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

President's Message

Greetings HD Families,

Fall is here! I hope this newsletter finds you will.

While we are trying to find our new norm, I hope that you can take a moment for yourself. Self-care and reflection are important. As I have had a moment to reflect on attending our first in-person event of the year to fundraise for Illinois HDSA I am reminded of all our supporters that are out there that help support our fight for a cure. The *Golf for HD* event was this past Sunday, and it was a great event put on by Wayne and his committee. We have had to modify how we have done our fundraising this year, and it has been amazing to see the response and support during this modification. The research to find the cure has not stopped, and the support through fundraising efforts helps in making it possible to working for that cure. I have mentioned before the great efforts of Dave and Susie Hodgson for their work on the *Virtual Naperville Walk*. We have two more walks wrapping up the Team Hope Walks for our state. You can still contribute to those walks on our website Illinois.hdsa.org. Your contributions to our Team Hope Walks, No-Baggo Fundraising Campaign, and your donations have helped Illinois HDSA moving forward in supporting our mission "To improve the lives of everyone affected by Huntington's disease and their families." I would like to thank you all for your support!

We are all here for all of you! Our 3 Centers of Excellence are working very hard to still meet with everyone, and they are producing and making resources available to our families that they can access from their home. If there are questions that you may have for them, reach out to them. They are working to serve you.

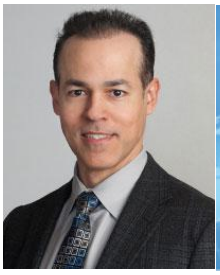
Emily is not only our social work for the chapter, but she is also working with National HDSA on the side of the National Youth Alliance (NYA). Emily is working to get our youth educated and involved in working towards the mission of the NYA.

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.

If you feel that you would like to help our chapter, please reach out to myself or any of our board members. We are always happy to answer any questions that you may have. If you would like to join our Board feel free to reach out to any of us as well.

Take care and be safe!

Larry Haigh
President, HDSA Illinois Chapter



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Non-pharmacological management of "outbursts" in Huntington's disease (HD)

Dear HD community and HD caregivers:

Many times, we get frustrated, overwhelmed when we do not know what to do when our loves one with a genetic disorder, including HD and Sotos's syndrome, primarily affecting their behavior starts acting out "out of the blue." Sometimes we limit our social life just because we are concerned about witnessing another "outburst" in a public place like a restaurant. It is scary, and perhaps, you as a caregiver are "just waiting for a behavior to occur while eating." Sometimes the outburst is hit or miss. Many times, when it happens, it is totally unpredictable. Disinhibition, irritability, impulsivity, and sudden outburst are part of the "package" in our lives. These non-motor symptoms are usually very troublesome and distressing and can significantly affect the quality of life for patients suffering the disorder, as well as families and caregivers. Some of these non-motor symptoms can be even more distressing than motor symptoms such as chorea, abnormal postures, incoordination, balance problems seen in HD.

What can we do?
The first step is to understand that this behavior is not their fault. They do not want to behave like that. They would like to behave well or at least "normal." As soon as you understand this concept, your level of tolerance increases, and you do not take the situation personally and less likely to escalate. The main step during these situations is to avoid escalation of "bad" behavior. I know it is "easier said than done", but with practice and experience, these situations are easier to predict and to deal with.

We all have "outbursts" or emotional responses to an external stimulus, but normally we can "control" it or at least minimize a negative reaction. However, patients with HD have abnormal anatomical and chemical changes in the brain, specifically in a deep nucleus called caudate. This area of the brain is connected to the frontal lobe and can lead to an inability to deal with unexpected events or stimuli. Since these essential anatomical areas are not working well, they cannot regulate their emotions. It is like having an "open gate" without control, leading to an extremely intense emotional negative response.

What else?
After acknowledging the first step described above, I summarized a few "hints & tips," mostly from e personal experience. Remember, sometimes data does not apply in real life.

