



V Illinois Chapter

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

## **President's Message**



Greetings HD Families,

opes and

Happy Holidays! I hope this newsletter finds you well.

This year has thrown many things at all of us, and I hope that we can all say that we have gotten stronger during these different times that we have gone through in 2020. It will definitely be a year that we will not forget for quite a while.

I am proud of the Illinois HDSA Board and all that they have accomplished. Our chapter did not let changes hold us back from accomplishing our goals. Navigating through 2020, our chapter overcame obstacles and worked to serve our HD community the best that we could. I could not be prouder of our Board, our Centers of Excellence, and all of you for not giving up. We are still planning to do things and move forward as we go into 2021.

Emily Zivin, our Social Worker, has worked hard to put together a monthly education series to help bring educational services to all of you. Starting in January and running through May, there will be opportunities to join in on presentations on various topics that pertain to our HD Community. The topics can be found in this newsletter.

I could not write this letter without thanking a few people. Each year we cycle our members through the board keeping up with our requirements from the National Office. I want to thank Holly Fraleigh for her time on our board. She has spent many hours working on HD related things from education days, serving on committees, advertising, and fundraising. Thank you, Holly, for your time and dedication to the Illinois HDSA!

I would like to also thank Dave and Susie Hodgson. Dave and Susie are retiring from the board after spending over 30 years with Illinois HDSA. We cannot thank them enough for their blood, sweat, tears, and dedication into this organization. Dave and Susie are not just names that are known in Illinois they are National level ROCK STARS! Dave and Susie are examples of what it means to be dedicated to a cause. Thank you, Dave and Susie from the bottom of my heart and from everyone else that you have had a part in their lives! Please, do not be strangers! (P.S. we are not letting them fully retire yet, they are still hosting the walk in May this year!)

The Illinois HDSA Board is still working to serve you, our family. We want to make sure that you are still getting the care and information that you need. Please remember to take care of yourself. As we navigate these times please do not hesitate to reach out and ask for help.

Thank you to all of you for your patience and staying with us as we ride through this storm. I hope that we can find some normalcy soon. Sending you warm wishes and greetings this holiday season!

Take care, be safe, and be well!

Larry Haigh President, HDSA Illinois Chapter



# **17th Annual Illinois Team Hope Walk**

Sunday, May 16, 2021 in Naperville, Illinois. We're hoping it will be a 'live' event instead of a virtual event. Stay tuned for more information via our newsletter, Facebook, and our chapter webpage.

## HDSA Illinois Chapter: Monthly Virtual Education Series 2021

Because we are unable to meet in person currently, the Illinois HDSA chapter is running monthly education sessions for the first half of the year. For questions or help with registration, please contact Emily Zivin at 630-443-9876 or ezivin@hdsa.org. Meetings are held in central standard time.

#### January: All About Medicare

Please Join Jeff Steele as he discussed his personal experience with Medicare after being on disability for two years. He will discuss the ins and outs of signing up, cost analysis, and a general overview. *Register in advance for this meeting:* 

https://hdsa-org.zoom.us/meeting/register/tJIrceitpz8sGNPpax2HBQ3EpKK4t2tINUzC

#### February: Nutrition and HD

Please Join Kristin Gustashaw, advanced licensed clinical dietician at Rush University Medical Center as she discusses nutrition and Huntington's Disease.

#### Register in advance for this meeting:

https://hdsa-org.zoom.us/meeting/register/tJwsd-ygrzIqEtMtq\_9sKhRY8rsDmfJpo14x

#### March: HD and Caregiving

Please join Ralph Cagna as he discusses his journey of caregiving for his HD family. Ralph is a motivational speaker with years of caregiving experience.

Register in advance for this meeting:

https://hdsa-org.zoom.us/meeting/register/tJcqfuGsqD0iHtzKqIZFI7hV6Cc\_LOy0h95H

#### **April:** Clinical Research and Updates

# Please join Dr. Danny Bega from Northwestern Medicine as he provides an overview of HD research. *Register in advance for this meeting:*

https://hdsa-org.zoom.us/meeting/register/tJMvceqvrD4jE9RX7mVgTFhRaY\_vzuCpRNkh

#### May: Planning for Late-Stage HD and Adaptive Devices Date: May 20<sup>th</sup>, 4:00 PM

Please join Dr. Deborah Hall from Rush University Medical Center as she talks about planning for late-stage HD and discusses adaptive devices that can help assist in caring for your loved one.

