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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.

President's Message



Dear HD Families,

I hope all of you are having a great summer! We kicked off the summer with the Team Hope Walk at the Naperville Riverwalk on May 15th. We had over 450 attendees at this long-standing trademark event for the Illinois chapter. It was wonderful to see and meet with so many members of the HD community on a beautiful summer day. I want to thank Larry Haigh and Karen Bennett for their efforts in organizing this remarkably successful event that Dave and Susie Hodgson started.

I am excited about the great events planned for the summer and early fall. We have 2 Baggo tournaments this summer, one organized by Larry Haigh (which was held on 6/25) and a second one on 8/6 organized by Charlotte Rybarczyk. In addition, I am excited about "A Night at the Races for HD" event on 8/20 organized by Wayne Galasek. For more information, please see the link:

<https://illinois.hdsa.org/races>.

In addition, I am organizing a food truck IL. COE appreciation day on 8/27 at Lake Shore Park in the City. Please see the details in this newsletter and contact me (avs2004@comcast.net or 703-599-6000) if you have questions.

Additionally, planning is in place for the Team Hope Galesburg Walk on 9/11, organized by Sarah Cozad. Finally, we have a date set (10/1) for Education/Wellness Day organized by our social worker, Emily Zivin. This should be a fantastic event for HD families

I was fortunate to attend the 37th Annual HDSA Convention in Atlanta, GA in early June. I was truly inspired by all the HD patients and families I interacted with at the convention. It was an excellent convention and a great opportunity to learn and connect with the HD community.

I look forward to seeing you at many great events later this summer and fall!

Arvind Sreedharan
President, HDSA Illinois Chapter



ILLINOIS HDSA CHAPTER

WELLNESS DAY 2022
Saturday, October 1st
10am to 2pm



Please join the Illinois HDSA Chapter for a half day Wellness event on Saturday, October 1st.

We will be hosting two wellness sessions and support groups.

Location: Harper College Woljck Conference Center
1200 W Algonquin Road, Paletine, IL 60067

Lunch will be provided

To Register : <https://illinois.hdsa.org/edday>

Questions: Please reach out to Emily Zivin at ezivin@hdsa.org or 630-443-9876

This event is funded by the Huntington's Disease Society of America with support from Genentech, Sage Therapeutics, Neurocrine and uniQure.

uniQure



Genentech
A Member of the Roche Group





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Branaplam, Antisense Oligonucleotides and Huntington's disease

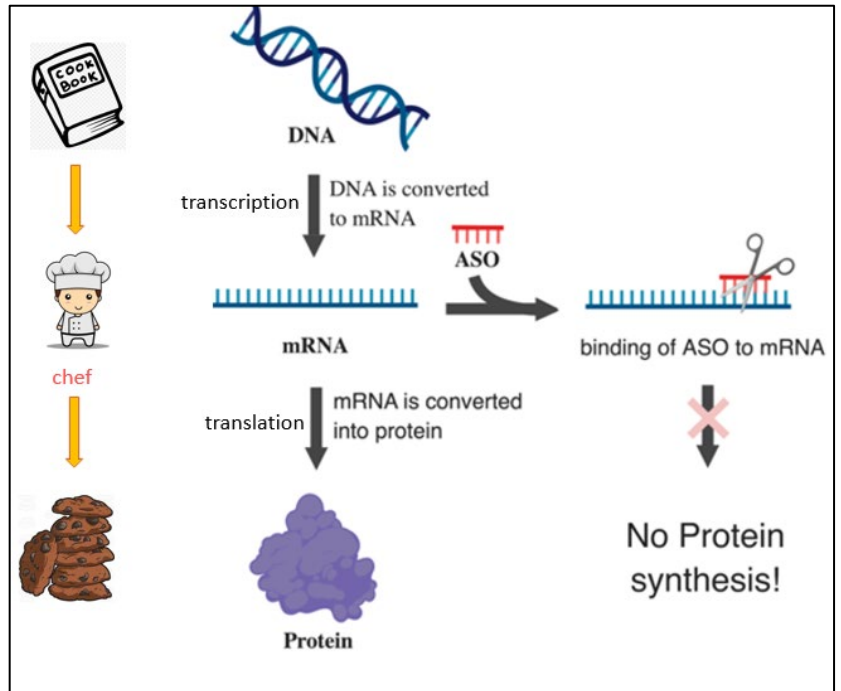
By Neepa Patel, MD, Associate Professor of Neurological Sciences, Director of the Interventional Movement Disorders Program

Branaplam is an antisense oligonucleotide (ASO) that recently received an FDA fast track designation for research in Huntington's disease (HD). In this article we will review how ASOs and Branaplam work in HD.

