



## President's Message

Greetings HD Families,

Spring has sprung (hope it stays a while)! I hope this newsletter finds you well.

As we approach the year mark of changing the way that we are accomplishing things, it is a reminder that we have not let anything stand in our way. As we navigate and learn what our new "normal" will be, we keep working towards our goals in every way of life.

Our Illinois HDSA Board is still working hard for you and your families to help carry on our mission of improving the lives of everyone affected by Huntington's Disease and their families. Emily Zivin, our Social Worker, has worked hard to put together a monthly education series to help bring educational services to all of you from the comfort of your home. The series is set to run 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. Stay tuned as she is working to possibly extend the series through the Summer.

The Illinois HDSA Board of volunteers is here to make sure that we can get everyone what they need. From education to fundraising, we are constantly working to make sure that you can receive the best that we can offer.

The Team Hope Walk Fundraiser that is hosted in Naperville is scheduled to happen in May on the 16th as a hybrid event. Being a hybrid event, they are offering in person walk opportunities as well as the option to walk from home. We want you to feel as comfortable as possible and still support our great cause. The planning is underway for the Team Hope Walk Fundraiser that is held in the Galesburg area. The Baggo Tournament and Golf Outing are in the planning stages as well. Being outdoor events, we are hoping to be able to make these events happen to bring our community together, educate, and serve our families.

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.

Take time to admire all the new beginning that Spring will be providing soon!

Take care, be safe, and be well!

Larry Haigh  
President, HDSA Illinois Chapter



# Save THE Date

## 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](mailto:ezivin@hdsa.org). Meetings are held in central standard time.*

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

**Date: April 19th, 7:00 PM**

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](https://hdsa-org.zoom.us/meeting/register/tJMvceqvrD4jE9RX7mVgTFhRaY_vzuCpRNkh)

### **May: Planning for Late-Stage HD and Adaptive Devices**

**Date: May 20th, 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/tJMscOugpzlsEta7GTXJzbg-R04fE117nSM>



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

### **July: Managing Difficult Behaviors**

**Date: July 10th, 1:00 PM**

Speaker: Dr. Eric Gausche

**Register in advance for this meeting:**

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

### **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](https://northwestern.zoom.us/meeting/register/tJUoc-uuqDMrG9Xu-1NhX_f-HRPHcGorhUfR)

Questions: Please contact Emily Zivin: [Emily.zivin@northwestern.edu](mailto:Emily.zivin@northwestern.edu)



# TEAM HOPE WALK



National Team Hope Sponsors

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A Member of the Roche Group

**teva**

## 17th Annual HDSA Illinois Chapter Team Hope Walk Sunday, May 16, 2021 – Naperville, IL

Our 17<sup>th</sup> annual Team Hope Walk will take place on Sunday, May 16, 2021, beginning at 9 A.M. at the Grand Pavilion on the Naperville Riverwalk! Due to the Covid-19 pandemic, there will be a few changes from previous years. While we would love to participate in all the fun activities of past years' walks, it just not possible yet. Many of the Illinois State restrictions have begun being lifted, but there are still some that prevent the normal activities of our past walks such as the "Now Famous HOT DOG LUNCH!" and the Carnival Bag Raffle.

Our walk will be a hybrid walk: for those that feel safe, you'll be able to walk in person along the Naperville Riverwalk as in past years. To participate in person, masks will be required. For others, you'll be able to walk "virtually" as we did last year. Walk around your home, your neighborhood, your driveway, or anywhere else that works for you.

Please register on-line here: <https://illinois.hdsa.org/about/naperville-team-hope-walk>.

### **FREE REGISTRATION**

**\*\$30 fundraising minimum to attend in-person and/or receive your t-shirt  
(If you plan to pay your own fundraising minimum, create your participant page and make your donation through your personal page)**

#### IN ORDER TO RECEIVE YOUR T-SHIRT

1. Register at the above link
2. Create your Participant Page using the Link in the email you receive
3. Donate OR Raise \$30 or more through your Participant Page

\*T-shirts will only be given to those that have created and raised \$30 or more on their participant fundraising page.  
(1 Shirt per Participant Page)

Join us as we AGAIN add to our record total of donations! Please find a pledge sheet elsewhere in this newsletter that you may use as you gather donations.