#### Register in advance for this meeting:

https://hdsa-org.zoom.us/meeting/register/tJMscOugpzIsEta7GTXJzbg-R04fE117nSM

#### Date: January 12, 2020, 7:30 PM

## Date: February 17th, 7:00 - 8:30 PM

#### Date: March 16th, 10:00 AM

Date: April 19th. 7:00 PM



Deborah Hall, MD PhD Professor, Neurological Sciences Director, Rush University HD Center of Excellence 1725 West Harrison, Suite 755 Chicago, IL 60612 312-563-2030 (main) 312-563-2024 (fax) Movement\_HD@rush.edu (email) http://www.rush.edu/services/conditions/huntingtons-disease

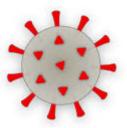
# **COVID-19 Variations, COVID-19 Vaccines, and Huntington's Disease**

It has been a year since my last Doctor's Corner column when I addressed this new Coronavirus Disease 2019 (COVID-19) for the first time. We now know a tremendous amount more about COVID-19. Healthcare providers have also spent months treating Huntington's disease patients during the pandemic, using all means necessary – by telemedicine, by telephone and in-person. Some of our patients have gotten COVID-19 (maybe without knowing they have it) and many have recovered, although some have not.

We are getting a lot of questions about COVID-19 in Huntington's Disease clinic. Here are some of the most frequent.

#### 1. Are Huntington's disease patients more at risk from COVID?

To date, there have been no specific studies looking at COVID-19 outcomes in Huntington's disease. However, we may be able to learn from other diseases that are similar to Huntington's disease. A study, that came out a few weeks ago, looked at people with dementia or major cognitive impairment reported outcomes in over 46,000



patients. Patients with Huntington's disease typically develop cognitive decline or dementia in the later stages, so we can learn from looking at this study. **The results showed that dementia was associated with a higher risk of COVID-19 infection, severe COVID-19, and death from COVID-19 infection.** The study authors recommend that patients with dementia have extra care and monitoring to minimize exposure to the virus. They also recommend the use of telemedicine and teams of specialists, like what would be seen at a Huntington's Disease Center of Excellence, for care. Now that the vaccine is available, this should also be considered.

#### 2. Do the Huntington's Disease doctors recommend the COVID-19 vaccine? Is it safe?

Dr. Hall and the team at Rush University in the Huntington's Disease Center of Excellence **recommend that all patients with Huntington's Disease consider getting one of the COVID-19 vaccines**. The two current vaccines that are available at the time of this writing: the Pfizer and the Moderna vaccines. Neither is FDA approved to prevent COVID-19, but both are granted Emergency Use Authorization by the FDA to be used now in the setting of the pandemic. Both vaccines show similar rates of prevention of the virus and two doses are required for it to reach an effectiveness close to 95%. The risks of getting the vaccine are similar to getting a flu vaccine: injection site pain, fatigue, muscle pain, headache, and others. A very small number of patients have had an allergic reaction. This also happens with the flu vaccine. Getting the vaccine in a health care setting may be safest if a reaction were to occur.



Dr. Hall receiving the COVID-19 Vaccine

#### 3. What is VUI 202012/01 and why should we be concerned?

Viruses frequently "mutate" or change over time. This is expected, and mutations occur approximately every two weeks with COVID-19. This variation of the virus is different from the COVID-19 that has been in the US because it is more "transmissible" or easy to spread. At the time of this writing, variant VUI 202012/01 had not been identified yet in the US, but history tells us that it may come to the US or already be here. VUI 202012/01 means it is the first variant under investigation from 2020, December. This new variation of COVID-19 reminds

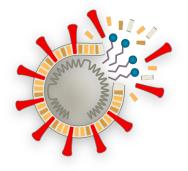
us to use all our strategies to stay safe. Infectious disease doctors and public health officials have told us that they expect the COVID-19 vaccines to also work against this new variation of the virus.