ASOs & HD

Huntington's disease is a genetic disorder which results in the abnormal production of the huntingtin protein (HTT). A gene is a portion of DNA that holds the code aka the "recipe" for how to make a protein. The messenger RNA (mRNA) helps to translate the code into the protein. Patients with HD have one normal gene that makes normal HTT and one mutated gene making abnormal HTT (mHTT). It is the abnormal mHTT that ultimately causes the symptoms of HD. Research in HD has been focused on trying to slow or stop that production of the mHTT without impacting the production of normal protein. The normal HTT protein is an important building block of the nervous system. The biggest challenge in HD research has been trying to stop the production of mHTT without impacting the normal HTT.

Antisense oligonucleotides are small molecules designed to interact with mRNA to alter or stop the production of a specific protein. In HD research it has been difficult to only target the abnormal mRNA without affecting the normal mRNA. Thus far the ASOs that have been studied in HD, including Branaplam, reduce the production of both normal and abnormal HTT protein by 40-70%. By reducing the total production of mHTT we hope to slow the progression of HD.



Branaplam

Branaplam is an oral medication that was first developed to treat spinal muscular atrophy (SMA). SMA is a genetic disorder causing severe weakness in infants and young children. ASOs have provided dramatic improvements in this condition. Researchers are now trying to apply similar the ASO technology and science to the treatment of HD. Preliminary studies demonstrate that Branaplam lowers mHTT levels in animals. However, to date this medication has not been studied in HD patients, with the recent FDA approval the company can start to develop clinical trials in humans and specifically HD patients. The FDA fast track designation means that the company developing this drug will receive more help and attention from the FDA to start up clinical trials as quickly as possible. The clinical trials will help us determine if this medication is safe and effective in HD.

Branaplam is not the first ASO studied in HD. The IONIS trials was stopped early because it did not demonstrate clear reduction in HD progression and was associated with several side effects. Branaplam is unique because it is an ASO that can be delivered by mouth. However, we do not know if it will be safe or effective in HD yet.

There is a lot of hope and excitement surrounding the recent FDA approval to start research with this medication. However, for many patients and families it is frustrating that they cannot get access to this medication right away. It is important to be patient with the research process, because at this time we are not sure that this medication is safe or effective in HD. We encourage you to discuss this medication and opportunities to participate in the clinical trials with Branaplam and other medications with your HD neurologist(s). With the help of our patients volunteering for studies we will be able to determine if this is the right medication to treat and change the progression of HD.



HDSA IL BAGGO TOURNAMENT

Double Elimination

Saturday, August 6, 2022 at 1:00

SPLIT THE POT
RAFFLES!
SILENT
AUCTION
1:00-3:00!

Team Check in at 12:30

(Rain date – August 7)

The Home of Charlotte Rybarczyk

3000 Owl Drive, Rolling Meadows, IL 60008



Vienna Hot Dogs, Beef Sandwiches and Lemonade included

Registration:

\$60/Team

\$20/Spectator

Sponsorship Opportunities Available

Your donation is 100% tax deductible

Each player on the winning team receives one of our custom Baggo sets!

Questions? Contact Charlotte Rybarczyk at 847-259-3593 or

charlotte82963@gmail.com

Return registration by August 1st to: Charlotte Rybarczyk, 3000 Owl Drive, Rolling Meadows, IL 60008 or register online at: <https://illinois.hdsa.org/baggo>

Checks should be made out to HDSA IL Chapter

TEAM NAME _____

PLAYER 1 NAME _____

PLAYER 2 NAME _____

PHONE NUMBER _____

E-MAIL ADDRESS _____

SPECTATORS: Names _____ How many? _____



Huntington's Disease
Society of America

ILLINOIS CHAPTER



A NIGHT AT THE RACES

Join us Saturday, August 20th at 6:00 PM
Hawthorne Race Course
3501 South Laramie Ave.
Stickney, Illinois 60804

Contact:
Wayne Galasek
708-289-1273
wgalasek@aol.com

*Join HDSA's Illinois Chapter on an evening of fun at the horse races!
There will be food, drinks, prizes and a great silent auction. Can't wait to see you then!*

