



President's Message

Greetings Illinois HDSA Families-

Happy Fall! As we are coming into this season, we are close to wrapping up another year. We have just finished up the last of our in-person fundraising events. If you were unable to attend in person you can still donate to our events. The money raised goes to help work towards our mission of improving the lives of people with Huntington's Disease and their families.

Congratulations to Charlotte Rybarczyk and her committee on a successful Baggo Tournament! The event was a great time had by all. Looking forward to seeing more participants next year!

Thank you to Wayne Galasek and his committee on his successful Golf for HD event. There was great weather for a day for participants to enjoy some time on the course and raising money for a great cause.

Great job on a successful Team Hope Walk in Galesburg to Sarah Cozad, Tara Guidinger, and their committee! The Team Hope Walk is a time for gathering with family, friends, and community members to come together for a day of working towards our mission!

We are very grateful for the contributions and support of all our volunteers and supporters of all our events. It is great getting to see everyone at our events as we navigate through our new norms. We appreciate your dedication to the Illinois HDSA!

While I am talking about dedication it is a great honor to announce that the Celebration of Hope that is organized by our Regional Division of HDSA is honoring our Chapter's very own Charlotte Rybarczyk! Charlotte has been a great board member, and mentor to the HDSA at all levels. The Celebration of Hope will be Sunday, December 5th at 1:00pm at the Ivy Room in Chicago. Visit our chapter website if you would like to attend the event and join in honoring Charlotte for her dedication to our great organization. Congratulations Charlotte!

If you have an interest in becoming more involved in the Illinois HDSA Chapter we would be happy to have you join us. Please feel free to reach out if you have questions on joining our Board and becoming a part of our great team. It takes a village and being a part of our village is a great opportunity and experience. We hope that you would consider joining us!

Thank you for all that all of you do in making progress towards our mission!

Take care and be well,

Larry Haigh
President, Illinois Chapter HDSA

**BE THE
CHANGE**
VOLUNTEER &
MAKE THE DIFFERENCE



News from Northwestern Medicine HDSA Center of Excellence



Virtual Patient and Family Education Series 2021

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/join/join/join/register/tJUoc-uuqDMrG9Xu-1NhX_f-HRPHcGorhUfR

General support group after presentation

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

Missed our event? Northwestern Medicine Virtual Education Series 2021

Managing Difficult Behaviors presented by Dr. Eric Gausche

To view session:

<https://northwestern.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=424dd70a-92e1-40c8-8bdd-ad76014b589b>

New Virtual Support Group programming: We will continue to offer monthly virtual support groups alternating between a General HD Support Group and Caregiver Support Group.

See full details of dates/times on the SUPPORT GROUP page (page 14) of this newsletter.



WE NEED YOU



We are currently planning for 2022 and **WE NEED YOU!!** Have you ever thought of volunteering on a committee or joining the board of directors? Do you want to do more but don't know how? Need more information?

If you answered 'yes' to any of these questions, please contact Charlotte Rybarczyk, nominating committee chair, at charlotte82963@gmail.com or 847-259-3593.

Whether you have a little time to spare or a lot, we can use your help in our mission to serve families dealing with HD. We look forward to hearing from you soon!

Caregivers go through more than they will ever tell you. They give up a lot and rarely have a social life. They can get sick and emotionally worn out. It's a lot for one person and you will never know until you have walked the road of a caregiver.

GOLFforHD 2021 is in the record books!

On Sunday, September 12th, 55 golfers, 10 volunteers, photographer and assorted guests/friends came out to enjoy a day on the links at Old Orchard CC in Mt Prospect, IL. The late summer weather was perfect - 80 degrees, slight breeze, partly cloudy. After the usual chaotic and joyful registration, we all joined in for a group picture before Wayne Galasek welcomed the crowd and golf pro Doug Brazzeau gave final golfing instructions for the shotgun, best ball scramble. Tee-off was 1 pm. Lunch and drinks were provided throughout the day as the players circled through the beautiful course.

