Researchers are looking for people aged 18 to 75 with motor manifest Huntington's disease to be randomized to receive Valbenazine or placebo for 18 weeks. Participants will come to Rush for 9 research visits to take surveys, complete physical exams, and have their blood drawn. If you or someone you know would like to take part in KINECT-HD, please contact Jacob Hawkins at 312-563-5563 or email Jacob_Hawkins@rush.edu.

KINECT-HD 2, an open label rollover study for continuing Valbenazine administration for the treatment of chorea associated with Huntington disease

Rush University Medical Center is excited to participate in an open label extension study of Kinect-HD. The purpose of this "rollover" study is to continue to gather safety and efficacy data on Valbenazine for the treatment of Huntington's chorea, while also providing study subjects who participated in Kinect-HD continued access to the study drug. In this open label study, all subjects are given Valbenazine, even if they received placebo during Kinect-HD. Kinect-HD 2 is open to research subjects who completed participation in Kinect-HD up to their week 14 visit and subjects whose study participation was interrupted due to the Covid-19 pandemic. For more information on Kinect-HD 2, please contact Jacob Hawkins at 312-563-5563 or email Jacob_Hawkins@rush.edu.

ENROLL-HD, a prospective registry study in a global Huntington's disease cohort

Researchers at Rush University Medical Center are looking for patients affected by Huntington's disease and their first-degree blood relatives to take part in an ongoing observational study. The data gathered in ENROLL-HD will be used to help doctors and scientists learn more about Huntington's disease and hopefully develop new treatments. Participation involves an annual visit conducted in the Rush Section of Movement Disorders at Rush University, where participants will complete surveys, cognitive tasks, family histories, and a blood draw. in ENROLL-HD, please contact Jacob Hawkins at 312-563-5563 or email Jacob_Hawkins@rush.edu.

Cortical Control of Balance and Walking in HD

A neuroimaging study investigating brain activation during balance and walking under single-task and multitask conditions in people with Huntington's disease. We are looking for individuals with a clinical diagnosis of HD, 30 years of age and older, who can stand and walk unassisted. Participation requires one, 3.5-hour visit to *Rush* University Medical Center. This study is actively recruiting both healthy control and HD participants. Please contact Nicollette Purcell (Nicollette.L.Purcell@rush.edu) if you are interested in participating and would like additional information.

Optimization of Telegenetic Counseling for Huntington's Disease

Rush University Medical Center will be offering telegenetic counseling services to HD patients and families as part of a new study that aims to assess feasibility and patient satisfaction of a telegenetic counseling program. Lack of access to genetic counseling has been recognized as a critical gap in care for many HD patients and their family members. 35 symptomatic or pre-symptomatic participants aged 18 or older will be recruited for this study and randomly assigned to a group that receives in-person genetic counseling first, followed by telegenetic counseling, or a group that receives telegenetic counseling first, followed by in-person genetic counseling. In-person visits will occur at Rush's HD Center of Excellence, while telegenetic counseling visits will occur via a video platform provided by Rush. Participants will then be administered a post-visit survey with questions regarding content of counseling, format of delivery, and their preferences. During the COVID pandemic, we will be doing telegenetic counseling exclusively. If you or someone you know would like to take part in this telegenetic counseling study, please contact Marc Rosenbaum at 312-563-0665, or email Marc_Rosenbaum@rush.edu

National Youth Alliance

The NYA offers programming for individuals 12-29. In their upcoming miniseries, they will be talking about important topics and conversations during one hour-long sessions every other Saturday.

Upcoming dates for NYA miniseries:

- 7/10: Different Coping Methods Between Siblings
- 7/24: To Test or Not to Test?
- 8/7: Managing HD and Advocating Through School
- 8/21: Managing Anniversaries: Grief of a loved one and testing
- 9/4: Testing Positive
- 9/18: Being a Young Caregiver: Dealing with Symptoms at Home
- 10/2: Anxiety and Depression

To Register: <https://fs22.formsite.com/hdsa/3cdcjkh2lu/index.html>

VIRTUAL 36TH ANNUAL HDSA CONVENTION WELCOMES THOUSANDS FROM AROUND THE GLOBE

Nearly 2,100 registrants from more than 33 countries participated in the Virtual 36th Annual HDSA Convention this past weekend. The four-day virtual event featured world-class presentations on the latest in Huntington's disease research and care. Despite not being able to meet in-person, the Virtual HDSA Convention allowed guests to connect virtually through the HDSA Convention app and visit the Virtual Exhibit Hall.