*In an effort to keep all event participants safe and well,
all attendees will be required to follow the HDSA Event Guideline.*

*We would like to express our sincerest thank you to
uniQure for sponsoring HDSA's Upper Great Lakes Region 2022 Events*

uniQure

HDSA IL COE APPRECIATION- FOOD TRUCK EVENT



Join us Saturday, August 27th at 1:00 PM
Lake Shore Park
808 North Lake Shore Drive, Chicago, Illinois 60611

Contact:
Arvind Sreedharan
703-599-6000 ~ avs2004@comcast.net

Join us for a FREE EVENT where we come together to show our appreciation to our HDSA Illinois Centers of Excellence staff. Staff members will be in attendance and this event is open to the entire HD Community.

This event is completely free - a donation to the HDSA IL Chapter would be greatly appreciated if you are willing!

****Online donations can be made at <http://hdsa.org/il>***

La Cocinita Food Truck will be available FOR FREE and serves gourmet Latin American cuisine. Food will include delicious tacos, rice and bean bowls, and Venezuelan arepas.

In an effort to keep all event participants safe and well, all attendees will be required to follow the HDSA Event Guideline.

We would like to express our sincerest thank you to uniQure for sponsoring HDSA's Upper Great Lakes Region 2022 Events

uniQure

Recap of 18th Team Hope Walk in Naperville

Sunday, May 15th brought the 18th Team Hope Walk in Naperville. The committee worked very hard to put on this event. It brought us great joy to see over 400 participants back in Naperville to walk and spread awareness of HD. We had a beautiful day, and a great turnout.

As we navigate through finding our “new normal” we did bring back an old favorite of enjoying a hotdog lunch at the park. It was great getting to catch up with old friends and meet some new friends too.

We appreciate our two Centers of Excellence stopping by and having a space to meet with our community. Thank you, Northwestern and Rush, for your support.

We cannot thank everyone enough for their donation and support in this Team Hope Walk event!

Mark your calendars for the 19th Team Hope Walk in Naperville... Sunday, May 21, 2023! We hope to see you there!



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

As the world and our communities open back up, people are spending more time with their loved ones and enjoying the world outside of their homes. All of us have different comfort levels with Covid-19 and it is important to respect the boundaries of one another during such a difficult time.

The power to community is very important and much of that has been lost over the last few years. This past May, our HDSA Illinois Chapter walk in Naperville had a great turnout. It was nice to see familiar faces and reconnect with one another.

This Fall, instead of hosting a typical education day, we will be hosting a wellness event. We want to bring everyone back together in a space that will create community and engage wellbeing. There will be a chair-based exercise class taught by an instructor who works specifically with people with neurodegenerative disease. An HD community member will teach a session on mindfulness and then we will come back together for support groups. Boxed lunch will be served.

It is time for us to come back together. We hope to see you this fall.



MEDICAL RESEARCH CORNER

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



NORTHWESTERN MEDICINE HDSA CENTER OF EXCELLENCE

Sage HD Clinical Trial - To start recruiting soon

A Randomized, Placebo-Controlled, Double-Blind Study to Evaluate the Effect of SAGE-718 on Cognitive Function in Participants with Huntington's Disease. The primary purpose of this study is to evaluate the effect of SAGE-718 oral capsules on cognitive performance and functioning in participants with premanifest or early manifest HD. This study requires up to 136 days of study participation. 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.

Development of the Virtual Unified Huntington's Disease Rating Scale (vUHDRS) - To start recruiting soon

The purpose of this study is to assess the reliability of virtually administered UHDRS compared to the in-person administration of the UHDRS to establish the use of the vUHDRS for clinical trial and regulatory purposes. This study will require up to 6 weeks of study duration. If you're interested in learning more about the study or how to get involved, please contact Destiny Gomez at 312-503-2778 or destiny.gomez@northwestern.edu.

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 period.
- 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 of the visits, you will be asked to complete a survey about your satisfaction with telemedicine visits.

Northwestern Movement Disorders Center Biorepository

The Movement Disorders Center (MDC) Biorepository is a registry aimed to collect biologic and clinical information, such as blood and tissue samples, and family and medical histories from patients diagnosed with a movement disorder. The purpose of studying materials from the registry is to identify factors that either cause these neurologic conditions or increase one's risk for developing them. Samples collected for this biorepository include a blood sample (or a saliva sample) and a skin biopsy. Participants may choose to donate one or both samples.

