



## President's Message

Greetings Illinois HD Families-

I hope this newsletter finds you well and healthy. During this unprecedented time in our nation remaining safe and healthy is very important. Be sure to follow the guidelines that have been put in place, and check in on your family, friends, and neighbors using social distancing practices.

These uncertain times have caused us to cancel events or find different ways to keep our fundraising efforts going. We are still working towards our mission to find a cure for Huntington's Disease. We still plan to get the education to you as best as possible. The board is looking at new ways to do fundraising from a virtual perspective. Please stay tuned as those efforts keep developing. Even though we are sheltering in place and not having contact with people, science does not stop. They still need funds to help in those efforts and continue with what we have planned on doing to support them. Research and trials are very important to our fight in finding a cure. Also, as a note the National HD SA Convention that was supposed to be held in New Orleans will be virtual this year watch for updates on that.

The Illinois Chapter is still offering resources to you via computer access, and telephone. We may not be able to have in person support group meetings, but Emily our Social Worker is working hard to make sure you still have the support that you need. We are working to get support groups through chats via phone and computer. If you are needing any assistance we are here to help you. Continue to watch our Facebook page and website ([www.illinois.hdsa.org](http://www.illinois.hdsa.org)) for more information and resources that are available.

This may be one of my shortest President Messages, but I hope you can find peace in the work that we continue to do during these unpredictable times. Continue to stay healthy, stay positive, and stay well!

Until next time,

Larry Haigh  
President, HDSA Illinois Chapter

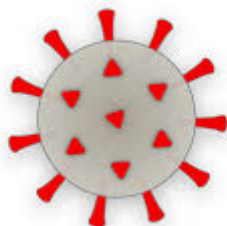




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## Staying Safe in the Middle of the COVID Pandemic

The COVID pandemic is upon us and all of us are getting a rapid course in what symptoms are seen in this disease, how to stay safe, and when to get care.



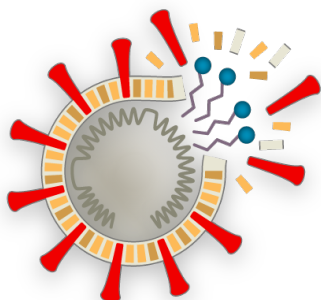
First, let's talk about the virus. Coronavirus disease 2019 (COVID) is an infection caused by a RNA virus. "Coronam" is Latin for crown, which refers to the crown-like appearance of the virus on a microscopic level, seen here in a picture from the New York Times. The virus binds to a receptor in the lungs and causes an immune reaction. In some patients who have higher risk, this reaction can be severe, causing tissue damage and requiring assistance with breathing.

**Most patients who get COVID (80%) have mild or no symptoms**, usually presenting with fever, cough, or shortness of breath. Other symptoms include muscle aches/fatigue. Severe

disease occurs in 15% and 5% require ventilation and risk failure of their organs. This virus is contagious and can be spread even if you don't feel sick. The disease may be milder in younger people and fever is only half as common in kids, making it hard to know who might have COVID. High risk patients for more severe COVID disease include the following: **age over 60 years old, diabetes, heart or lung disease, or people with a compromised immune system.** These risks were noted in the first studies coming out from Asia and Europe and may expand as the disease spreads in the US.

Symptoms of COVID	Percentage of Patients
Fever	93% (adults)
Cough	63%
Shortness of Breath	46%
Muscle aches/fatigue	29%
Sore throat	11%
Reduced smell/taste	9%
Headache	8%
Diarrhea	6%

There are several measures that have been shown in pandemics like COVID to reduce your chance of infection. **Staying home and limiting interaction with others** is one of the most important ways of prevention. This means being no more than 6 feet closer to others, avoiding public transportation, ordering in groceries, and only interacting with those people you live with. **Wash your hands with soap and hot water** for 20 seconds multiple times daily. In this picture from the New York Times, soap destroys the virus by wedging itself into the virus and prying it apart. Other important tools to stay safe include avoiding touching your face and cleaning surfaces regularly.



