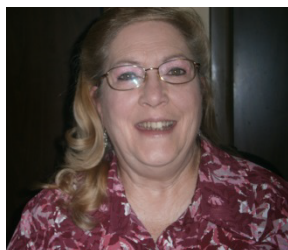


President's Message



I have been thinking and reflecting about a word most of us use often, with varied meanings, depending on the context of the conversation we are having or the situation we find ourselves in. That word is...HOPE. I am going to share about HOPE and how using your hope, dreams, drive, courage and determination can help to give us all a more positive outlook and hope for the future.

If you were to ask a friend, relatives, or even a passer-by on the street what HOPE means to them, you most likely are going to get a variety of answers. Why? Because we are each unique individuals. Our life experiences, our tests and trials are going to put our own unique perspective on what HOPE means to us.

I decided to check out Webster's Dictionary and refresh myself with their definition.

1. To entertain or indulge hope; to cherish a desire of good, or of something welcome, with expectation of obtaining it or belief that it is obtainable; to expect; - usually followed by for.
2. To place confidence; to trust with confident expectation of good; - usually followed by in.

In 1999 at the HDSA National Convention a group of 8 teenagers expressed their need to have a program geared to their needs to address life situations that they were having to deal with daily as members of an HD family. Several of these young people had already been diagnosed with HD or Juvenile Huntington's Disease, others were at risk, others knew something was wrong with mom or dad and were feeling very angry about not being told what was happening in their family.

The following year, there was still no programming for these young people. The convention was for adults; children who came with their parents should be seen and not heard. It was the parents that needed the programming so that they could continue with hope in their daily struggle with HD.

These young people were hurt and disappointed, but they did not give up their hope, their belief that there were many young people who wanted and needed something, anything, as a means to help them move forward positively while still dealing with what HD was doing to their families. As young people will do, they decided they would take things into their own hands. They began talking to every young person they met at the convention, and telling them there would be a meeting for young people to get together and share. When that group met in 2000 that small group of 8 had tripled.

These young people were determined to be heard, full of hope that the adults would see that this was needed, that THEY would be the hope and driving force of HDSA in the future. As a group they decided that if they wanted to be taken seriously, they would need to be organized. First they needed something to get the attention of the adults and those who did the programming for the convention. And their mission was born..."TO BE THE LAST GENERATION OF HD". They also decided that if they were going to be able to make this happen they needed a name and THE NATIONAL YOUTH ALLIANCE (NYA) was born. They also decided that to make their hope and dream of a National Youth Alliance a reality that would be recognized by the leaders of the National Huntington's Disease Society, they needed to have a voice, someone that would be listened to...they needed to have an adult who would speak for them, stand up for them, fight for them. They asked Jean Miller and me to be their "adult advisors".

It was a tough sale convincing parents that their children needed this, convincing National leaders that we were missing the boat if we did not provide the programming needed to equip these young people to face life and the world with hope and courage in the face of living and fighting the battle of HD.



In 2001 at the National Convention in San Diego we had the first organized and planned programming tracts that were specifically for young people living with HD. We had over 50 young people registered that year. The following year that number doubled again.

Each year I have watched as this determined group of young people has forged ahead. They have grown to the point that when the National Convention is being planned there is now a day specifically for our young people. A whole day is planned and directed to meeting their needs, to equip them to live with hope, and to remain positive even in the face of such a debilitating disease.

I have watched as this group has grown to a membership of over 300. I have watched them grow, mature and become leaders. And yes, I have watched and cried as too many of these beautiful young people have lost their battle with HD. It is my hope that every chapter and every affiliate of the Huntington's Disease Society of America will recognize this vast and largely untapped group. That they will reach out, determined that they will provide what is needed by the young people in their respective areas. There are many chapters and affiliates that do have planned programming for young people. It is my hope and desire that our chapter will soon be among those paving the way for our young people...Our future...our HOPE.

Most sincerely,

Family is everything

Susie

Susie Hodgson
HDSA Illinois Chapter President
(hdsailchapter@gmail.com)

National Youth Alliance 2016 Youth Retreats - Free!

An NYA Youth Retreat is a day of fun, learning and community building for young people ages 12-22 that are affected by Huntington's disease. We'll have professionally-led talks about issues that are important to young people affected by HD, as well as camp activities and a group art project to end the day!

Thanks to generous support from Teva Pharmaceuticals, all NYA Youth Retreats are free to attend, and HDSA is able to offer young people attending a retreat free hotel accommodations if needed!

Want to learn more about HDSA's National Youth Alliance and get involved?

For more information & to register visit: nya.hdsa.org or email Jennifer Simpson at jsimpson@HDSA.org.

