Huntington's Disease Society of America
Northeast Ohio CHAPTER

SPRING 2019

HAPPENINGS

PRESIDENT'S MESSAGE

SPRING HAS SPRUNG!

A time for renewal! Renewal for growth and development in our personal lives as well as in our own HD community. We can start to let go of the old and start to relish in the new year ahead. A year full of hope for tomorrow and help for today. As President of the North East Ohio HDSA Chapter, I am thrilled to write to you all and shine some sunshine on our collaborative efforts and monumental progress as we embark on what will surely be a year full of tremendous growth and opportunity for us in 2019.

New ideas are starting to sprout! This week marked the first inaugural meeting for our Huntington's Disease Advisory Board for the HD Center of Excellence at the Cleveland Clinic. Katie Dykman, Wes Johnston, and I were invited to join as new Board Members and speak on behalf of patient advocacy and provide feedback which will be utilized to create a better patient experience during Huntington's visits at the clinic. We talked about many new exciting approaches that will provide ease to the patients and caregivers. Please stay tuned for more on this topic to be shared during our HDSA NEO Education Day on Saturday, May 11th 2019.

Clinical trials are in full bloom! In February, I was humbled and honored to join the global HD-COPE team in New York, NY for our quarterly meeting designed to provide an HD patient and caregiver perspective during break outs with several pharmaceutical companies. We met with WAVE, CHDI, and Roche over 4 days to discuss current clinical trials and observational studies in the pipeline and to provide a patient/caregiver voice that will fundamentally allow these companies to design their trials for the patient, by the patient. It's important for me to share that the end goal was clear- comfort and ease for the patient and caregiver. While I can't go into great detail of the specific sensitive discussions of our sessions, here is a fantastic outline of clinical trials or therapies in the pipeline from the Huntington's Therapeutic Conference that you may find encouraging: https://en.hdbuzz.net/268. Thank you HDBuzz for continuing to keep us informed! Also continue to stay up to date on the newest observational studies available from Enroll-HD at https://www.enroll-hd.org/.

HD-COPE session with WAVE

This Spring I'd like to recognize some busy bees! I'm reminded of how vital each one of our North East Ohio Board Members is to our Chapter. I would like to recognize the unique roles that the board members play. They serve as advisers, decision makers, problem solvers, and the advocates to HDSA and their families. It should be noted that they are volunteers who put in countless hours in meetings and in this community. Being a board member is a challenging role, an important role, to help lead our HDSA community. I am proud of the continued growth that our organization benefits from every day from the dedicated energies and time devoted by the 12 members of our board. Thank you for all that you do. *(continued on next page)*

HD-COPE session with Roche & Genentech

President's Message *(continued from previous page)*

And speaking of growth, we are continuously seeking new energetic individuals who are interested in joining us to serve as board member, volunteers, or charity event committee members. Please email me directly at Jesse.M.Lis@Huntington.com to inquire.

This year is already coming up roses, but what's next for HDSA NEO? Well, we have so much planned and I'm so excited to see each of you at all our events forthcoming, so be sure to mark your calendars! This May 11th is our annual Education Day where we will partner with the Cleveland Clinic COE to deliver some fantastic trial information, panel discussion with amazing Doctors, PGD in vitro fertilization program, NYA for the youth, and so much more! Then, lace up your sneakers for our annual Team Hope Walk on Sunday, June 2nd at the Cleveland Zoo! There will be a fantastic lunch, prizes, a great DJ, a 5K race, lions, tigers, bears, and much more! On Saturday, Sept 28th we are bringing back the Fore- A-Cure Golf Outing! Beer, Golf, Beer, Golf… who's got a foursome? Then we close out our year with our beautiful Celebration of Hope Gala in late November. And Ladies and Gentlemen, please don't miss this one! It will be on Friday, November 22nd 2019. Imagine a lovely Winter Wonderland, where you can bask in the success and gratitude of friends and family, cheers to finishing out 2019 with hope in our hearts. You are all cordially invited to "SPARKLE," A Celebration of Hope and A Festival of Trees.Respectfully and graciously,

Jesse Lis, *President, Northeast Ohio Chapter HDSA*

Social Worker's Q & A:

What is the difference between Medicare and Medicaid?

Medicare is a federal program, while Medicaid is a state program; both provided health insurance coverage for those who qualify. Medicare and Medicaid both have requirements that need to be met in order to qualify for coverage.Generally speaking Medicare is available for people that are 65 years old or older, younger people who have disabilities, or people that have permanent kidney failure. Medicare helps with medical costs but does not cover all medical costs. Those with HD unfortunately have to wait 2 years after approval for SSD benefits to receive Medicare benefits. The HD parity act aims to waive that Medicare 2 year wait period.Medicaid provides coverage to eligible low income adults, children, pregnant women, older adults, and people with disabilities. Each state manages Medicaid according to federal requirements. You must meet financial requirements in order to qualify. If you are unsure if you meet, you should still apply. In Ohio, you can apply for Medicaid online or in person at your local Department of Jobs and Family Services office.If you have questions about either program, please email me or call me.