**Are Huntington's disease patients more at risk from COVID? This may depend on the stage of disease that Huntington's disease patients are in.** In milder stages of the disease, Huntington's disease patients likely have the same risk as the general population, unless they fall into a high-risk category as described above. However, Huntington's disease patients who are later in the disease who have swallowing problems or frequent pneumonias may develop more serious illness.

What does a Huntington's disease patient do if they get sick? **Most people with COVID infection have mild symptoms and can be treated at home.** Many hospitals are now offering drive-by testing for COVID infections, with an order from a healthcare provider. **We recommend Huntington's disease patients do not come into the emergency department unless your**

**symptoms are more severe and cannot be managed at home.** This decreases the change you will get COVID at the hospital if you do not have it already. In the emergency room, COVID testing, oxygen therapy, and admission to the hospital can all occur depending on symptoms. Milder patients are sent home to recover.

**We recommend you continue to see your Huntington's disease provider by telephone or video when you are due for your next visit.** Most Huntington's disease clinics are closed to in-person visits, unless it is urgent. However, your doctor would like to keep in touch with you during this pandemic to make sure you are doing OK. If you think you have COVID and need to be evaluated or need an order for testing, you can call **Rush at 1-888-352-RUSH (7874)** where a health provider will evaluate you by phone and/or video. Other online resources include the following:

- <https://www.tenpercent.com/coronavirussanityguide>: Practical, actionable ways of coping with stress, fear, and anxiety
- <https://www.downdogapp.com>: Yoga and other workouts now available on their app for free through April 1st
- <https://www.headspace.com>: Mindfulness for everyday life, with free support during the coronavirus pandemic.

**Stay safe and social distance everyone and we look forward to seeing you in person when this pandemic is over.**

# 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](mailto:zsazsa.brown@northwestern.edu).

### **Telemedicine for Huntington's Clinical Care**

Dr. Danielle Larson and Dr. Danny Bega recently received the "Human Biology Project Fellowship" grant funding from the Huntington's Disease Society of America to start the research study "TeleHD," a study of Telemedicine Visits for Huntington's Disease Clinical Care. This study is ready to begin and will study if clinical visits for Huntington's patients can be done by video camera, if this type of visit decreases time/cost burden and is liked by patients and their care partners. Participants must be clinical patients of Northwestern's Huntington's clinic. Please e-mail research study assistant Robert Modiest at [robert.jr3@northwestern.edu](mailto:robert.jr3@northwestern.edu) to let him know your interest, or if you have any questions.

## **RUSH UNIVERSITY HD CENTER OF EXCELLENCE**

### **Uniqure, a gene therapy study for Huntington's disease**

Rush University Medical Center is excited to participate in a new gene therapy trial for Huntington's disease, sponsored by Uniqure. The therapy is called AMT-130 and will hopefully slow the progression of HD by lowering the level of huntingtin protein in the brain. "Gene therapy" works by targeting genetic abnormalities that contribute to us getting sick. Administration of the therapy involves a small incision in the skull through which AMT-130 is delivered to the brain. Researchers are looking for people aged 25 to 65, with at least 40 CAG repeats in their huntingtin gene, and specific brain structure that will be assessed by MRI. Eligible participants will be randomized to receive the real treatment or a "sham" surgery involving a small mark made on the skin without making an actual incision. Study duration is approximately 5 years, during which time participants will complete physical assessments, treatment dosing, lumbar punctures, blood draws, and MRIs. Assessments and treatment will be completed across multiple sites. If you or someone you know would like to take part in the Uniqure study, please reach out to Jacob Hawkins at 312-563-5563, or email [Jacob\\_Hawkins@rush.edu](mailto:Jacob_Hawkins@rush.edu). We anticipate being ready to enroll patients in the next few months.