- Speak in short sentences to them and offer choices instead of open-ended questions.
- Use calendars, predictable schedules, and regular daily routines. They are triggered by sud to you like an insignificant change in their routine, could be a big deal for them, which c event.
- Do not try to select food for them, but you can give no more than two options. Let them eat only food that they really enjoy.
- Keep directions or commands to one or two simple steps.
- Speak slowly
- If an "outburst" is imminent.
    1. Stay calm. Getting frustrated and yelling back is not going to help.
        - Do not point or shake a finger; this will escalate the situation.
        - No confrontation or ultimatums. However, you might try becoming mildly stern in a low tone voice with direct eye contact and telling them, "this behavior is unacceptable." This might work in some patients.
    2. Assess the situation and look for any possible triggers. It can be as simple as a shoe untied, or environmental factors (too much noise or any other excessive stimulation, extreme temperature).
    3. Try the distraction or redirection "card"→take him/her outside away from the source of anger if possible or change the topic of conversation.
    4. Let them express their feeling rather than react to their behavior.
    5. A firm handhold might have a calm effect.

Hopefully, these techniques help you to minimize those spells. Remember, patience and practice are key!

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 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 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 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 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 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.

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

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

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

How to Access Community Resources - Emily Zivin, LCSW
https://northwestern.zoom.us/rec/share/uqnYexaTESs4HUeZZn9pvFbkyum49moh2yfSudad12wMQhBZRytfltaE7kT_Tnul.RNbziq3H6kkZr-ss

News from Our Illinois Chapter Social Worker Emily Zivin, LCSW

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There are many aspects to consider when planning for unexpected emergencies. Being prepared will help make challenging times a little bit easier. Here are some tips that will help with unexpected emergencies:

- Identify nearby family/friends who can come to your home for an urgent need/emergency.
- Consider who you can ask/hire to provide care for 2-4 weeks as needed.
- Create a list of what your loved one needs and have a digital copy available, so it can be shared easily.
- Provide a list of all medications and medication schedules.
- Organize a list of medical doctors and contact numbers.
- Have all the legal documents such as DNR, Power of Attorney for Health Care and Property easily accessible.
- If you have younger children, have their weekly schedules listed and available to share.

Memorials and Tributes

In Memory of Linda Laskowski from Steven and Debra Grant

Volunteer. Educate. Advocate. Donate.

HDSA.org **(800)345-HDSA**

DONATED RECENTLY? YOU MAY BE ELIGIBLE FOR A MATCHING GIFT!

Thank you so much for your recent gift, we're so grateful. Did you know your contribution to HDSA could have twice the impact?

Many employers have matching gift programs that match charitable contributions made by their employees. Some companies even double or triple the amount of your gift **AT NO COST TO YOU!**

Simply search your employer's name at https://hdsa.org/get-involved/matching-gifts-program/ to see if they match and what you need to do to complete a matching gift request. If your employer does not come up, talk with a human resources representative in your office to see if it's possible.

As always, thank you for your support!

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SATURDAY, NOVEMBER 14, 2020
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Huntington's Disease Society of America Center of Excellence

When genes are unstable: targeting somatic instability in HD

Dr. Rachel Harding and Dr. Leora Fox September 08, 2020

CAG repeats expand in some parts of the body and brain as people with HD get older, a phenomenon known as somatic instability. Learn more about how researchers are exploring somatic instability and DNA repair to design therapies for HD.

What is somatic instability?

We tend to think of DNA as a fixed blueprint, an overarching plan for the biological bricks and bridges that constitute our cells, organs, and bodies. But like any good plan, DNA is dynamic and adaptable. It gets frequent use as a template for creating the RNA messages that pave the way for the proteins we are made of. For this reason, DNA requires constant checking, maintenance, and repair. In fact, our cells have an entire workforce of DNA repair proteins whose main job is to ensure that our DNA is in top condition.