Meanwhile, volunteers finished preparing a generous Silent Auction selection. Players and guests had all day to peruse the interesting mix of food, candy, meat, golf rounds, sports memorabilia, sports equipment, liquor, and cocktail baskets, fall tasty consumable baskets, and more before signing up. After golf there was additional time to up-bid for favorite prizes.

The triumphant golfers returned around 6 pm and had a final access to the Silent Auction items. After a brief presentation and confirmation of the event's goals and purpose, Wayne handed out the fun and skill golf prizes, everybody's favorites! Then, closing remarks and heartfelt gratitude for everybody's support of this year's event were made before everybody was able to pick up their winning Silent Auction items.

With direct donations to HDSA, final donations still coming in and checks needing to clear, we estimate that this event will raise over **\$8,000!**

The entire HD family is grateful for the efforts, contributions and donations received from hundreds of supporters. Your efforts will help find a cure for this horrible disease, while also providing critical support for families, caregivers, doctors, and healthcare workers.

Our photo album, courtesy of Brian Gross, is available for your enjoyment at:
<https://gallery.briangrossphoto.com/golfforhd2021/>



For downloading, either the whole galley can be downloaded or individual pictures. The whole gallery download button is at the top right of the gallery of images. For individual images hover mouse over the photo and download icon will appear in bottom right corner of the thumbnail. Pin # is 6498

Thank you all and hopefully we will see you again in 2022! Please email back if you are interested in supporting us next year via working committee or day-of volunteer!

Wishing you all a wonderful Fall and joyous Holiday Season!

~ GOLFforHD Board



Danny Bega MD, MSCI
Associate Professor, Department of Neurology,
Division of Movement Disorders
Northwestern HD Clinic
Galter Pavilion, 675 N. St. Clair, #20-100
Chicago, IL 60611
312-695-7950 (main)
312-695-5747 (fax)
hd@nm.org (email)
<http://huntingtons.nm.org>

Meaning Intervention for Newly Diagnosed with Huntington's disease (MIND-HD)

Article authored by Leonard L. Sokol, Neurology Resident - Northwestern

Despite more than 40,000 people in the USA who live with Huntington's disease (HD), limited evidence guides what medications may improve emotional health-related quality of life. We also lack understanding into what non-pharmacological treatments could lessen the emotional disability associated with HD. Consequently, a growing and recent interest surrounds identifying and testing potential psychotherapeutic interventions that have worked in other populations and applying them to HD.

Having shown promise in alleviating emotional distress within other serious illnesses, one candidate area for an HD intervention might entail easing the sense of *meaninglessness*, as 18-20% of people with HD report substantial difficulties finding meaning at the time near HD diagnosis and onward. These symptoms often consist of a feeling that life lacks purpose, remains incomprehensible, and does not matter. A multi-million five-year USA study, called HDQLIFE™, determined HD's essential health-related quality of life priorities. HD stakeholders, including patients, caregivers, and clinicians, decided that the sense of meaning and purpose is paramount to emotional health-related quality of life. Overwhelmingly, since HDQLIFE's conclusion, an additional study determined that around 90% of HD clinicians believe that a high sense of meaning and purpose predicts better emotional health outcomes (e.g., depression) in the future. Correspondingly, more than half of HD clinicians also assert that an absence of meaning and purpose contributes to patient requests to hasten death.

We proceeded to scientifically evaluate these viewpoints, which would further support the development of a meaning-intervention. Using the HDQLIFE cohort, we demonstrated the vital link between a high sense of meaning and purpose and high joy, life satisfaction, and happiness—regardless of the burden of other physical, emotional, social, and cognitive symptoms—across all disease stages. We also discovered that a high sense of meaning and purpose predicts better emotional and social health outcomes at 12 and 24 months, clusters with less burdensome HD symptoms, and uniquely contributes to overall health-related quality of life beyond the influences of depression and anxiety.