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

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

### 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. If you or someone you know would like to take part in ENROLL-HD, please contact Jacob Hawkins at 312-563-5563 or email [Jacob\\_Hawkins@rush.edu](mailto:Jacob_Hawkins@rush.edu).

### Cortical Control of Balance and Walking in HD

A neuroimaging study investigating brain activation during 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 are able to 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 Nicolette Purcell at [Nicolette\\_L\\_Purcell@rush.edu](mailto:Nicolette_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](mailto:Marc_Rosenbaum@rush.edu).

## Yes! Count me in!!

### 2020 Pledge Drive



Your pledge helps to support the HD SA mission to improve the lives of everyone affected by Huntington's disease and our vision of a world free of Huntington's disease.

- Research efforts
- Family services
- Advocacy
- Support groups
- HD awareness
- Our chapter social worker
- In-Service Presentations to Care Facilities

Please complete the information below and return with your pledge:

Your Name \_\_\_\_\_

Email Address \_\_\_\_\_



- ☐ Benefactor (\$500.00 [donation](#))    ☐ Patron (\$250.00 donation)    ☐ Angel (\$100.00 donation)    ☐ Supporter (\$50.00 donation)  
☐ Member (\$25.00 donation)    ☐ Friend (\$\_\_\_\_\_ donation)

Make your check payable to **Huntington's Disease Society of America** and mail to:

P.O. Box 1454, Lake Villa, IL 60046

To make your pledge online go to [HDSA.org/il](http://HDSA.org/il), click DONATE and click on PLEDGE DRIVE CONTRIBUTIONS.

**Family is everything**

Your contribution is tax deductible to the extent allowed by law.



# Illinois State Conference Canceled

Due to the Coronavirus we had to cancel our 2020 State Conference scheduled for April 4<sup>th</sup>. We are saddened that we will be unable to gather in person, but we do encourage you to explore the resources available to you at [HDSA.org/IL](http://HDSA.org/IL). Under the drop-down menu titled "More About Illinois Chapter" you can find information on HD Specific Medical Centers, Picking a Nursing Home, Genetic Testing, and much more.

The National Convention in June is now being converted to a virtual event. This event is typically several days in length and contains valuable information on everything from A to Z on HD. This Virtual Convention will continue to take place in June, but the exact timing of events is likely to change to accommodate a nationwide online audience. Keep checking the website at [HDSA.org](http://HDSA.org) for details as they become available.

As we navigate this unprecedented time, it helps us all to remember what we in the HD community live by, FAMILY IS EVERYTHING!

## MEMORIALS AND TRIBUTES

**In Memory of Bob Leck** from Ted & Sarah Larkin, Betty Tucker, Karen Bennett, Marilyn Bulson & Craig Day, Ted Ross, and Emmanuel Baptist Church.

**In Memory of Dennis Ross** from Melinda Dubbelde, Cynthia Scott & Lynn Picoran, Don & Theresa Taylor, Ardella Maxwell, Matthew & Rhonda Glan, Lawrence & Kristen & Laura Sweet, Ted Ross, Steve & Audrey Ball, Bill Amdor, Shelley Wilson Miller, Jeff & Lynette Switzer, Lori Valentine, Steven Button & Lucinda Pasley, Lisa & Michael Waight, Mike & Susan Walters, Dennis & Gloria Stuckey, Donald & Barbara Lynn, Vickie & Chris Kauffman, Jack & Valerie Ross, and Battery Specialists + Golf Cars.

**In Memory of Linda Larkowski** from Shirley Pike.

**In Memory of Terry Bruno** from Craig and Teresa Srajer.

**In Honor of Valerie Wotkun's birthday** from Catherine & Richard Evers

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This newsletter attempts to report items of interest relating to the individuals with Huntington's Disease, their families, healthcare professionals, and interested friends and supporters. HDSA and the Illinois Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Illinois Chapter.