But sometimes the repair team makes mistakes. This is especially true when there's already a problem with the DNA – like the HD mutation, an extra-long stretch of CAG repeats in the huntingtin gene. Lengthy repeating sections of DNA can be harder to maintain. Have you ever tried to re-fold a large city map, only to end up with a bundle of paper twice as big as what you started with? When DNA repair goes awry, repeating sections of the DNA code can become unstable. In the case of Huntington's disease, this means that over a person's lifetime, the already-expanded HD gene gains even more CAGs, in certain cells of the brain and body. This phenomenon is known as somatic instability.

The more repeats in the huntingtin protein, the more likely it is to perform poorly, form toxic clumps in brain cells, and disrupt other normal functions. So, the formation of longer and longer huntingtin proteins could be part of the reason that HD affects people more as they get older. In the past few years, large genetic studies have confirmed that HD symptoms may begin earlier due to somatic instability. HD scientists are now digging even deeper into the questions of when, where, and why somatic instability occurs. Armed with that knowledge, they have begun to develop the tools and drugs to combat CAG repeat expansion, and new companies have formed with the goal of testing therapies in people with HD.

By targeting DNA repair, researchers hope to stop or slow somatic instability and therefore delay symptom onset or progression.

When does somatic instability occur?

Since HD has a known genetic cause (extra CAG repeats in the DNA code), adults can choose to get a blood test if they wish to confirm that their symptoms are a sign of HD or want to learn whether they will experience symptoms later in life. This test reveals the number of repeats in the person's huntingtin gene. Since everyone inherits two copies of every gene, one from each biological parent, a person with HD will almost always have one "normal" CAG number (10-26), and one "expanded" CAG number (around 36-40 or higher). Those gene copies are found in every single cell of the body, and the expanded copy is what causes HD.

Because long CAG repeats can be unstable, a child who inherits an expanded copy of the HD gene from their parent doesn't necessarily inherit the same number – sometimes dad has 40, and his son has 41, and his daughter has 48. CAG repeat length influences age of onset, so these closely related family members might start to experience symptoms at very different ages. Changes in CAG repeat number from generation to generation are sometimes known as "germline instability."

Somatic instability is a bit different, because it occurs during an individual's lifetime, and only in certain parts of the body and brain. For example, a 25-year-old person with HD might get a blood test that shows 42 CAG repeats. If they were to repeat the test many years later, their blood would probably still show 42 CAG repeats. That's because somatic instability of CAG repeats doesn't happen frequently in blood cells. It would be too dangerous to test parts of people's brains while they are alive, but scientists can investigate somatic instability in the brain thanks to the extraordinary people who have donated their brains to HD research. Now we know that a person with HD whose blood test showed 42 repeats as a young adult, may at the time of their death thirty years later have some cells in the brain with 45, 60, 100, or even 1000 CAG repeats.

What genes influence somatic instability – and why do we care?
In the past few years, genetic studies of thousands of people with HD have clued us into several important facts about somatic instability and DNA repair. One finding is that continued expansion of CAG repeats in an individual could cause symptoms to come earlier than expected. Another important discovery is that single-letter differences in DNA repair genes can influence the age of onset of HD. One big study a few years ago showed that people with slightly different versions of a DNA repair gene called FAN1 had huge differences in when their HD symptoms began. **"**Observational studies are essential in planning drug trials, helping researchers make informed decisions about when treatments should be given to patients and what regimens should be followed.*"*

FAN1 normally contributes to DNA repair by helping to separate strands of the double helix that have gotten sticky. Without FAN1, the machinery that copies DNA seems to get stuck at CAG repeats and can accidentally add extra ones. A study published in June of 2020 dove deeper into FAN1 and its role in HD. The experiments were carried out by a consortium of HD geneticists in the US and UK and led by Dr. Jong-Min Lee at Harvard Medical School. They found that depending on what form of the FAN1 gene a person has, there might be more or less FAN1 protein, or it might be slightly better or slightly worse at its repair job. Normally these miniscule genetic differences in FAN1 don't matter, but when a person has HD, excellence in DNA repair is critically important. People with certain forms of FAN1 had much earlier or much later onset of symptoms than would be expected.