KINECT - HD: Recruitment complete

This is a study for a new treatment for chorea associated with Huntington's disease. If you have chorea that is not currently being treated we need you. 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: Recruitment open again

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 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 Zsa Zsa Brown at 312-503-4121 or zsazsabrown@northwestern.edu.

Hi-DEF Scale Study: Recruitment complete

Individuals with Huntington's disease are invited to participate in the Hi-DEF Scale Study. The purpose of this study is to learn more about impact of Huntington's disease on cognition and everyday functioning. The study involves a one-time commitment that lasts about 2.5-3 hours. Participants will be asked to complete some online questionnaires and two online cognitive tests. Once finished, the participant will be compensated for their time. If you're interested in learning more about the study or how to get involved, please contact Destiny Gomez at 312-503-2778 or destiny.gomez@northwestern.edu.

PROOF-HD - Recruitment complete

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.

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 the open label extension study of Kinect-HD, a clinical trial of Valbenazine for the treatment of Huntington disease chorea. The purpose of this "rollover" study is to gather more safety and efficacy data on Valbenazine. Valbenazine is an FDA approved medication used to treat another type of disorder that causes involuntary movements called tardive dyskinesia. In this open label study, all subjects will be given real Valbenazine for up to two years. Kinect-HD2 is now open to all qualifying patients, not just those who participated in Kinect-HD. Researchers are looking for people aged 18-75 with motor manifest Huntington's disease. Participants will come to Rush to

take surveys, complete physical exams, and have their blood drawn. The study is sponsored by the Huntington Study Group and Neurocrine Bioscience. If you or someone you know would like to take part in Kinect-HD2, please contact Jacob Hawkins at 312-563-5563 or email him at Jacob_Hawkins@rush.edu.

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

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

Cortical Control of Balance and Walking in HD

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

Optimization of Telegenetic Counseling for Huntington's Disease

A neuroimaging study investigating brain activity 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 (≥ 40 repeats), 30 years of age and older, who can stand and walk unassisted. A study visit requires participants to come to Rush University Medical Center to perform cognitive assessments and walking and balance tasks while wearing a portable neuroimaging cap, followed by an MRI at the nearby University of Illinois-Chicago. Testing can be completed in one visit or split into two shorter visits. This study is actively recruiting both healthy control and HD participants. Individuals will be compensated for their participation. Please contact Nicollette Purcell (Nicollette_L_Purcell@rush.edu) if you, or someone you know, are interested in participating and would like additional information.

News from HDSA Center of Excellence at Northwestern Medicine



Virtual Patient and Family Education Series 2022

Saturday, August 13th (via zoom or in-person TBD)

Couples Retreat

Please join Emily Zivin and she provides an interactive education session for couples to talk about their HD journey together with other couples in the community

Register in advance for this meeting:

[https://northwestern.zoom.us/meeting/register/tJYlc-qsqDkuH9fUN4UUJ4jAHjLI7FHw0g8w](https://northwestern.zoom.us/join/https://northwestern.zoom.us/meeting/register/tJYlc-qsqDkuH9fUN4UUJ4jAHjLI7FHw0g8w)

*General HD support group after education session

Saturday November 12th at 10 am via zoom (Date subject to change)

Clinical Research Update

Dr. Danny Bega

Register in advance for this meeting:

[https://northwestern.zoom.us/meeting/register/tJUvde6vrz8tHNB-iwdeFGriQxTkcU6d47wy](https://northwestern.zoom.us/join/https://northwestern.zoom.us/meeting/register/tJUvde6vrz8tHNB-iwdeFGriQxTkcU6d47wy)

*Caregiver support group to follow education session

Memorials and Tributes

In Memory of Susan Opesky

from Steven D. and Nancy Kari

In Memory of Gloria Kari

from Steven D. and Nancy Kari





*Huntington's disease research news.
In plain language. Written by scientists.
For the global HD community.*

Artificial intelligence to save the day? How clever computers are helping us understand Huntington's disease.

Scientists at IBM and the CHDI Foundation have used artificial intelligence to analyse datasets from Huntington's disease observational trials to model progression of the disease. They hope their findings will help improve clinical trial design.