**16<sup>th</sup> Annual  
Team Hope  
Walk**

**Sunday,  
May 17,  
2020**

# **'Virtual' Team Hope Walk**

**THE NAPERVILLE TEAM HOPE WALK IS STILL ON!**

**WE ARE INTRODUCING A NEW, VIRTUALIZED EVENT THAT  
WILL BE FUN AND ENGAGING FOR EVERYONE.**

**THIS CHANGE IN FORMAT ALIGNS WITH THE NEWLY  
RELEASED [CDC GUIDANCE](#) FOR LARGE EVENTS, TO HELP  
ENSURE THE SAFETY AND HEALTH OF OUR PARTICIPANTS.**

**Event Inquiries: Dave Hodgson**  
[dchodgson1946@gmail.com](mailto:dchodgson1946@gmail.com)

## **Join the Naperville Virtual Team Hope Walk**

A virtual walk is a real walk, but on your terms: You get choose your own course, you can walk in your driveway, neighborhood, in your house and even on treadmill! Sign up now and participate in the virtual walk by raising money and awareness. Your family, friends, colleagues and health care providers can join your Naperville Virtual Team Hope Walk on May 17, 2020.

### **Step 1. Register for the Illinois Chapter Naperville Walk, IT'S FREE!**

<https://illinois.hdsa.org/about/2020-naperville-team-hope-walk>

Set your fundraising goal and begin making a difference in the lives of HD families. Recruit a team of friends, neighbors, and family to participate with you.

**Step 2.** Whether you walk around the block, the neighborhood or do a 1K run up & down your street when, where and how far you walk is up to you. We are walking together all over the state on Sunday May 17, 2020.

**Step 3.** Supporting HD families is an incredible reason to raise money. But we think you deserve something for your efforts. When you individually raise your first \$100, you'll receive a Team Hope Walk t-shirt that will be mailed to you. For this year just wear last year's shirt or make your own. Keep raising funds to be eligible for even more great fundraising rewards.

**Step 4.** Share a photo of yourself and use #VirtualTeamHopeWalk to let us know where you are walking for HDSA. You can also tag us @HDSA on Twitter, Instagram or Facebook. And remember—a little thanks goes a long way. Be sure to tag supporters and thank those who have joined you to help you reach your goal.

**\*ONLY VIRTUAL WALKERS WHO RAISE \$100 OR MORE WILL BE MAILED A TEAM  
HOPE T-SHIRT AFTER THE EVENT\***

Please continue to register your teams and continue asking for donations so that we can support the mission of HDSA (see form on following page)!

Your hosts, Dave and Susie Hodgson, will be walking in their neighborhood with their daughters as well as Ajax, their dog. After the walk, we hope families will roast your own hotdogs for lunch! Don't forget to take lots of pictures. If you have a Facebook account, feel free to post those pictures on the HDSA Illinois Chapter page. Wear any color Team Hope Walk t-shirt you may have from previous walks you've attended. Feel free to "GO LIVE" on Facebook so family, friends, and neighbors know we have NOT given up!

Carry homemade signs to let your neighbors know why you're walking. Let's make THIS virtual walk the biggest in the nation.

## **GO TEAM HOPE ILLINOIS!**

# 'VIRTUAL' TEAM HOPE - PLEDGE SHEET

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



Collect pledges from family members, friends, co-workers, neighbors, church members, teachers, or anyone who would like to join you in your personal fight against HD. For checks received as donations, please make sure all checks are made out to **HDSA**. In the memo section, write **IL Chapter Team Hope Walk Naperville**.

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

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

	NAME	ADDRESS	AMOUNT
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OFF TO A  
GOOD  
START

Getting  
Closer

*You did it!*

KEEP  
ON  
GOING

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

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

Email: \_\_\_\_\_ Phone: \_\_\_\_\_

This form may  
be reproduced.