In addition to FAN1, there are a variety of other genes found to influence the age of onset of HD, all known as "genetic modifiers". Right now, these genetic variations are NOT something that an HD specialist or genetic counselor can test for. However, the recent study suggests that screening people with HD for FAN1 and other genetic modifiers of symptom onset might be useful in the future. This personalized approach could help to better predict an individual's onset or progression, or make it possible to run smaller, faster clinical trials with a more uniform set of participants. Importantly, a better understanding of the influence of FAN1 and other DNA repair genes on HD is already leading to new therapeutic strategies to improve DNA repair and slow CAG repeat expansion. None of this is possible without the participants who donate their time, energy, and blood samples to observational studies like Enroll-HD.

Where does somatic instability happen?
Somatic instability is happening to a certain degree in every part of our body, but the levels do vary widely between different types of cells. For example, cells in our blood have low levels of instability which is why the genetic test (which uses a blood sample) may give the same result if taken repeatedly in an HD patients lifetime, even if instability is going on elsewhere.

Recent studies have completed more extensive analysis of how much somatic instability is going on in different parts of our bodies and even breaking down the precise levels of instability in particular regions of our brains. In an international collaboration between Harvard (USA) and Bochum (Germany), Drs. Vanessa Wheeler, Ricardo Mouro Pinto, Larissa Arning and team recently showed that specific regions of the brain, called the cortex and caudate, have the highest levels of instability in the CAG repeat of the HD gene. This analysis was possible thanks to donations of HD patient brains after they had passed. Interestingly, this team also showed that other genes which have CAG repeats, like the genes associated with spinocerebellar ataxia (SCA) diseases, also have instability in the cortex and caudate.

Beyond our nervous systems, it seems that the liver and testes have the highest levels of instability. When Mouro Pinto and colleagues looked at HD patient spinal fluid samples, they could observe instability there too, although at fairly low levels. Measuring instability levels in a living patient's brain is currently impossible to do safely, so scientists are keen to find a good proxy by measuring other tissue samples. It seems that the levels of instability in the spinal fluid, although low, are a potentially good readout for overall instability levels in a patient and could be another good biomarker for healthcare practitioners to monitor disease progression. Normally, minuscule genetic variations don't matter, but in HD, they can be critically important.

How can we target somatic instability to treat HD?
Scientists researching HD have known for a long time now that the levels of somatic instability in a patient will influence the age when disease symptoms start. The hypothesis is that increased levels of somatic instability will lead to longer CAG repeat lengths which in turn will mean that disease symptoms will start earlier. If researchers can find a way to lower the levels of instability, this may be a good strategy for making new medicines for HD.

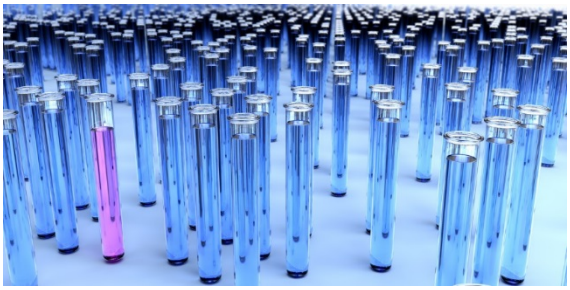
Datasets published in the last ~5 years, which look at other genetic factors influencing HD, have shone a light on why instability might be higher in some patients than others. If patients have single letter changes in proteins like FAN1, it is

thought that their levels of instability will change, and therefore the age of onset for symptoms will also change. If we can target some of these so-called modifiers of HD, we might be able to prevent expansion or even shrink the CAG repeat length.