The HDSA Convention was kicked off by an inspiring keynote address from world-renowned speaker and best-selling author Jon Gordon who gave valuable tips on the power of positive thinking. In addition to the incredible workshops, attendees also enjoyed the NYA Talent Show, Back to the 80's Trivia & Costume Contest and the Closing Ceremony. During Sunday's Closing Ceremony, HDSA's President & Chief Executive Officer Louise Vetter along with Dr. Victor Sung, Chair of HDSA's National Board of Trustees, presented the following national awards:

- **Person of the Year Award: Yvonne Sweeten**
- **Marjorie Guthrie Award: E.J. Garner**
- **Woody Guthrie Award: Doug Schulte**
- **Youth / JHD Award: Jenna & Gia Mannone**
- **Chapter of the Year Award: HDSA Illinois Chapter**
- **Affiliate of the Year Award: HDSA San Francisco Bay Area Affiliate**

The Closing Ceremony also featured the annual candle lighting ceremony and announced that the 37th Annual HDSA Convention will be held in Atlanta, GA on June 9-11, 2022 at the Marriott Marquis.

Thank you to our incredible sponsors, exhibitors and partners who helped make the Virtual 36th Annual HDSA Convention a massive success.

All recorded sessions from the Virtual 36th Annual HDSA Convention will be available in early July at www.HDSA.org/convention. See you next year in Atlanta!



Please welcome our new Faculty Member



The Rush HD Program continues to grow!

It is our great pleasure to introduce Dr. Neepa Patel to the HD program. Dr. Patel comes to Rush from Henry Ford Hospital in Detroit. During her time there, she worked collaboratively with the Michigan chapter of the HDSA to establish the first multi-disciplinary clinic for Huntington's disease patient's in metro-Detroit, which received a Center of Excellence designation in 2020.



Dr. Patel has spoken at the annual Michigan HDSA education day and she has also spoken at several support groups and local events to raise awareness and education within the HD community. She is excited to join the Rush team and work with the Rush HD clinic. Dr. Patel will be working with Dr. Hall and Christa Cooper, PA in the HD program and attending the weekly Rush HD team meetings.



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

Advocacy
Works!

Advocacy needed for the HDSA Parity Act

HDSA is actively lobbying congress to pass the HDSA Parity Act (S 868/ HR 2050).

Currently, once a person with HD is deemed eligible for SSDI benefits, a process that can take years, they wait two years to receive Medicare. The HDSA Parity Act will waive the two-year Medicare waiting period as well as the 5-month benefit waiting period for individuals with HD. The two-year waiting period for Medicare has been devastating for individuals with HD.

Current lobbying efforts include meeting with legislators across the 50 states asking them to co-sponsor this bill in both the Senate and House of Representatives.

What we need from you:

We need you to write letters to your senators. In Illinois, our Senators are Dick Durbin and Tammy Duckworth.

To contact Senator Duckworth, please email: stephanie_deluca@duckworth.senate.gov

To contact Senator Durbin, please email: max_kanner@durbin.senate.gov

To find the contact person for your local congressperson:

<https://www.govtrack.us/congress/members/IL#representatives>

We need you to share your HD story with your legislators and let them know why this bill is important to you. In addition to sending letters, please use your social media platforms to tag your legislators and let them know why they need to pass the HDSA Parity Act.

Need more information? Visit HDSA's advocacy efforts: HDSA.org/takeaction.

To join HDSA's Advocacy Caucus please visit HDSA.org/caucus.

For sample letters and general questions about how to advocate for this important bill, please reach out to me directly: 630-443-9876 or ezivin@hdsa.org

Memorials and Tributes

In Memory of William Vos from Tod Buenger and Grace Hansen.

In Memory of Bonnie McHugh from Larry and Judith Hanson.

In Memory of Clara Gardner Michael and Kelly Howard, Harold Jenkins, Jana Marks, Julie A'Hearn, Luigi and Doris Spinillo, Jeffrey and Julie Day, William and Angela Murdock, Rosalie Burgess, Renee Butler-Burton, Bradley Stevenson, John Kennedy, Randy and Cynthia Marquith, Harold and Carol Hawkinson, Stanley Hillier, Rebecca Kirgan, Patrick and Debra Pendergast, Wayne Hannam, Genevieve Oest, Vicki Legge, Mike and Lori Landon, Kenneth and Linda Maurizi, Patricia and David Asbury, Nancy and Robert L Baughman, Joseph and Marci Switzer, Harold and Susan Burmood, and Shawn and Tonya Weigand.





uniQure begins high dose treatment in AMT-130 trial

uniQure issued a press release this week stating that two more patients have been added to their clinical trial of HD gene therapy AMT-130. So far there are twelve participants in the trial, all of whom have undergone a surgery to reach the deep areas of the brain most vulnerable to HD. Seven participants have received the drug and five have received an imitation surgery.

The two participants highlighted this week are the first to receive a higher dose of the drug – an exciting step, because it means that everything has gone safely and smoothly with lower doses so far. Each of 26 total participants in this Phase 1 / 2 trial will be monitored very closely for a year and then less frequently for up to five years. Through this unprecedented trial of the first HD gene therapy uniQure hopes to learn whether AMT-130 is safe and whether it can lower levels of huntingtin protein.