**Waiver:** I hereby waive all claims against the Huntington's Disease Society of America, sponsors or any personnel for any injury I might suffer from this event. I attest that I am physically fit and prepared for this. I grant full permission for organizers to use photographs of me to promote this event.

Signature \_\_\_\_\_



**March 20, 2020**  
**Community Update on HDSA's 35th Annual Convention**

Dear Friends of HDSA,

Thank you for your support and commitment to HDSA as we navigate this unforeseen public health event. We know that fighting Huntington's disease is overwhelming in the most normal circumstances, and certainly the COVID-19 (coronavirus) crisis has augmented these challenges.

HDSA is committed to continuing the resources and support that you have come to expect from our nationwide network of Chapters, Affiliates, Social Workers and Support Groups. We encourage you to visit [www.HDSA.org](http://www.HDSA.org) for more information about our online tools and virtual resources, as well as HDSA Community Updates regarding upcoming events and activities.

Unfortunately, our ability to host face-to-face meetings right now is greatly curtailed. Out of an abundance of caution and concern for our HD families, volunteers and staff, we have made the difficult decision to convert the **35<sup>th</sup> Annual HDSA Convention to a VIRTUAL event**. We will not be hosting a physical Convention in 2020.

For the first time in HDSA's history, we will be streaming our world-class presentations and much-anticipated research updates online, directly to your home – **FOR FREE!** The event will continue to take place in June, but the exact timing of Convention events is likely to change to accommodate a nationwide online audience.

The HDSA Convention has been described by many as a great "family reunion" – and to play our part in flattening the curve and controlling the spread of coronavirus – the HDSA staff will work tirelessly with our presenters to produce this milestone event featuring interactive workshops filled with all of the information, support and hope that you have come to expect at the HDSA Convention. In addition to the educational sessions and keynote speakers, we'll be integrating highlights from the more social events as well, including National Youth Alliance activities and Volunteer Awards.

Unfortunately, exercising social distancing means we will not be able to enjoy all the hugs that the HDSA Convention famously features, but we can save them for the 36<sup>th</sup> Annual HDSA Convention in 2021 in ... well, we can't give away all our secrets! **Follow us at [HDSA.org/convention](http://HDSA.org/convention) as we build out an incredible virtual program and reveal the location of the 36<sup>th</sup> Annual HDSA Convention in 2021!**

For those of you who had already made your travel plans for New Orleans this June, our team is committed to working with you to ensure you're refunded.

**To receive your full registration refund**, please email Robert Coffey at [rcoffey@hdsa.org](mailto:rcoffey@hdsa.org).

**If you booked your hotel room through HDSA's room block**, your room will be canceled automatically by HDSA and the Sheraton. If you booked your room outside of HDSA's room block, you will need to contact the hotel directly to cancel your reservation by May 15<sup>th</sup> (though we suggest doing it sooner rather than later).

**With few exceptions, the airline industry is honoring flight cancellations.** We encourage you to contact your carrier soon to request either a refund or a full credit.



Additionally, HDSA's Leadership Day, NYA Day and Professional Training for Social Workers will be converting to virtual events. If you were planning to participate in one of those events, stay tuned for more information from the appropriate HDSA team member.

Most importantly, we continue to follow the guidance of our friends at the Centers of Disease Control & Prevention (CDC), World Health Organization (WHO) and your state and local health departments and urge you to work with your personal clinician if you have any concerns regarding your personal risks for COVID-19.

If you have additional questions or concerns related to HDSA's work during this public health crisis, please contact your HDSA team member or write to us at [info@hdsa.org](mailto:info@hdsa.org). Thank you all for hard work and concern during this difficult time.

Please take care of one another and be safe.