These encouraging findings point to the possibility that a **Meaning-centered Intervention for Newly Diagnosed with HD (MIND-HD)** could improve emotional health-related quality of life for people with HD. Indeed, over the past twenty years, a large body of work from Memorial Sloan Kettering Cancer Center supports that a meaning-centered intervention, called "Meaning-Centered Psychotherapy," improves spiritual well-being and alleviates existential distress, depression, and anxiety in the cancer populations. Based on the works of the late neurologist, Dr. Viktor Frankl, M.D., Ph.D., Meaning-Centered Psychotherapy involves connecting and re-connecting to four forms of meaning (attitudinal, experiential, historical, and creative) through didactic and experiential activities. Delivery of the intervention occurs within individual or group formats, via in-person or video conference technology, and involves seven to eight one-hour sessions.

With funding from the Huntington disease Society of America and backing from Memorial Sloan Kettering Cancer Center, we plan to adapt Meaning-Centered Psychotherapy to people with HD. Researchers will optimize the intervention to meet the unique emotional, cognitive, and language needs of people with HD, based on input from multiple stakeholders. The initial MIND-HD clinical trial will determine the feasibility and acceptability of the intervention to people in the prodromal and early stages of the disease. Delivery will occur through one-on-one interactions through video conference technology. Based on the necessary adaptations discovered during MIND-HD, future clinical trials will involve recruitment from multiple HD Centers of Excellence to examine its efficacy and the potential to influence several pathways that promise to improve health-related quality of life.

THE RUSH PARKINSON'S DISEASE AND MOVEMENT DISORDERS SECTION



**PRESENTS THE THIRD ANNUAL
HUNTINGTON'S DISEASE PATIENT AND CAREGIVER SYMPOSIUM**

**A VIRTUAL EDUCATIONAL EVENT
SATURDAY, OCTOBER 30, 2021
9:00am – 12:00pm**

**PLEASE RSVP TO THE EVENT AT
[HTTPS://REDCAP.RUSH.EDU/RECAP/SURVEYS/?S=Y4TXYTDAYA](https://redcap.rush.edu/recap/surveys/?S=Y4TXYTDAYA)**

OSF HealthCare Illinois Neurological Institute Huntington's Disease Symposium

November 6, 2021
8:00 A.M.
Peoria, IL 61637

You're Invited!

Please join us for a day of support, conversation and education for families affected by Huntington's disease.



The registration link is: <http://ini.org/hd>



Celebration of Hope

Help for Today. Hope for Tomorrow

Save the Date

December 5, 2021, 1:00 pm

Sunday Brunch

The Ivy Room, Downtown Chicago

12 East Ohio Street

Register at www.hdsa.org/coh-chicago



Entertainment by Shelby Lentz

- ☛ Sunday Brunch
- ☛ Signature Cocktails
- ☛ Fabulous Auction



2021 COH Honoree
Charlotte Rybarczyk

Let's Get In the Holiday Spirit Together

MEDICAL RESEARCH CORNER

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



NORTHWESTERN MEDICINE HD SA CENTER OF EXCELLENCE

Hi-DEF Scale Study: NOW RECRUITING

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.

Kinect-HD Study for Chorea

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

Kinect-HD 2 Study

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

PROOF-HD Study

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

Telemedicine for Huntington's Clinical Care

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

HD SA CENTER OF EXCELLENCE AT RUSH UNIVERSITY

Uniqure, a gene therapy study for Huntington's disease

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

study, please reach out to Jacob Hawkins at 312-563-5563, or email Jacob_Hawkins@rush.edu. We anticipate being ready to enroll patients in the next few months.

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

Rush University Medical Center is recruiting participants for a clinical trial evaluating a drug called Valbenazine for the treatment of chorea. Valbenazine is already an FDA approved medication for another type of movement disorder that causes involuntary movements called tardive dyskinesia. The study is sponsored by the Huntington Study Group and Neurocrine Bioscience. Researchers are looking for people aged 18 to 75 with motor manifest Huntington's disease to be randomized to receive Valbenazine or placebo for 18 weeks. Participants will come to Rush for 9 research visits to take surveys, complete physical exams, and have their blood drawn. If you or someone you know would like to take part in KINECT-HD, please contact Jacob Hawkins at 312-563-5563 or email Jacob_Hawkins@rush.edu.