Katie Dykman
Huntington's Disease Society of America
Northeast Ohio Chapter Social Worker
(440) 742-1284 or kdykman@hdsa.org.

HD BUZZ When interrupting is good

Genetic hiccups that protect against Huntington's disease. Multiple teams find small differences in the 'CAG repeat' bit of the Huntington's disease gene. They don't directly change the huntingtin protein, but do alter the age of symptom onset. What's behind this enigma and what does it mean for patients?

By Dr Jeff Carroll March 14, 2019 Edited by Dr Ed Wild

Multiple new studies have identified what may be the most important new fact about the genetics of Huntington's disease since the gene was discovered in 1993. At least two research groups around the world simultaneously report that a tiny genetic hiccup in the HD gene has a big impact on HD symptoms.

What's CAG and why do we care about it?

Huntington's disease is caused by a single mutation in a single gene. Because of its relationship to HD, we usually refer to it as the HD gene, though scientists formally refer to it as HTT. Everyone has two copies of the HD gene - one each inherited from mom and dad.

Three 'letters' in the DNA, like CAG or CAA, instruct the cell to add one amino acid building block, such as glutamine, to a protein it's making.

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Each gene is a recipe - a set of instructions on how to make a protein. Our genes are written in the language of DNA, which uses four chemical letters that scientists abbreviate A, T, G and C. If you zoomed way into a cell and looked at the DNA you wouldn't actually see these letters, but they help scientists understand and decode the language of genes.

Very near the beginning of the HD gene is a long, repetitive, stretch of the DNA letters C-A-G. Even in people without HD, this sequence repeats itself, on average around 17 times.

CAG size is important for HD onset

In every person destined to develop HD, this stretch of CAGs in DNA is longer than normal. The average HD patient has something like 44 repeats, and some have many more. In general, the more CAGs found in a person's HD gene, the sooner we would expect them to develop HD symptoms – though this varies a lot between individual patients.

Extremely long CAG repeats give a clear example of this effect. Very long repeats (over about 65) tend to cause very early onset of HD, or juvenile-onset Huntington's disease (JHD).

Very recently, two separate research groups published the same startling discovery about these CAG repeats. Before we describe their findings, we have to get just a little bit into the weeds.

CAGs and glutamines

The first thing to understand is that the protein-making instructions in DNA work in a very specific way. The DNA has a 4-letter alphabet: A, C, G and T. Proteins, on the other hand, are made from long strings of building blocks called amino acids. There are twenty different amino acids to choose from, like twenty differently-shaped beads that can be threaded onto a string one by one in any order.

To get from 4 letters in the genetic alphabet, to twenty amino acids to choose from in the protein-making world, our cells have a rule that DNA is interpreted in 3-letter chunks. For example, C on its own doesn't mean anything, and nor does CA. But CAG is an instruction to add the building block called glutamine to the protein that's being built.

Because of all this, there is a direct correspondence between how many CAG repeats someone has in their HD gene, and the number of glutamines in the resulting protein, called huntingtin. Someone who inherited a CAG repeat of 42 from their HD-affected parent should make HD proteins with 42 sequential glutamines. We think this is why bigger CAG repeats cause HD symptoms to emerge earlier: more CAGs in the gene means more glutamines in the protein. We don't know how exactly, but this seems clear.

OK, easy enough. DNA is interpreted three letters at a time to build proteins. Each CAG in the gene causes one glutamine to be added to the protein. And more glutamines is bad!

Genetic testing of CAG size

When HD family members undergo a genetic test to determine whether they are destined to develop HD or not, the lab measures what we call their CAG size. But through a quirk of the way the test is done, it can't actually pick up these little CAG interruptions.

That's because the test doesn't actually read the genetic information directly. Instead, the length of the stretch of DNA containing the CAG tract is measured precisely. That tells us the size of the CAG tract – but crucially, not whether it contains that CAA interruption just before the end.

Until now, we haven't really had any reason to be concerned about this, but the new findings suggest we should probably start paying attention to the actual sequence of this region.

New findings

Very recently, multiple groups around the world have observed a very surprising thing. First, the GEM-HD consortium is a team of researchers interested in understanding what genetic differences in HD patients contribute to symptom onset or progression.