#### 4. What do I do if I get COVID-19?

Most people with COVID infection have mild symptoms and can be treated at home. Drive-by testing for COVID infections is now widely available. We recommend Huntington's disease patients do not come into the emergency department unless your symptoms are more severe and cannot be managed at home. This decreases the chance you will get COVID at the hospital if you do not have it already. In the emergency room, COVID testing, oxygen therapy, and admission to the hospital can all occur depending on symptoms. Milder patients are sent home to recover. COVID-19 patients have a recovery rate of 98% in Illinois, although some patients are left with lingering symptoms. If you are not sure what to do, call your primary care doctor or HD Center of Excellence Doctor.

#### 5. How can patients stay safe during this pandemic?

We continue to be reminded of the strategies we can use to stay safe. Many of the Huntington's Disease patients we see at Rush are practicing these measures and have not gotten COVID-19. **Staying home and limiting** 



**interaction with others** is one of the most important ways of prevention. This means being no less than 6 feet closer to others, avoiding public transportation, ordering in groceries, and only interacting with those people you live with. **Wash your hands with soap and hot water** for 20 seconds multiple times daily. In this picture from the New York Times, soap destroys the virus by wedging itself into the virus and prying it apart. Other important tools to stay safe include avoiding touching your face and cleaning surfaces regularly. Other resources:

- Illinois related resources and statistics: dph.illinois.gov
- Vaccine related questions: www.cvdvaccine.com
- Vaccine adverse event reporting: https://vaers.hhs.gov/reportevent.html

# Northwestern Patient and Family Huntington's Disease Symposium Video Presentations:

*Clinical Research and Updates - Dr. Danny Bega, MD, MSCI* <u>https://northwestern.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=9c0982fc-ba30-4583-8bdd-ac280148c71f</u>

Huntington's Disease and Physical Therapy - Shari Marchbanks, PT, DPT, NCS <u>https://northwestern.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=2ce1f871-a148-4532-9dd3-ac280148fa14</u>

How to Access Community Resources - Emily Zivin, LCSW https://northwestern.zoom.us/rec/share/ugnYexaTESs4HUeZZn9pvFbkyum49moh2yfSudad12wMQhBZRytflta E7kT\_Tnul.RNbzig3H6kkZr-ss



\*\*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 participating in a new 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. We are very excited to participate as one of several sites around the country. 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 will be participating in an open-label extension study of Kinect-HD. The purpose of this study is to continue to gather safety and efficacy data on Valbenizine 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 Zsa Zsa Brown at 312-503-4121 or zsazsabrown@northwestern.edu

#### **PROOF-HD Study**

Northwestern is excited to be participating in 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.

#### Who is Eligible?

- Have a diagnosis of Huntington's Disease
- Ages 18 to 70
- Have a computer, laptop, tablet or phone with a camera, microphone, and internet access
- Fluent in English

#### What will you be asked to do?

- Complete two telemedicine visits (by camera at home) in addition to your two regular in-person Huntington's Clinic visits over a 6-9-month time.
- During the visits, a neurologic exam will be performed, and you will complete two cognitive tests. The telemedicine visits will likely take less than 30 minutes.
- After each clinic visit, you will be asked to record the time and travel burden of your visit.
- After all the visits, you will be asked to complete a survey about your satisfaction with telemedicine visits.

Please e-mail research study assistant Robert Modiest at <u>robert.jr3@northwestern.edu</u> 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 upcoming open-label extension study of Kinect-HD. The purpose of this "rollover" study is to continue to gather safety and efficacy data on Valbenizine 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 firstdegree 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 cognitive, balance, and walking assessments in people with Huntington's disease. We are looking for individuals with a clinical diagnosis of HD, 35 years of age and older, who can stand and walk unassisted. Participants will come to Rush University Medical Center for 1-2 visits to complete a neuropsychological exam and walking and balance assessments while wearing a lightweight imaging cap. Recruitment will begin as soon as COVID-19 restrictions are lifted and continue for approximately two years. If you or someone you know would like to take part in this study, please contact Nicollette Purcell at Nicollette\_L\_Purcell@rush.edu.