One of the most promising drug targets which has arisen from these large genetics studies is another DNA repair protein called MSH3. Single letter changes to this gene can also affect the age at which HD patients start to get symptoms. Scientists think that if they are able to make a medicine to target the MSH3 protein and stop it from working in our cells, this would reduce the levels of somatic instability which would be beneficial for patients. There are numerous teams of scientists looking into different strategies to target the MSH3 protein and some exciting unpublished discoveries were presented at the HD therapeutics meeting in Palm Springs this year.

Who is involved in making medicines to target somatic instability in HD patients?
The HD community has dozens of companies and organizations involved in discovering new therapies for patients, focused on HTT lowering as well as other strategies. One way to learn more is to check out some of the research talks presented to families at HDSA's 2020 Virtual Convention. With many recent studies connecting somatic instability to DNA damage repair, there are now numerous companies seeing if they can make medicines to stop CAG repeats from expanding or even shrink repeats by targeting the process of somatic instability.

One company working in the DNA repair space is LoQus23 Therapeutics, a recently formed company from the folks at the Dementia Discovery Fund, a collaborative organization that invests in new medicines for neurodegenerative diseases. They are interested in targeting proteins involved in DNA damage repair, with small molecule drugs that could be taken as a tablet. During their presentation at HDSA's Virtual Convention, representatives from LoQus23 used a family of stuffed bunnies and bears to create an excellent explanation of DNA damage repair and somatic instability. Another company aiming to target somatic instability is Triplet Therapeutics, an enterprise focused on making medicines for repeat expansion diseases like HD. Similar to HTT lowering therapies, their approach uses small pieces of genetic material called antisense oligonucleotides (ASOs) and small interfering RNAs (siRNAs) to reduce protein levels. Both companies hope that by impairing the actions or reducing levels of specific proteins involved in DNA repair, they can stop or slow somatic instability and therefore delay symptom onset or progression.



In the case of somatic instability, uncovering the importance of DNA repair using thousands of donated patient samples was a game changer.

In fact, Triplet Therapeutics has recently embarked on a study that takes a close look at HD progression, called the SHIELD-HD natural history study. It aims to observe 60 HD patients over the course of two years in order to better understand HD-related changes in somatic instability and DNA damage repair genes over time. The study will take lots of different measurements of the patients, looking at HD symptoms as well as taking samples of blood and spinal fluid for analysis. Observational studies like these are essential in planning drug trials, helping researchers make informed decisions about when treatments should be given to patients and what regimens should be followed.

Participating in the future of HD Research
Hopefully this investigative dive into the "who, what, when, where, why, and how" of somatic instability has convinced you that this growing field presents a new and exciting pathway towards novel HD therapeutics. The journey from uncovering drug targets to the beginning of an exploratory human trial like SHIELD-HD is normally far longer. One of the main reasons that HD science is moving so quickly from discovery to potential therapy is community participation in clinical trials. Data and samples collected in large observational studies are powering the analyses that will identify tomorrow's drugs. More active participants in studies like Enroll-HD means that HD researchers in academia and industry can faster and more accurately identify the next set of targets.

In the case of somatic instability, uncovering the importance of DNA repair using thousands of donated patient samples was a game changer. Researchers were quickly able to use this information to further investigate the biology of DNA repair, decide which proteins were most important, and begin to design drugs and clinical studies. Our understanding of somatic instability in HD has continued to deepen, and the recent studies highlighted above point to the specifics of genetic modifiers and highlight shared vulnerability across different types of brain disease. Although we have not yet reached a point where genetic testing for variations in DNA repair proteins is possible or even useful for an individual HD patient, these discoveries will no doubt drive medical innovations in the near future.

SUPPORT groups

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)
2020 Meetings: 2/11, 4/14, 6/9, 8/11, 10/13, 12/8
Southside Christian Church, 1000 Broadmoor Avenue
Contact: Cindy Rogers (219-836-2369); clrogers111@comcast.net

RUSH/Northwestern/Cellini Foundation Groups

2020 Meetings: 9/19, 10/17, 11/21, 12/19
Saturdays (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)
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.