Sincerely,

Louise Vetter - President & CEO  
Huntington's Disease Society of America



## 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](mailto:ezivin@hdsa.org)

The Huntington's Disease Society of America (HDSA) recently welcomed Allison Bartlett, Esq. to the newly created position of Manager of Disability Programs. Ms. Bartlett is a disability attorney who specializes in guiding people with rare, chronic conditions, like Huntington's disease, through the complex Social Security disability system. She comes to HDSA from the Caring Voice Coalition, where she represented patients with rare diseases, including HD, in their navigation of the legal processes associated with securing disability support.

HDSA also recently launched disability chat webinars. Each month, Disability Chat will feature a topic of interest for either HD families or HD social workers. Each segment will include a 45-minute presentation followed by 15 minutes for discussion with the audience. All webinars are recorded and can be found on the HDSA YouTube channel for later viewing and to serve as an enduring resource.

Upcoming Events include:

**May 21, 2020, 12PM Eastern Time: Disability Red Flags.** What you need to know about the 6 common red flags in a disability claim and how to mediate or avoid them.

**July 16, 2020 12PM Eastern Time: Completing Disability Forms (Wk Activity, ADF, Wk Hx, Pain Q, Anx Q).** An overview of what Social Security disability forms you may receive during the disability application process and how to complete them

To find out more about upcoming events please go to: <https://hdsa.org/find-help/healthcare-and-future-planning/disability-benefits-and-hd-2/>.

To contact Allison regarding disability inquiries she can be reached at [abartlett@hdsa.org](mailto:abartlett@hdsa.org) and 212-242-1968.



## New molecule can reverse the Huntington's disease mutation in lab models

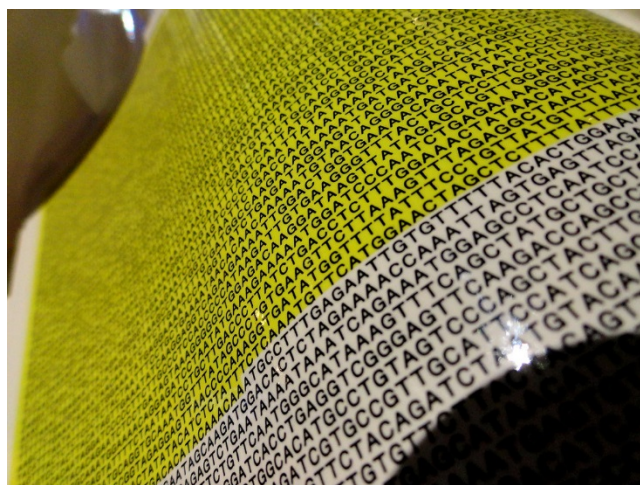
*A collaborative team of scientists from Canada and Japan have identified a small molecule which can change the CAG-repeat length in different lab models of Huntington's disease.*

By Dr Michael Flower March 13, 2020 Edited by Dr Rachel Harding

A collaborative team of scientists from Canada and Japan have identified a small molecule which can change the CAG-repeat length in different lab models of Huntington's disease.

### CAG repeats are unstable

Huntington's disease is caused by a stretch of C, A and G chemical letters in the Huntingtin gene, which are repeated over and over again until the number of repeats passes a critical limit; at least 36 CAG-repeats are needed to result in HD.



The CAG repeat of the huntingtin gene sequence can be changed to include more and more repeats, in a process called repeat expansion Image credit: "Gattaca?" by IRGlover is licensed under CC BY-NC 2.0

In fact, these repeats can be unstable, and carry on getting bigger throughout HD patients' lives, but the rate of change of the repeat varies in different tissues of the body.

In the blood, the CAG repeat is quite stable, so an HD genetic blood test result remains reliable. But the CAG repeat can expand particularly fast in some deep structures of the brain that are involved in movement, where they can grow to over 1000 CAG repeats. Scientists think that there could be a correlation between repeat expansion and brain cell degeneration, which might explain why certain brain structures are more vulnerable in HD.

### But why?

This raises the question, what is it that's causing the CAG repeat to get bigger? It seems to be something to do with **DNA repair**.