# TEAM HOPE - PLEDGE SHEET

Your challenge...have at least 10 FRIENDS sponsor you!



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. For checks received as donations, please make sure all checks are made out to **HDSA**. In the memo section, write **IL Chapter Team Hope Walk Naperville**.

Please enclose a note, along with your check(s), identifying the event, individual and team your check(s) are meant to support. Please send all your check to:  
**Huntington's Disease Society of America, 505 Eighth Avenue Suite 902, New York, NY 10018**

## Team Hope – Walk for a Cure – 5K Walk

|    | NAME | ADDRESS | AMOUNT |
|----|------|---------|--------|
| 1  |      |         |        |
| 2  |      |         |        |
| 3  |      |         |        |
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OFF TO A GOOD START

Getting Closer

*You did it!*

KEEP ON GOING

Name: \_\_\_\_\_

Address: \_\_\_\_\_

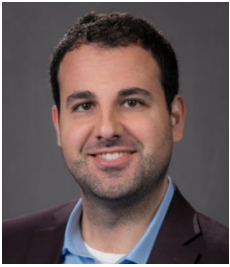
City: \_\_\_\_\_ St: \_\_\_\_\_ Zip: \_\_\_\_\_

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 \_\_\_\_\_



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## Talking Openly About Palliative Care in Huntington's Disease

Leonard L. Sokol<sup>1</sup>, MD; and Danny Bega<sup>1</sup>, MD, MSCI

(1)Ken and Ruth Davee Department of Neurology, Northwestern University, Feinberg School of Medicine, Chicago, IL, 60611

Palliative care is a specialty within medicine focused on evaluating and treating many symptoms of people living with serious illnesses. These include physical (e.g., pain), psychosocial (e.g., feelings of belongingness), existential (e.g., meaning in life), and spiritual. Palliative/supportive care services can be provided either by your neurologist/psychiatrist or other members of your Huntington disease (HD) team during a routine visit to your appointment at an HDSA Center of Excellence. Alternatively, it can be delivered concurrently by a specialized (palliative) multidisciplinary team before or after your visit with the neurologist or psychiatrist. A palliative team typically includes several members. These include a chaplain, social worker, nurse, and board-certified palliative medicine physician, who may be trained in internal medicine, neurology, psychiatry, or related field.

Data shows that supplemental palliative care improves the health-related quality of life across patients with various diseases. It is recognized as a whole-person and holistic approach. While historically studied in people with cancer, studies also show a compelling role for people with neurological illness, including other neurodegenerative diseases such as Parkinson's disease ("neuropalliative care").

Palliative care is not synonymous with end-of-life care, although palliative care can sometimes be introduced in that setting. A service called hospice is an aspect of palliative care for those with a prognosis of six months or less. Yet not all palliative care is hospice. Today, palliative care services are often used as a supplement, sometimes right when a person receives a diagnosis of a serious illness. These palliative services are often viewed as an "extra" layer of support for the patient and their loved ones to be used throughout the illness trajectory.

A project across the United States recently looked at the instruments we use to measure the quality of life in HD – it is called the HDQLIFE study. In this study, gene-positive individuals, caregivers, and their clinicians all jointly determined **several essential factors impacting the quality of life**. These include, but are not limited to, the following: (1) addressing abnormal motor behaviors, (2) optimizing mobility, (3) maintaining cognitive function, (4) treating swallowing and speech difficulties, (5) participating in social roles and activities, (6) addressing stigma, (7) having a sense of meaning & purpose, (8) engaging in end-of-life planning, (9) addressing concerns around death & dying, (10) treating anxiety, anger, and depression, and (11) upholding a positive affect and well-being. These factors were found to be significant across all disease stages. Indeed, your neurologist/psychiatrist or palliative medicine team, who will collaborate with your HD neurologist/psychiatrist, may frequently revisit all, or a subset, of these factors.