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

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

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

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

in ENROLL-HD, please contact Jacob Hawkins at 312-563-5563 or email Jacob_Hawkins@rush.edu.

Cortical Control of Balance and Walking in HD

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

Optimization of Telegenetic Counseling for Huntington's Disease

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



Fourth Baggo Tournament a Success!!

Many thanks to all the sponsors, participants, and volunteers who helped to make our fourth HDSA Illinois Chapter Baggo tournament a success!

On Saturday, August 28th in Rolling Meadows, 19 teams played in a double elimination bracket vying to win \$100 plus their choice of custom Baggo games built by R&R Custom Cabinetmaking.

It was a hot day as everyone played and enjoyed an Italian Beef and hot dog lunch provided by Vienna Beef. A silent auction and split the pot raffle rounded out the festivities.



Winning for the third time, Sully & John (AKA Team Freight Train), were undefeated for the day! And, best of all, over \$8,000 was raised for our HD families in Illinois!

Mark your calendars as we look forward to next year's event to be held on August 27, 2022!

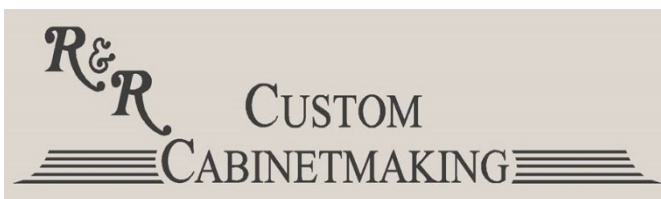
A HUGE THANK YOU TO OUR BAGGO SPONSORS:



Monson Rose Law

YURAN LI

JOE RYBARCZYK



LARRY HAIGH





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

NYA Mentorship Program

HDYO and HDSA have partnered to launch, implement, and support the Youth and Young Adult Mentorship Program originally designed from our friends at the Huntington Society of Canada!

The mentorship program is designed to support young people across the United States who face the everyday challenges of growing up in a family affected by Huntington's Disease. The HDSA and HDYO are committed to offering a nationwide mentoring program that provides youth (mentee) with one-on-one time and attention with another person within the HD/JHD community (mentor) who will receive training, and ongoing support from a Youth Social Worker within the HDSA.

The goal of the program is to offer young people the opportunity to connect with a mentor who will be able to provide them with valuable support at critical points in their lives. The mentors will be committed to supporting, guiding, and being a friend to the youth.

Those interested in becoming a mentor or a mentee must complete the application and consent forms.

All the information you provide is confidential in the application and within the program, except under very specific circumstances. Please read about the limitations of confidentiality outlined on the consent form and please ask questions for clarification.

Once your completed application is received and reviewed, you will be contacted by the Manager of Youth & Community Services. They will discuss your application and the next steps that need to be taken to continue towards becoming a successful mentor and mentee.

If you have questions/concerns about the application process or the program in general, please contact: MaryAnn Emerick- Manager of Youth & Community Services: memerick@hdsa.org

Memorials and Tributes

In Memory of Alvin Eckhoff from Joyce Carls

In Tribute to Teresa Srajer from John and Valerie Wotkun

In Memory of Shane Bennett from Bennett Family Fund

In Memory of Susan Opesky from Steven D. and Nancy A. Kari

In Memory of Gloria F. Kari from Steven D. and Nancy A. Kari



Another tool in the box: Creation of a molecular “dimmer switch” advances gene editing

A new system has been developed that allows researchers to fine-tune gene expression with oral drugs, work that provides a powerful tool for gene editing.

By Dr Leora Fox August 30, 2021; Edited by Dr Sarah Hernandez

A team of scientists recently created an innovative genetic system where a drug taken by mouth could be used to control the action of a gene editor, like those used in CRISPR systems. This has useful applications for research studies in cells and animals, and perhaps most importantly, could lead to improvements in the safety and accuracy of future gene therapies in humans. The technology can be applied broadly for studying genes and diseases, and was developed by researchers with HD expertise, incorporating a drug that is relevant to HD. Though actual clinical trials are a long way off, the company that has recently licensed the technology has an existing interest in HD.