HDBuzz on Pridopidine: How it Works

Pridopidine is a drug that has been developed for treatment of HD and was initially studied as a medication for chorea. Initial motor studies found that pridopidine was safe and tolerable. Although the drug did not meet its key goal of improving motor symptoms, it had positive effects on Total Functional Capacity (TFC) in people with HD. A Phase III clinical trial, **PROOF-HD**, is currently recruiting participants to look for conclusive evidence that pridopidine does improve TFC in individuals with HD, and scientists have been evaluating the drug in the hopes of identifying exactly how pridopidine might affect these changes.

HDBuzz gave us the summary on three recently published peer-reviewed journal articles that highlight sigma-1 receptor (S1R) proteins as likely targets for pridopidine's effects on neurodegeneration in HD. S1R proteins are found in brain regions in areas affected by HD and help nerve cells survive under stress. These studies have found that pridopidine helped to improve indicators of stress in cells and animal models of HD. For the full scoop on pridopidine and the latest research on how it works, check out HDBuzz's newest article at www.HDSA.org.



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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.



Due to Covid restrictions, all support groups will be virtual through Zoom. Please email the support group leaders directly to receive the Zoom meeting invite.

We invite all those diagnosed with Huntington’s Disease, their families, caregivers and individuals who are at risk to attend our Support Group meetings. Meetings provide a supportive environment where participants can share concerns, challenges, and successes. In addition, participants can lend emotional support to one another and lessen feelings of isolation. Meetings are always free to attend, and all locations are accessible. Your involvement is important for our support groups! At a meeting you might learn about a community resource, discover a new research study or hear from a guest speaker. Please consider joining us! For further information about any of the support groups, please contact Emily Zivin at 630.443.9876 or email at ezivin@hdsa.org. Cancellations may occur in the case of inclement weather. We will attempt to notify everyone with advanced notice by email. If you are concerned that a meeting may be cancelled, please contact Emily Zivin at 630.443.9876 to confirm.

Geneva/Rockford/Bloomington Groups

4th Sunday of Every Month (2:00 – 3:30pm)

For more information and Zoom details please reach out to one of the follow support group leaders;

Bloomington: Larry Haigh, larryhaigh@gmail.com

Geneva: Joe Wiedemann, joseph.wiedemann@gmail.com

Rockford: Charlotte

Rybarczyk, charlotte82963@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)

MUNSTER, IN

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

2021 Meetings: Contact Cindy Rogers for specific dates/format

Southside Christian Church, 1000 Broadmoor Avenue

Contact: Cindy Rogers (219-836-2369); clogers111@comcast.net

Caregiver Support Group ‘ZOOM’ Meeting

Wednesday (7:00 – 8:30pm) ~ 8/4, 10/6 and 12/1

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

Email ezivin@hdsa for ZOOM meeting login details

Northwestern Medicine/Cellini Foundation Support Groups

2nd Saturday of Every Month (10:00 – 11:30am)

For meeting invite, please email Emily:

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

We will be alternating between general support groups and topic drive discussions. **Please note - for the Saturday education events, support groups will be held after.

July 31st, 1PM

Education event and support group

Topic: Managing Difficult Behaviors

Speaker: Dr. Eric Gausche

General support group after presentation

August 14th: Conversation, Planning for the future

September 11th: General Support Group

October 9th: Conversation, Caregiving

November - TBD

Education event and support group

Topic: HD Research and Panel discussion

Speaker: Dr. Danny Bega, Leora Fox and research participants

General support group after presentation

December 11: Conversation, Thinking about testing

Rush University Medical Center Group

4th Saturday of Every Month (10:30am – Noon)

For more information and Zoom details please reach out to the following support group leader:

Sarah Strait, RN (312-563-2900); sarah_strait@rush.edu

Meeting Guidelines - We read the guidelines before each meeting to remind us that we are all responsible for following and committing to the group standards, which are in place to keep this group a safe place to share.

Share the air time - Everyone who wishes to share has an opportunity to do so. No one person should monopolize the group time.

One person speaks at a time - Each person should be allowed to speak free from interruptions and side conversations.

What is said here stays here - This is the essential principle of confidentiality and MUST be respected by all participants.

Differences of opinion are OK - We are ALL entitled to our own point of view.

We are all equal - We accept cultural, linguistic, social and racial differences and promote their acceptance.

Use "I" language - It's important to use "I" language because you are talking about yourself and not a vague person or group of people.

The use of "I" helps avoid someone feeling like they are being attacked - Examples include: "I feel like you handled that difficult situation the best that you could have" "I had good experiences with antidepressant meds in my family"

It's OK not to share - People do not have to share if they do not wish to.

It's everyone's responsibility to make the group a safe place to share We respect confidentiality, treat each other with respect and kindness, and show compassion.

 SAVE THIS DATE!

August 28 th	HDSA IL Chapter Baggo Tournament
September 12 th	HDSA Golf Outing
October 30 th	Rush University HD Symposium (RSVP to email: movement_hd@rush.edu)
November 6 th	OSF HealthCare Illinois Neurological Institute Symposium

Northwestern Virtual Patient & Family Education Series	
July 31 st	Managing Difficult Behaviors
November 13 th	HD Research Panel Discussion

<https://hdsa.org/il>



SUMMER 2021