End-of-life planning, often referred to as "advance care planning," is a vital component of palliative care services and occurs even early in the disease trajectory. This is especially important since cognitive impairment becomes more problematic as the disease advances. It is essential for people with HD to understand their illness and share what is meaningful, purposeful, and valuable in their life even at an early stage. This, in turn, allows your HD medical team to assist with aligning future medical care that meets your goals. It also helps to ensure that your wishes are honored and that another trusted person (for example, a loved one or friend) is familiar with those wishes and documented within the medical record. Some may be fearful of these topics as they think they will increase negative feelings about the future. However, studies have shown that talking about these topics increases a sense of comfort, peace, and well-being among people with serious illness, their caregivers, and other loved ones. This will not be a one-time event. Instead, these end-of-life planning discussions will occur periodically throughout your condition as your goals evolve and what is meaningful to you in life deepens. Topics may include life-sustaining treatments (e.g., a feeding tube for artificial nutrition) when certain situations arise in the future (e.g.,



the loss of the ability to communicate), where and how you wish to die, the discussion about the death and dying process, and your preferences surrounding how you would ultimately die.

Finally, advanced HD is characterized by an inability to care independently, weight loss, and difficulty swallowing. When these symptoms arise, and if your HD clinician or palliative medicine team determines that your prognosis may be less than six months, then hospice may be appropriate. Ideally, conversations about if hospice is right for you will be discussed several years before this point arises. Referral to hospice may be suitable for you if it aligns with your goals. Hospice focuses on providing comfort, preserving your dignity, and maintaining peace with you and your loved ones. Oxygen, pain medications, and other interventions may all be used to alleviate distress if they serve the goal of promoting comfort. Your team can make a referral when criteria are met. Medicare covers hospice and includes a palliative medicine team. Services are provided either at home or in a skilled nursing facility. If palliative care is not formally broached during an HD visit, feel free to raise the topic with your clinician if you would like more information or support on this topic.



## Memorials and Tributes

**In Memory of Alvin Eckhoff** from JoDee Poole, Joel and Diane Murphy, Matthew and Christine Ginzal, Warren and Norma Zehr, Joy Belsey, Randy and Barbara Weber, Jeffrey and Tina Bell, Carolyn Raber, M.G. and J.M Ginzal, Dennis Carls, Rick and Carol Zehr, Larry and Mona Folkerts, Jeff and Tracy Barth, Lincoln School Flower Fund, Eileen Eckhoff, Ronald Folkerts, Wendell and Linda Vissering, Carl and Serese Wiehardt, Melvin Matter, John and Marla Weber, Tammy Zinser, Michael and Amy Theesfield, Arlene Martin, Carolyn and Gary Flowers, Mary Weers, David and Teresa Rapp, Jeffrey and Judy Wahls, Ronald and Alice Raber, Alan and Susan Rients, Jeff and Patty Rients, David and Deanna Janssen, Steven and Mary Carls, and Evergreen FS, Inc.

**In Memory of Bonnie McHugh** from Larry Haigh, Russell and Dawn Haigh, Linda and James Schultz, Debbie and Timothy Cyr, Robert and Denise Bess, Larry and Judith Hanson, David and Beth Elliott, Allen and Katherine McNeely, Timothy and Melody Elliott, Valerie and Randall Smith, Goddard's Auto Body, Inc, and Helen Kelly.

**In Tribute of Judy Cuccinotto** from Alice DePaul, Mary and John Helphrey, and Bob and Christine Williams.

**In Memory of Shane Bennett** from the Bennett Family Fund.

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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.

# 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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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

Due to Covid-19, we are all facing long periods of social isolation. Research has shown that social isolation leads to loneliness, poor mental and physical health. We are now using new forms of technology to help stay connected to friends, family, and work. Although we are limited in what activities we can participate in, there are creative ways that can help make this difficult time a little easier.

**Keep a schedule** - Start each day with a plan. It will help keep you occupied and give you a sense of accomplishment at the end of the day.

**Stay informed** - Keep up to date on the news but limit the amount of information you are receiving. It is important to stay informed, but remember, too much content can be overwhelming.