The new publication from the GEM-HD crew describes an analysis of over 9,000 HD patients participating in the ENROLL-HD study. This analysis revealed that the normal CAA interruption near the end of the HD gene's CAG tract was occasionally missing. This occurred about once in every three hundred people.

People who were missing this interruption, and therefore had only "pure" CAG's in their HD gene, had significantly earlier onset of HD symptoms than we would predict.

The missing CAA interruption may influence the progression of HD by making it harder for cells to repair their DNA accurately, allowing the HD gene's CAG tract to grow even bigger in some cells.

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At the same time, the group detected another very rare variation that appeared to do the opposite, and actually delayed the onset of symptomst. This quirk was seen in about one in a hundred people. These folks actually had two CAA interruptions in their CAG tract, rather than the more common single CAA.

The effects of these two rare genetic variations tell a very compelling, if very surprising, story. Seeing both a bad and good version of the variation suggests this effect is real. It also means that a lot of the variation we see between HD patients could be influenced not by the length of the CAG length, but on how 'interrupted' it is.

What's spooky about this is that whether there's a CAA or a CAG in the HD gene, the cell will build the same protein by adding the same glutamine building block. But if the protein is the bad guy, as most researchers still believe, why does it matter whether that glutamine came from a CAA or a CAG in the gene?! We'll come back to that shortly.

Like every piece of science, this finding needs to be repeated and validated. But if it's found to be correct, it has very important impacts on how we think about HD.

Read more about this research at https://en.hdbuzz.net/271

THANK YOU!

HDSA Celebration of Hope

Cleveland. Cleveland.

Celebration of Hope

A HUGE thank you to all Celebration of Hope sponsors:

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This years 41st Anniversary Gala was a fabulous affair attended by more than 200 guests. Wewere able to raise **$183, 518!** Thank you so much to our major sponsors once again. Cleveland CLeveland was truly a success. Congratulations to Wes Johnston for Receiving the Eva Weissman Award.

Thank You to all who attended Cleveland Cleveland, and to all those who generously gave of their treasure, time and talents.

Huntington's Disease Society of America

TEAM HOPE

The 11th Annual

Team Hope Walk & 5K

Sunday • June 2, 2019

1 Mile Walk • 5k Run

Cleveland Metroparks Zoo

Please join us **June 2nd, 2019** as we run and walk with the animals. Runners/Walkers who come for the walk, may also stay in the zoo all day. Look for detailed information in mail and email soon.

If you would like to be on the planning comittee, have a team, want to sponsor, or donate to the HDSA Team Hope event, please contact our Walk Volunteer Coordinator **Randi Zubin** randi@zmykprint.com

We are looking for sponsors, teams, and support for this year's event. And of course, we want you, your family, and all of your friends, neighbors, coworkers, etc. to participate.

Register your team today! www.hdsa.org/thwcleveland

SAVE THE DATE!

Saturday September 28

FORE-A-CURE

H·D·S·A

In loving memory of Steven Minor.... he attended every outing.

Area Support Group Meetings 2019

Cleveland Area:

Meets on the second Monday of every month
6:30p.m. – 8:00p.m.

Jan 22
Feb 26
Mar 26
April 23
May 28
June 25
July 23
August 27
September 17
October 22
November 26
No December

Cleveland Clinic Independence Family Health Center
5001 Rockside Road • Independence, OH 44131

Akron Area:

Meets on the first Tuesday of every month
6:30p.m. – 8:00p.m.

No January
February 5
March 5
April 2
May 7
June 4
July 2
Aug. 6
Sept. 3
Oct. 1
Nov. 5
Dec. 3

Ellet Community Center
2449 Wedgewood Drive • Akron, OH 44319

Painesville Area:

Quarterly pending room availability
7:00p.m. – 8:30p.m.

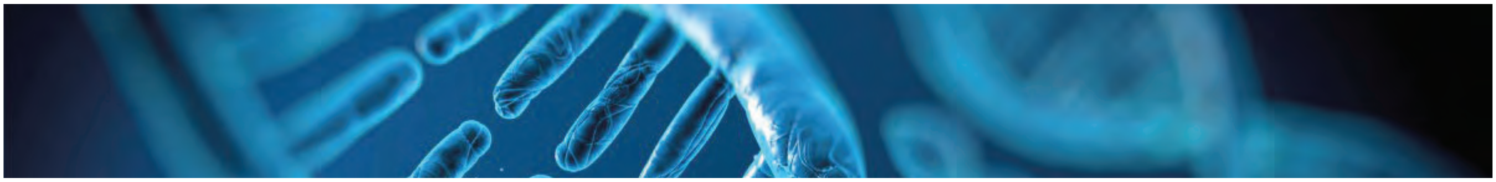
The Morely Library
184 Phelps Street • Painesville, OH 44077

Youngstown Area:

Meets quarterly pending room availability
6:30p.m. – 8:00p.m.