We're all exposed continually to an onslaught of DNA damage every day, from sunlight and passive smoking, to ageing and what we eat. Over millions of years, we've evolved a complex web of DNA repair systems to rapidly repair damage done to our genomes before it can kill our cells or cause cancer. Like all cellular machines, that DNA repair machinery is made by following instructions in certain genes. In effect, our DNA contains the instructions for repairing itself, which is quite trippy but also fairly cool.

"What is it that's causing the CAG repeat to get bigger?"

We've known for several years that certain mouse models of HD have less efficient systems to repair their DNA, and those mice have more stable CAG repeats. What's more, deleting certain DNA repair genes altogether can prevent repeat expansion entirely.

But hang on, isn't our DNA repair system meant to protect against mutations like these?? Well normally, yes. However, it appears a specific DNA repair system, called mismatch repair, sees the CAG repeat in the huntingtin gene as an error, and tries to repair it, but does a shoddy job and **introduces extra repeats**.

## Why does this matter?

There's been an explosion of interest in this field recently, largely because huge genetic studies in HD patients have found that several DNA repair genes can affect the age HD symptoms start and the speed at which they progress. One hypothesis to explain these findings is that slowing down repeat expansion slows down the disease. What if we could make a drug that stops, or even reverses repeat expansion? Maybe we could slow down or even prevent HD.

## So what's new?

Although the NA molecule is not a medicine for HD, it will serve as an important tool for scientists wishing to study the HD mutation and repeat expansion. Chris Pearson's group in Toronto have developed a compound called naphthyridine-azaquinolone, which we'll just refer to more easily as 'NA', which binds CAG repeats and could prevent repeat expansion.

Using cells from HD patients in a tissue dish, NA was shown to successfully slow, and possibly even lead to a small reduction in CAG repeat length. Pearson showed that blocking transcription, the process in which genes are used as templates to make proteins, prevents repeat expansion. This suggests that during transcription, the huntingtin repeat might be bent into an abnormal shape, which mismatch repair machinery in the cell recognizes and then tries to repair. However, precisely how NA works in this process remains unclear.

Pearson's team injected NA into one side of the brain of an HD mouse model. They targeted the striatum, a region known to show lots of CAG expansion. Compared to the untreated side, NA prevented expansion and even caused some shrinkage of the repeat number.

Next, they showed NA reduced the build-up of clumps of toxic huntingtin protein in the mice's cells. It is not clear yet whether the treated mice have improved symptoms or increased lifespan. This will be important for scientists to work out before deciding whether preventing repeat expansion has potential as a therapy for people.

## What's the catch?

"NA was shown to successfully slow, and possibly even lead to a small reduction in CAG repeat length"

A huge obstacle to making new drugs is getting them into the cells that most need them; in the case of HD, that means throughout deep regions of the brain. NA is able to freely enter different cells once in the brain, but this current version of the molecule cannot cross the blood-brain-barrier. Scientists would need to modify and improve the NA molecule to avoid needing to be directly injected into the brain.

Fiddling around with DNA repair, one of our body's major defense systems, could be dangerous, and there's the potential for major side effects like cancer. Pearson showed that NA didn't affect the core function of mismatch repair, which is to remove DNA bases when they get put in the wrong place. However, it did induce some minor mutations elsewhere in the genome, in a similar way that chemotherapy can.

It is possible to imagine treating HD patients at an early age, before they develop any symptoms; this might stabilize the CAG repeat and could prevent or at least delay the onset. CAG repeat shrinkage in their sperm or eggs could even mean they wouldn't pass the disease on to their children.

However, for NA there is still a lot of work to do. For starters, we would need to show that preventing CAG expansion slows down the disease, we would then need to come up with a way to get NA into the deep regions of the brain, and finally we would need to be sure it is safe with limited side-effects. Early treatment could also mean being exposed to risks like cancer for even longer, so there's clearly a lot to be worked out.