**Stay active** - Spending weeks in isolation without exercise will have a detrimental effect on your ability to cope. There are many at-home activities that you can help keep you active. Take a walk, stream an exercise video, download exercise apps, weightlifting, etc.

**Do something meaningful** - Doing something meaningful each day. This will help give you a sense of purpose and identity.

**Connect with others** -While you may not be able to visit with family and friends in person, that does not mean you cannot connect. Some suggestions include:

- Send a handwritten letter or postcard
- Call someone on the telephone or video chat using services like FaceTime or Zoom
- Post on social media or respond to posts on social media
- Send texts or instant messages

#### **Find sources of comfort**

- Take a bath
- Focus on your pet
- Cook healthy comfort food or bake a nice treat
- Watch a favorite TV show or read a book
- Have afternoon tea
- Make sure you are getting enough rest

#### **Create Something**

Work on a photo album, art, creative writing, home project, etc.

Practice mindfulness and be compassionate to yourself.

Please remember, if you find yourself feeling isolated and/or experiencing poor mental health, it is important to reach out for help.



## Vaccines and HD

Many HD families have questions about vaccination for the coronavirus - RNA sounds scary! HDBuzz helps unpack the headlines about vaccine safety and HD.

By Dr Jeff Carroll and Dr Rachel Harding February 25, 2021 Edited by Professor Ed Wild

Families around the world are being impacted by COVID-19, but hope is on the horizon in the form of revolutionary new vaccines which were developed in record time. How is the coronavirus impacting HD families, and should they be worried about any of the vaccines coming to market? Should HD patients get the vaccine? We'll unpack this below, but the short answer is - absolutely, yes!!

### HD and infectious disease

Making it through everyday life for Huntington's Disease families can feel like a marathon. The stress induced by the coronavirus has made things even tougher. HD patients often struggle with isolation and being stuck in and out of lockdown only compounds these feelings of loneliness. Accessing regular medical care to deal with HD-related issues is also much more challenging, when doctors' offices and hospitals can feel very threatening and scary.

Prof. Ed Wild has been busy in his spare time vaccinating people against COVID-19

In a series of incredible breakthroughs, infectious disease scientists were able to develop a number of highly effective vaccines for the coronavirus in record time. As 2021 gets underway, we find ourselves with several vaccines that have been approved by regulators, with several more on the way.

For good reasons, HD families are nervous about anything that could impact the well-being of their loved ones with HD. So, should they encourage the HD patients they love to get a vaccine? Below, we unpack some of the concerns that HDBuzz has heard from the HD community about the coronavirus and vaccines, but if you just want the short answer - our strong opinion is that anyone who is eligible for the vaccine should get it, including HD patients.

### mRNA sounds scary?

One concern voiced by the community is that several of the new vaccines - tested and sold by Pfizer/BioNTech and Moderna - rely on a novel technology called messenger ribonucleic acid (or mRNA). At HDBuzz we're often talking about mRNA in the context of Huntington lowering trials, such as those using ASOs, which we've talked about a lot [here](#) and [here](#). These drugs target a specific mRNA in our cells - the one that tells them how to make the Huntingtin protein - for destruction.

If drugs like ASOs target mRNA to try and cure HD, and these vaccines have mRNA in them, should we be worried? No! mRNA is one of the most common types of components of our cells, each of which contains literally tens of thousands - if not hundreds of thousands - of different types of mRNAs. mRNA messages are plentiful in almost all living things so we safely ingest mRNA all the time when we have fruits and vegetables and other foods, at much higher levels than anything that is in mRNA vaccines.

If our cells contain a vast library of mRNAs, the Huntington lowering drugs that we're hopeful about are like sneaking into the library, taking one book off the shelf and tearing it up. The new vaccines that rely on mRNA technology are like sneaking an entirely new book - one that teaches our cells how to recognize the coronavirus - and quietly putting it on the shelf.