Improving the control of gene therapy

Although the methods for delivery of gene therapies have improved vastly in recent years, it hasn't yet been possible to control the actions of those therapies once they reach their targets in the brain or other parts of the body. Ideally, when modifying human genetics, we'd want to be able to fine-tune things like the location of the genetic change, the amount of change that occurs at once, and the ability to stop the change in surrounding cells if it proves harmful – those last two have proved to be a particular challenge in gene editing, until now.



A recently developed genetic switch system, dubbed X^{on}, addresses some of these challenges in a novel way. It was created by a team of scientists led by Beverly Davidson at the Children's Hospital of Philadelphia, joined by researchers at the pharmaceutical company Novartis. The idea behind X^{on} was to create a gene editing technology that could be precisely delivered and then controlled over time using a drug that acts like an on/off switch.

How does it work?

Imagine a red traffic light that is on all the time and can only be disabled with a special tool. There's no way to move forward until the red light turns off.

With the X^{on} system, scientists can put a stoplight in front of any gene, by inserting the gene and the stoplight together into a genetic package and delivering it to cells in a dish or in a living animal. The new gene is present but inactive, meaning it can't produce messages or proteins, until the stoplight is removed. But when a particular drug reaches the cell, it acts as the tool that turns off the genetic stoplight, activating the gene.

The reason that this is an exciting scientific innovation is that the X^{on} system allows researchers to insert a gene and turn it on and off by simply adding a drug to a dish of growing cells, or by giving the drug to a research animal. This could be a new way to understand what happens when there is too much or too little of a given gene or protein, or to create a disease model to easily explore genetic interventions at different time points during aging.

In a recent publication in the journal *Nature*, Davidson's team tested the technology using a variety of genes involved in neurodegenerative diseases and cancers to show that their levels could be controlled based on when and how much of the stoplight-disabler drug was given.

Combining X^{on} with CRISPR gene editing

Even more interesting is the potential application of the X^{on} system to technologies like CRISPR and the future of gene editing as a therapeutic. This recent paper demonstrates the ability of the X^{on} system to be combined with CRISPR-Cas9 technology, for more precise control of CRISPR editing using a drug fed to mice. Davidson's team demonstrated this using an artificial gene that can make a mouse's liver cells glow green. But ultimately the hope is that it could be applied to human therapies.

A system that can help us gain better control of CRISPR gene editing is an exciting prospect because it provides more hope of safely adapting this technology for future medicines. This is not currently possible for most diseases, because direct, irreversible changes to human DNA can have drastic consequences. We wrote recently about the first ever successful safety trial of a CRISPR drug for a human disease that commonly affects the liver. Although it would be marvelous in theory to cut out or correct the HD gene in people, the knife-like CRISPR system almost always leads to additional unwanted changes in other genes. Therefore, we've so often emphasized that gene editing needs to come a long way before we can apply it to the treatment of human brain cells, which can't be regenerated like cells in the liver.

Coupling X^{on} with a CRISPR-Cas9 system that targets a disease gene (like the HD gene) would mean that an oral drug could turn the gene editor on and off. The dose could also be adjusted to control the amount of gene editing – not just acting as a tool to disable the red stoplight, but also acting as a “dimmer switch” for precise regulation. Most importantly for safety, if anything went awry, the treatment could be stopped to prevent further changes to their DNA. Right now, this is all theoretical, because the X^{on} system and other gene editing “dimmer switches” are in early developmental stages. Nevertheless, this publication hints at the possibility of applying it to therapies in people, and Novartis has licensed the X^{on} technology.

So why has this innovation made HD research news?

First and foremost, we know that HD is caused by a change to a single gene, so it has always been a prime candidate for genetic therapies, and dozens of researchers and companies worldwide are developing innovative solutions to treat HD at its source. HDBuzz (and HD researchers) always have an eye out for new technologies that improve upon existing methods. Furthermore, the leaders of the team that published the recent *Nature* paper are respected HD researchers who have devoted much of their careers to the development of gene therapies.