By Dr. Rachel Harding; Edited by Dr. Sarah Hernandez; Originally published on June 20, 2022

Scientists have developed a new model that maps out the different stages of Huntington's disease (HD) in detail. Using artificial intelligence approaches, the researchers were able to sift out information from large datasets gathered during observational trials contributed by Huntington's disease patients. A team of researchers from IBM and the CHDI Foundation have published a new model of HD progression in the journal *Movement Disorders* that they hope will improve how HD clinical trials are designed in the future.

Predicting the progression of HD symptoms is complicated

HD is caused by an expansion in the huntingtin gene which leads to the production of an expanded form of the huntingtin protein. Studies of lab models of HD as well as people carrying the HD gene, show that having the expanded gene and making the expanded form of the protein causes a cascade of problems. Starting with small molecular changes, people with HD will eventually end up experiencing a range of different symptoms related to thinking, movement and mood that get worse over time.

Symptoms of HD typically start to show between the ages of 30 and 50, but a number of factors influence when this happens. We have known for a long time that people with bigger expansions in their huntingtin gene tend to get symptoms earlier, healthy lifestyle choices like a balanced diet and regular exercise can delay symptom onset, and other so-called genetic "modifiers" can also influence how early the disease might affect a gene carrier.

However, there's still a lot we don't understand about how Huntington's disease progresses over time and how the symptoms get worse. To try and tackle this problem, scientists from around the world have run numerous observational trials and natural history studies where patients' symptoms, biomarkers, and other measurements are monitored over time. These include PREDICT-HD, REGISTRY, TRACK-HD, and Enroll-HD. Together these studies have generated very large datasets which comprise more than 2000 different measurements recorded from 25,000 participants. This is tons of really helpful data, all made possible by the dedication of HD families to participating in these trials.

Machine learning helps us learn more about HD progression

Scrutinising all these datasets at once can help scientists spot new patterns and make novel conclusions but doing this type of analysis manually is extremely laborious and challenging. This is where the clever computer scientists come in! Scientists are able to use cool new methods to get the computers to look at all the data at the same time using special types of programs often referred to as artificial intelligence or AI.

One commonly used AI approach is called machine learning. This type of AI software becomes better at making predictions of certain outcomes by building models from training data sets which it uses to "learn" without being explicitly programmed to do so. Machine learning is a field in its own right in biomedical research but also has lots of different applications for things like email filtering and speech recognition.

"Together these studies have generated very large datasets which comprise more than 2000 different measurements recorded from 25,000 participants. This is tons of really helpful data, all made possible by the dedication of HD families to participating in these trials."

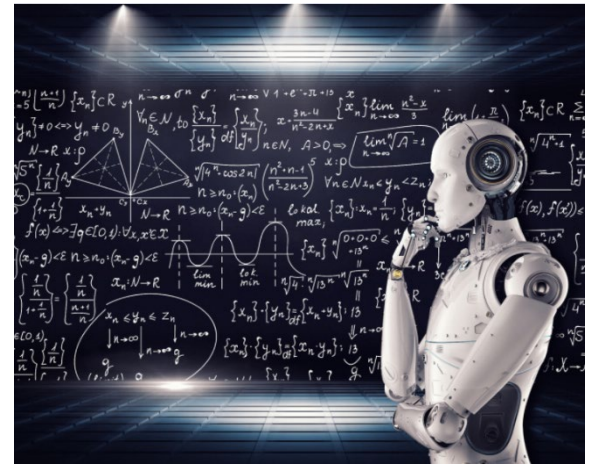
IBM and CHDI researchers used machine learning approaches to build and test a new model to understand how HD progresses and to categorise different disease stages. The model was then tested against a number of different measurements commonly collected and compiled in HD research that track disease progression, including the Unified Huntington's Disease Rating Scale (UHDRS), total functional capacity (TFC), and the CAG-age product, also called the CAP score.

The new model defines 9 states of HD, all specified by different measurements that assess movement, thinking, and day-to-day function. These states span from the early stages of the disease before motor symptoms begin, all the way through to the late-disease stages that have the most severe symptoms. The model was able to predict how likely participants in the studies were to transition between states as well as how long participants spend in the different phases of HD. While other studies have determined that the entire disease course occurs over a period of about 40 years, this is the first time researchers have predicted the expected amount of time HD patients will spend in each of the 9 states that were described in the new model.