In summary, NA is an exciting research compound, but there is still a long road ahead before something like it might be a drug that could be taken by people to prevent or treat Huntington's disease.

# SUPPORT groups

***NOTE: Face-to-face meetings CANCELLED due to COVID-19 until further notice. Please reach out to CONTACT info for your meeting for additional information as many of the local support groups will be utilizing zoom video conferencing.***

***\*\*Whether you have HD, are at-risk, a caregiver, friend or just someone who wants to know more about HD, you are welcome!\*\****

## CENTRAL ILLINOIS

**2nd Sunday of Even Months (2:30 – 4:30pm)**

2020 Meetings: 2/9, 4/13, 6/14, 8/9, 10/11 (no Dec. meeting)

OSF PromptCare Fort Jesse, 2200 Fort Jesse Road, Normal, IL  
Contact: Larry Haigh (815-383-1877); larryhaigh@gmail.com

## ROCKFORD

**2nd Sunday of Every Month (2:00 – 4:00pm)**

OSF St. Anthony Medical Center, 5666 E. State Street,  
St. Anthony Room (Use main entrance – second one back from  
parking lot entrance. As you enter building, you'll see a counter  
staffed by volunteers. Turn right, before you reach the counter.  
St. Anthony room is straight ahead)

Contact: Charlotte Rybarczyk (847-528-7354);  
charlotte82963@gmail.com

## GENEVA

**3rd or 4th Sunday of Odd Months (2:00 – 3:30pm)**

2020 Meetings: 1/19, 3/29, 5/17 (no mtg), 7/19, 9/20, 11/15

Northwestern Medicine – Delnor Hospital, 300 Randall Road  
Conf. Room #4, Medical Office Building 351 (park near the south  
entrance to the hospital and enter at the southeast corner of the  
building. Turn left, go past the gift shop and cafeteria, then  
follow the sign for Building 351. Conference Room #4 is a short  
ways down the hall on the right)

Contact: Joe Wiedemann (847-505-3933);  
joseph.wiedemann@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 and directions)

## 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); cdrogers111@comcast.net

## CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL

**Saturdays (see dates below) (10:00 – 11:30am)**

2020 Meetings: 1/18, 3/7, 5/16, July, Sept, Nov. TBD

Logan Square Library, 3030 W. Fullerton Avenue, Conference  
Room (Free ground-level parking available; building is  
handicap-accessible)

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

## CHICAGO – RUSH UNIVERSITY MEDICAL CENTER

**3rd Saturday of Every Month (10:00am – 12:00pm)**

2020 Meetings: 1/18, 2/15, 3/21, 4/18, 5/16, 6/20, 7/18, 8/15, 9/19,  
10/17, 11/21, 12/19

Rush Oak Park Hospital, 520 S. Maple, Oak Park, IL 60304  
Conference Room 1B

Parking is Free; Refreshments will be provided  
Each group will have a short presentation from a professional  
(dietician, therapist, etc.)

Contact: Samantha Lunde, AM, LSW (312-942-2163) or  
Samantha\_R\_Lunde@rush.edu

## SOUTH SUBURBAN

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

2020 Meetings: 1/14, 3/10, 5/12, 7/14, 9/8, 11/10

Thomas Cellini Huntington's Foundation, 3019 East End Ave.  
South Chicago Heights, IL

Contact: Maryann Moynihan (708-955-3080);  
shamrock1959@att.net OR TCHF Office (877-687-8243)



## Caregiver Support Group

**Wednesdays (see dates below) (7:00 – 8:30pm)**

2020 Meetings: 2/19, 4/15, 6/17, 8/12, 10/21, 12/2

Northfield Branch Library, 1785 Orchard Lane, Northfield, IL 60093

The library is difficult to find. It is in the same building as the post  
office. The librarian will be able to direct you.

Meeting will be held in the Community Room

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