However, the main reason this publication has popped up as news for the HD community is that the X^{on} system relies on an existing drug to flip the gene editing switch – and that drug is none other than branaplam. Yep, branaplam, the oral drug developed to treat children with SMA, which Novartis will soon be testing in clinical trials for adults with Huntington's disease.

This does not mean that X^{on} gene editing has any part in upcoming trials for HD. It simply means that branaplam, a drug with genetic cut-and-paste abilities, forms part of an elegant new system that can be adjusted to control the activity of any gene scientists want to study. “Dimmer switch” systems for gene editing could potentially be designed to use a completely different drug, but in these early experiments, X^{on} and its precise control with branaplam has stood up to many tests of flexibility and accuracy.

The take home message

The X^{on} system is a really cool early-stage technology, and though it's not ready to be applied to human treatments, it is a novel element of the gene editing toolbox. Furthermore, it was created by researchers with HD expertise, and has now been licensed by a major pharmaceutical company which is already invested in HD therapeutics. That bodes well for its continued development in the study and potential treatment of HD and related genetic disorders.

CHAPTER OFFICERS

PRESIDENT – Larry Haigh
815-383-1877 ~ larryhaigh@gmail.com

VICE PRESIDENT – Arvind Shreedharan
703-599-6000 ~ avs2004@comcast.net

TREASURER – Andy Hucker
224-715-0729 ~ ahucker1549@comcast.net

SECRETARY – Mary Bos
630-830-5329 ~ mary_bos@att.net

BOARD MEMBERS

Karen Bennett – karben22@hotmail.com
847-212-1240

Sarah Cozad – cozinns.sc@gmail.com
309-299-0284

Wayne Galasek – wgalasek@aol.com
708-289-1273

Jenny Malave – jenniferplacek09@gmail.com
630-995-6440

Erin Riley – erin.m.bentz@gmail.com
630-201-7396

Charlotte Rybarczyk –
charlotte82963@gmail.com
847-259-3593

Ann Terry – ann_terry5@yahoo.com
312-339-9356

OTHER CHAPTER MEMBERS

Emily Zivin –Social Worker
630-443-9876 ezivin@hdsa.org

Camille Colletti – Regional Director
847-849-0680 ccolletti@hdsa.org

Maryann Moynihan – Newsletter Editor
708-955-3080 shamrock1959@gmail.com

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(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.

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 Chapter Online Support Group

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

Contact: Charlotte Rybarczyk
charlotte82963@gmail.com

Caregiver Support Group Meeting – IN PERSON

New Date: Tuesday, October 12th (7:00pm)

December date: TBD

Location information:

Winnetka Library, Community Room, lower level

768 Oak Street, Winnetka

Contact: Emily Zivin at 630-443-9876 or ezivin@hdsa.org

MUNSTER, IN

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

2021 Meetings: Contact Cindy Rogers for specific dates/format

Southside Christian Church, 1000 Broadmoor Avenue

Contact: Cindy Rogers (219-836-2369); clrogers111@comcast.net

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)

Northwestern Medicine/Cellini Foundation Support Groups

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

For meeting invite, please email Emily:

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

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

October 9th: General Support Group

November 13th

Education event and support group

Topic: HD Research and Panel discussion

Speaker: Dr. Danny Bega and research participants

Caregiver support group after presentation

December 11th: General Support Group

Rush University Medical Center Group

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

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

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

***NEW* Online Quarterly Support Group for Individuals who are Gene Positive**

Thursday, December 9th (7:00pm)

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

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!

Northwestern Virtual Patient & Family Education Series
November 13th HD Research Panel Discussion

Rush University Patient & Caregiver Symposium
October 30th A Virtual Educational Event

November 6th OSF HealthCare Illinois Neurological Institute Symposium – Peoria, IL
December 5th Celebration of Hope Event – Chicago, IL

<https://hdsa.org/il>