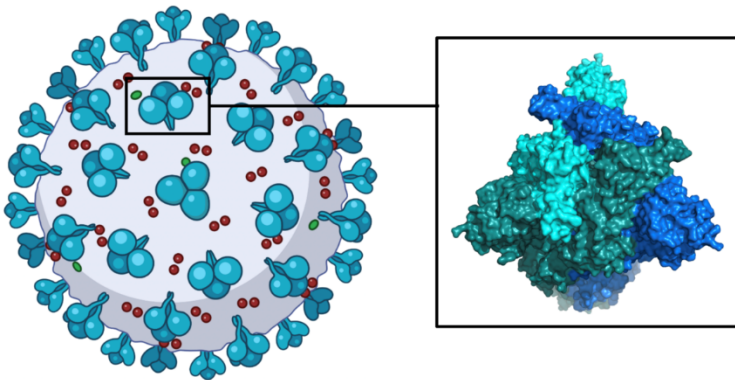
### How can fast trials properly assess new vaccines?

But what about the fact that these vaccines were tested so quickly, doesn't that mean that they're not as rigorously tested as other drugs? Thankfully, the answer to this is a clear no. The initial development of the coronavirus vaccines did happen very quickly, but this was in fact building upon a huge foundation of work on mRNA vaccines, prepared for by many years of work by scientists around the world who were making mRNA vaccines for other illnesses who could then apply their technology to help fight the pandemic.

All of the available vaccines have been very carefully tested and have been shown to meet very strict safety criteria determined by different independent drug agencies, like the Food and Drug Administration (FDA) and the European Medicines Agency (EMA). It is true that this happened faster than normal, but the corners cut to speed up the process were mainly bureaucratic rather than scientific. Because there was such an urgent need for the vaccine, all the different players involved in making, testing and assessing the vaccines, worked very closely together and removed administrative roadblocks which often slow down the approval of new medicines.

## The reality of HD and infections

HD is a demanding illness for families and the added complications of dealing with COVID infection for a person with HD or their caregiver can really add to the daily struggles which they might face. Although people with HD are not at any increased risk of contracting COVID, having COVID is certainly to be avoided as far as possible.



mRNA COVID-19 vaccines give our bodies the instructions to make a harmless fragment of the COVID-19 spike protein which is found on the surface of the virus. When our immune system encounters the spike protein, our bodies will develop an immune response against this protein. That means that if we are infected with COVID, we will then be able to fight it off. Image made with Biorender.

We still know very little about whether people with HD are affected by COVID infection worse than other groups of people but the data for the wider populations has shown that COVID can have devastating effects in otherwise healthy people. It is important we all do our

best to stop the spread of this disease by following public health advice to stay home as much as possible, wash our hands, follow social distancing rules and wear face masks - things we are probably all too familiar with now one year into this pandemic.

Vaccines are another important part of stopping COVID infection in its tracks. COVID vaccines have been shown to be some of the most effective vaccines scientists have made to date with over 90% efficacy in some cases! There is no data to suggest that HD patients specifically should not get the vaccine, which was tested in a very broad range of people and has now been administered to huge swathes of the populations in countries like the USA and Israel. So far, the groups who are advised to hold off from getting the vaccine are people who are immunocompromised and those who have allergies to ingredients in the vaccines. This means that most people with HD have the green light to go ahead and get vaccinated.

## What do the doctors say?

We spoke with some expert HD doctors to hear what they think about the COVID vaccines.

*"We are incredibly fortunate to be living in an era in which medical science has advanced to the point that we have vaccines less than a year into a pandemic. I and my colleagues in the Cardiff HD centre have now been vaccinated and I'm delighted to see that our local HD community are starting to be offered the vaccine. COVID-19 is a nasty condition and, especially considering what we now know about its impact on the brain in some individuals, it is clear that having the vaccine is far safer than catching COVID-19."* - Professor Anne Rosser PhD FRCP

*"To be vaccinated is to be given a superpower - the ability to defeat an enemy you haven't even met. I volunteered for the clinical trial of the AstraZeneca vaccine and have been spending all my free time since Christmas eve vaccinating the people of London. The choice to consider isn't between the vaccine and nothing, it's between the vaccine and covid, which is the biggest threat currently facing the HD community. The vaccines are safe, incredibly effective, and pose no special risks to people with HD now or in the future. We need to do everything we can to get all our HD family members protected and safe from covid, so that we can get back to fighting HD together."* - Professor Edward Wild MA MB BChir FRCP PhD