#### 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



# 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

Planning for the future is an important conversation to have with your loved ones. There are key legal documents that need to be addressed as individuals age or are faced with a chronic illness. Hiring an attorney or financial planner is best practice. Some important documents to consider include:

## Power of Attorney for Property

The State of Illinois recognizes the right of adults to appoint an agent to make property decisions for them. This form can be used to designate agents to act on an individual's behalf if the individual becomes unable to do so. **Sample form can be found at URL below**:

https://www2.illinois.gov/sites/gac/Forms/Documents/POAProperty2015.pdf

## Power of Attorney for Health Care

The State of Illinois recognizes the right of adults to control all aspects of personal care and medical treatment, including the right to decline medical treatment or to direct that it be withdrawn, even if death ensues. This form can be used to designate agents to act on an individual's behalf regarding health care matters if the individual becomes unable to do so. **Sample form can be found at URL below:** https://www2.illinois.gov/sites/gac/Forms/Documents/POAHealth2018.pdf

## **Declaration of Mental Health Treatment**

An adult of sound mind may put into writing preferences regarding future mental health treatment. The preferences may include consent or refusal of mental health treatment and may be stated on the forms provided. **Sample form can be found at URL below:** 

https://www2.illinois.gov/sites/gac/Forms/Documents/DMHTForm.pdf

## **Advanced Directive/Living Will**

An advanced directive is a legal document that informs physicians, hospitals and families what kind of medical care a person wants if unable to communicate.

Sample form can be found at URL below:

https://www2.illinois.gov/sites/gac/Forms/Documents/POA Living Will.pdf#search=living%20will

An important document to be included in the living will includes a **DNR** (Do Not Resuscitate). A DNR order will let your medical team know that you do not want CPR if your heart stops beating or you stop breathing. **Sample of DNR document can be found at URL below:** 

https://eforms.com/images/2018/02/Illinois-Do-Not-Resuscitate-Order-Form-POLST.pdf

# BUZZ

# Clinical Research Updates from the Huntington Study Group Conference

Highlights included an announcement from Novartis of plans to initiate a clinical trial of branaplam, a drug that could be taken by mouth to achieve huntingtin-lowering, and Prilenia that are entering clinical trials.

#### Prilenia Initiates PROOF-HD Study of Pridopidine

Prilenia stating that their drug pridopidine has entered a large Phase 3 clinical trial for HD. This study builds on a previous study of pridopidine in HD, which did not meet its key clinical goals. However, because the drug showed some promise for helping people with HD to maintain their daily functions, pridopidine will now be tested for longer in a larger group of people. According to the press release and a presentation at last week's HSG conference, the study will enroll 480 participants aged 25 or older who have been diagnosed with HD. Participants will take pridopidine for up to 78 weeks (about a year and a half) and there will be an optional open-label extension, meaning that participants can opt to continue receiving the drug following the trial. There will be around 60 study centers in the U.S., Canada and Europe.

As they begin recruiting, US and Canadian sites will be listed at <u>www.hdtrialfinder.org</u> and at <u>https://clinicaltrials.gov/ct2/show/NCT04556656</u>.

## **Memorials and Tributes**

In Tribute to Craig Srajer from Catherine and Richard Evers

**In Memory of Cindy Pasley Button** from Jack and Valerie Ross, Dennis and Gloria Stuckey, Gary Wright, Steve and Robin Taft, Lisa Ross, David and Cathy Coker, Virginia De Paul, M.D., Durante Funeral Group, and Pathfinders Sunday School



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Hopes & Dreams is the official publication of the Illinois Chapter of Huntington's Disease Society of America, Inc., 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.

# 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); clrogers111@comcast.net	RUSH/Northwestern/Cellini Foundation Groups 3 <sup>rd</sup> Saturday of Every Month (10:00 – Noon) For more information and Zoom details please reach out to one of the follow support group leaders: Samantha Lunde, AM, LSW (312-942-2163); Samantha_R_Lunde@rush.edu Emily Zivin (630-443-9876); emily.zivin@northwestern.edu

Caregiver Support Group 'ZOOM' Meeting Wednesday (7:00 – 8:30pm) ~ 2/3, 4/7, 6/2, 8/4, 10/6 and 12/1 Contact: Emily Zivin (630-443-9876); ezivin@hdsa.org Email ezivin@hdsa for ZOOM meeting login details

**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.

Its 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.



May 16, 2021HDSA IL Chapter Team Hope Walk - Naperville, ILMonthly Virtual Education SeriesJanuary 12All About MedicareFebruary 17Nutrition and HDMarch 16HD and CaregivingApril 19Clinical Research and UpdatesMay 20Planning for Late-Stage HD and Adaptive Devices

## https://hdsa.org/il

## **WINTER 2021**