New models of HD progression will hopefully inform clinical trial design

Having this handy new 9-state model of HD progression can help scientists and clinicians learn more about the different stages of HD and the timeframes it takes people with HD to move from one state to the next. With this information in hand, the researchers at IBM and CHDI believe this could help select the best-suited participants for particular HD clinical trials, identify robust biomarkers for monitoring how the disease progresses, and also help design better clinical trials.

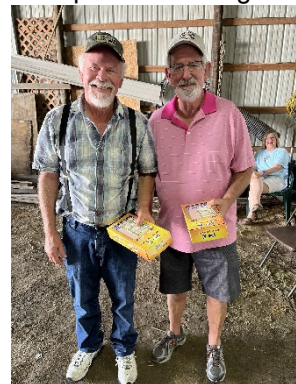
This is an exciting step forward for HD research and we look forward to learning more about other AI applications in HD research as novel approaches are designed and this exciting field of science matures further.



Recap of East Central Illinois Baggo Tournament

On Saturday, June 25th we held the first East Central Illinois Baggo Tournament in Clifton, IL. The event was a friendly competition while spending time together, and spreading awareness about HD.

In preparation for this event, we were able to gain the support of many donors and sponsors. We cannot thank our donors and sponsors enough for their generosity and support. The sponsors of the event included **ProHarvest Seeds, Country Chevrolet, Vienna Beef, Joanie Boudreau Family, Charlotte and Steve Rybarczyk, Nutrien Ag Solutions in Dwight, Dave and Arlene Lanoue, and Dralle Chevrolet in Watseka.**



The weather detoured some folks from attending, but we did have 8 teams compete in the double elimination tournament. Congratulations to the first place team members Dave Lanoue and Dale Weaver. Second place was awarded to the Adam Weber and Casey Bronson team. A great time was had by all!



SUPPORT groups

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.

Illinois HDSA Chapter Virtual Support Group

3rd Tuesday of Every Month (7:00pm)

Register in advance for this meeting:

<https://hdsa-org.zoom.us/join/mtg/join/mtg/register/tJEufumvpjosHtGoWGckn3GCqwnTf8Ftn6>

Questions? Contact Charlotte Rybarczyk at charlotte82963@gmail.com

Northwestern Medicine Virtual Support Group

2nd Thursday of Every Month (7pm via Zoom)

Odd months - Caregiver Support Group

Even months - General HD Support Group

Register in advance for this meeting:

<https://northwestern.zoom.us/join/mtg/join/mtg/register/tJlqf-2vqT8qE9KddKdiOkVyTijeHFvyhYL>

Questions? Contact Emily Zivin at emily.zivin@northwestern.edu

MUNSTER, IN

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

2022 Meetings: Contact Cindy Rogers for specific dates/format

Southside Christian Church, 1000 Broadmoor Avenue

Contact: Cindy Rogers (219-836-2369); crogers111@comcast.net or Monica at 219-616-1393

Rush University Medical Center Virtual Group

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

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

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

Illinois HDSA Chapter Caregiver Support Group

June 29/August/October/December (7:00pm)

Contact Emily Zivin for exact dates

Winnetka Library, Community Room, lower level

768 Oak Street, Winnetka

Questions? Contact Emily Zivin at emily.zivin@northwestern.edu

*****IN PERSON*** 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)

*******IN PERSON*******

NORTHWEST INDIANA HUNTINGTON'S AWARENESS, SUPPORT & HOPE

3rd Thursday of Every Month (6:00 – 7:00pm CST)

Methodist Hospital Southlake, 200 East 89th Avenue, Pavilion B, 1st Floor Conference Room, Merrillville, IN 46410

Contact: Amy Turner Ladow (Mobile: 610-241-2753); nwiHDASH@gmail.com or amyturnerladow@gmail.com.



Here is the link to the NWI Facebook Meeting Event which has all the details in the body.

<https://www.facebook.com/events/1088870821982032>

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

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

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

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

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

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

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

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

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

 SAVE THIS DATE!

August 6 th	HDSA IL Chapter Baggo Tournament – Rolling Meadows, IL
August 20 th	HDSA IL Chapter Night at the Races – Stickney, IL
August 27 th	HDSA IL Chapter Food Truck Event – Chicago, IL
September 10 th	HDSA IL Chapter Team Hope Walk – Central Illinois
October 1 st	HDSA IL Chapter Wellness Event – Harper College
December 4 th	Celebration of Hope Brunch – Ivy Room, Chicago, IL

<https://hdsa.org/il>