Hospice of the Valley - Hospice House
9803 Sharrott Road • Poland, OH 44514

We invite anyone touched by Huntington's Disease to attend our confidential support group meetings. Meetings provide a supportive environment where participants can share challenges and successes. For more information please contact Katie Dykman, Chapter Social Worker, at kdykman@hdsa.org or (440) 742-1284. ***Please consider joining us!***



HD Research Webinars Series

In an effort to increase research communication between HD families/patients and the HD Scientists around the world, HDSA offers the HD Research Webinar Series, a series of monthly webinars on current research topics presented by HD experts from around the globe. The webinars commence at 12:00 PM EST and run for approximately 30-40 minutes, with 20-30 minutes for a Q&A ession through a chat feature. Each session will end by 1:00 PM EST. We chose this time to allow you to participate in this over your lunch hour, making this a virtual luncheon seminar.

If your have questions or suggestions for future seminar topics, please send them to researchupdates@hdsa.org

Save the Dates 2019

Saturday, May 11th 2019
HDSA NEO Education Day

Sunday, June 2nd, 2019
Team Hope Walk

Saturday, Sept 28th, 2019
Fore- A-Cure Golf Outing

Friday, November 22nd, 2019
Celebration of Hope Gala

June 27-29, 2019 • 34th Annual HDSA National Convention

FACILITIES FOR HUNTINGTON'S DISEASE TESTING AND GENETIC COUNSELING:

Cleveland Clinic
Genomic Medicine Institute
Desk NE-50
9500 Euclid Avenue
Cleveland, OH 44195
Amy Shealy, MS, LGC
(216) 445-1251

Center for Human Genetics
University Hospitals of Cleveland
11100 Euclid Avenue
Cleveland, OH 44106
Suzanne DeBrosse, MD
Joanna Horn, MS, LGC
(216) 844-7215

Division of Medical Genetics
Akron Children's Hospital
One Perkins Square
Akron, OH 44308
Catherine Ward-Melver, MD
Susan Woods, MS, LGC
(330) 543-8792

Genetics Center
MetroHealth Medical Center
2500 MetroHealth Drive
Cleveland, OH 44109
(216) 778-4323

HD Care:

HDSA Center of Excellence at Cleveland Clinic

Center for Neurological Restoration, U3
1950 East 89th Street
Cleveland, OH 44195
For an appointment or for more information, please call (216) 444-3596

University Hospitals Neurological Institute
Huntington's Disease Clinic

UH University Suburban Health Center
1611 South Green Road, Suite 204
South Euclid, OH 44121
For an appointment or for more information, please call (216) 844-2724

MetroHealth Medical Center

Interdisciplinary team approach for individuals with Huntington's disease

2500 MetroHealth Drive
Cleveland, OH 44109
For an appointment or for more information, please call (216) 778-4323

WANT TO KNOW MORE ABOUT HUNTINGTON'S DISEASE?

The national website at www.hdsa.org is the best resource for the most recent information on HD. From this site, you can link to other sites such as HDYO which is a new organization that provides information and education along with support for young people affected by HD. Another great site is HD BUZZ, which includes Huntington's disease research news in plain language, written by scientists for the global HD community.

Publications are also available for free, or for a nominal fee. They can be downloaded from www.hdsa.org/publications or obtained by contacting *Anita Mark Paul*, HDSA Information and Fulfillment Coordinator, at (800) 345-4372, ext 219, or by email at amarkpaul@hdsa.org.

DOUBLE YOUR DONATION THROUGH THE MATCHING GIFTS PROGRAM

Stretch your donation when your company doubles your contribution! Support HDSA when you and your company participate in the HDSA Matching Gifts Program. Many employers have these programs in which the company matches the tax-deductible contribution you make to HDSA. Your gift doubles (or more) when your company belongs to HDSA's Matching Gift Program.

To make your gift to HDSA grow, simply obtain a matching gift form from your Human Resources Department, enclose it with your gift and mail to the Chapter Office. Anyone can make an online donation at **www.hdsa.org/neohdon.**

DONATIONS TO HDSA NOW MADE EASIER THROUGH PAYROLL DEDUCTIONS

such as contributions through Community Health Charities.

Contact Mike Ryan at mryan@healthcharities.org or at (614) 891-2566 for more information.

HDSA on FACEBOOK!

Huntington's Disease Society of America (HDSA) Great Lakes Region

Huntington's Disease
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Northeast Ohio CHAPTER

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