*"Patients and their families are asking about Covid-19 and Huntington's disease. We are learning more and more about the pandemic and the vaccines to prevent the infection. There is a lot that we know and a lot that we do not know. Covid-19 is a potentially fatal condition. There are risk factors that make it more dangerous including older patients and those with other medical problems. Patients with Huntington's disease are more likely to become sicker due to Covid-19 if they become infected. We do not have data about this in detail, but most physicians agree that HD patients should do everything that they can to prevent infection. I encourage all my patients to get approved vaccines when they are available. There are some*

*risks to the vaccines, but these are minimal compared to getting the infection. There is no indication that taking medications for the treatment of HD will make someone more susceptible to the infection or make their condition worse. There is also no indication that any of the investigational drugs that are being tested for HD either for symptomatic improvement or reducing the rate of progression will make HD patients worse or increase the risk of getting Covid-19. In balancing risks and benefits, in summary, get vaccinated as soon as possible.” - Mark Guttman MD FRCPC*

*“The science supporting the approved COVID vaccines is compelling. They are safe and effective, and while not tested specifically in the HD population, I would still encourage people in HD families to consider being vaccinated if they are offered.” - Professor Victor Sung MD*

### **The bottom line**

The science shows very clearly that the COVID vaccines are safe, effective and our best chance at combating this pandemic.

## **HSA offers 8 free phone therapy sessions for HD individuals families**

Need support? Don't forget that the HDSA offered 8 free phone therapy sessions for families affected by HD. The sessions are provided by AmWell Telehealth and therapists have been educated on HD.

To learn more: <https://hdsa.org/find-help/community-social-support/hdsa-telehealth/>

## **HDSA online support groups**

HDSA offers video based online support groups for gene negative in an HD family, HD positive (early symptoms), parent caregiver, caregivers and at-risk. To access groups, dates and time: [https://www.supportgroupscentral.com/groups\\_detail.cfm?cid=27&CFID=2035993&CFTOKEN=bc20abb86aebf611-99E965AF-F1E3-120F-E2600DF5BCB3281F](https://www.supportgroupscentral.com/groups_detail.cfm?cid=27&CFID=2035993&CFTOKEN=bc20abb86aebf611-99E965AF-F1E3-120F-E2600DF5BCB3281F)

## **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:**

- 4/10: Mental Health
- 4/17: Being/Living at Risk
- 5/1: Research 101
- 5/15: Sharing Your Story: Normalizing HD
- 5/29: JHD
- 6/26: Post Convention Blues
- 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>





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) ~ 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

**Northwestern Medicine/Cellini Foundation Support Groups**

**2<sup>nd</sup> 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.

**April 10th:** Conversation, Gene negative or non-HD in an HD family

**May 8th:** General Support Group

**June 12th:** Conversation, Gene positive

**July 10th, 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**

**4<sup>th</sup> 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.



|                  |   |
|------------------|---|
| May 16, 2021     | HDSA IL Chapter Team Hope Walk - Naperville, IL           |
| June 10-13, 2021 | Virtual 36 <sup>th</sup> Annual HDSA Convention           |
| August 28, 2021  | HDSA IL Chapter Baggo Tournament – More details to follow |
| Sept. 12, 2021   | HDSA Golf Outing – More details to follow                 |

Monthly Virtual Education Series

|                        |   |
|------------------------|---|
| April 19 <sup>th</sup> | Clinical Research and Updates                   |
| May 20 <sup>th</sup>   | Planning for Late-Stage HD and Adaptive Devices |

Northwestern Virtual Patient & Family Education Series

|                           |                              |
|---------------------------|------------------------------|
| July 10 <sup>th</sup>     | Managing Difficult Behaviors |
| November 13 <sup>th</sup> | HD Research Panel Discussion |

<https://hdsa.org/il>



**SPRING 2021**