July 30: Pittsburgh, PA
August 12: Iowa City, IA
October 15: Denver, CO

National Youth Alliance

The NYA is a collection of youth who are affected by Huntington's disease ranging from ages 9-29. We work closely with our local chapters and affiliates to fundraise, advocate and spread awareness. It is our mission to be the last generation with HD. All money that is raised for the NYA goes to our convention scholarship fund to be able to help get members to National Convention and NYA day. NYA day is the day before convention where members will get to participate in team building, learn about advocating, and get the opportunity to spend time with other kids affected by HD. We also spend the rest of convention going to session directed towards youth interests and continuing to do other fun activities such as our talent show.

The NYA is an amazing opportunity and is very important to its members.

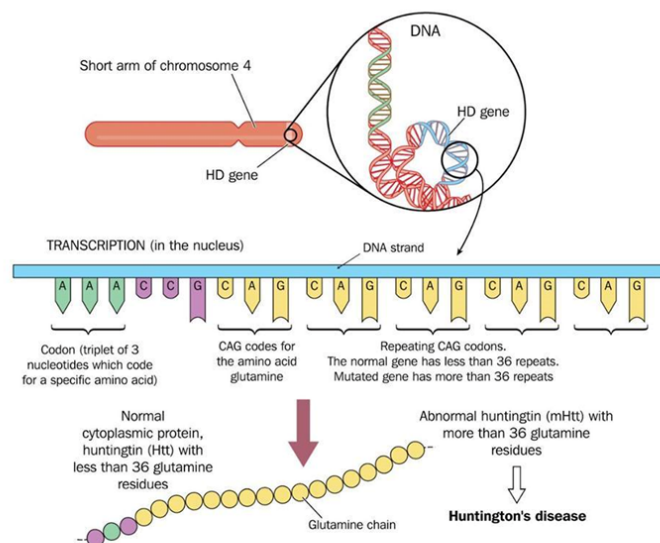
When youth get involved with the NYA it teaches them more about fundraising and advocacy within their chapters and affiliates, which help them gain leadership experience with HDSA. It is also very important to its members because youth may feel more comfortable when talking to other young people about HD then they do at home, and the NYA provides them with never ending support from people who can relate to them. The bonds young people make within the NYA are ever lasting friendships.

For more information, please contact Miranda Spencer at michiganNYA@yahoo.com.



#LetsTalkAboutHD

The Gene That Causes Huntington's Disease



**Huntington's Disease
Society of America**

Volunteer. Educate. Advocate. Donate.

HDSA.org

(800) 345-HDSA

#LetsTalkAboutHD Turns Up The Volume On Huntington's Disease Awareness

This past May during HD Awareness Month, HDSA coordinated the world's largest HD awareness campaign ever recorded called **#LetsTalkAboutHD**. The powerful campaign brought together HD families and celebrities who shined a bright light on the effects of Huntington's disease.

Thank you to all who participated and let's keep talking!
Navigate to the link below to view the #LetsTalkAbout HD Compilation Video:

<https://www.youtube.com/watch?v=QPkw1R5penU>





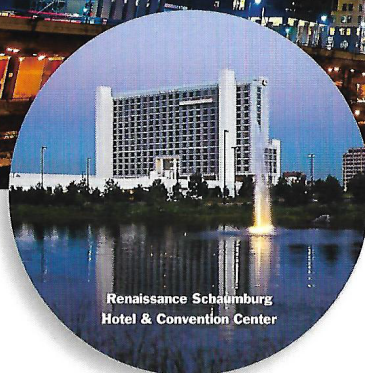
July 23, 2016 - We are the charity partner for the **Amita Fitness for America Sunset half marathon, 10k & 5k** (and night time glo run!) in Hoffman Estates, IL. We have a coupon code available for runners of any distance, and a donor drive page set up at the link below. We are also looking for 40 volunteers for this event (i.e., handing out water and finishers medals, etc.)

<http://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=971>

October 9, 2016 - We are currently out of guaranteed spots for the **Chicago Marathon**, but runners are encouraged to sign up with the general public via the registration lottery, and fundraise with us if accepted. We have a donor drive page set up at the following link: <http://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=912>

Anyone with questions can reach out to Sara & Rachel at TeamRunforHD@gmail.com for more information!

Annual Convention Coming to CHICAGO in 2017!



Save the Date!

Join us for the 32ND Annual HDSA Convention right outside of Chicago at the elegant Renaissance Schaumburg Hotel & Convention Center.

June 22-24, 2017 / Schaumburg, IL

Stay tuned for more details at HDSA.org

 Huntington's Disease Society of America



Record Set at 12th Annual Team Hope Walk



Once again, great weather blessed the Illinois Chapter's 12th Annual Team Hope Walk. And once again we set a record for participants and donations. Over 700 walkers met at the Grand Pavilion on Naperville's beautiful Riverwalk to advocate for those that suffer with Huntington's disease. Check-in began early with walkers showing up to claim a picnic table or



shaded area for their family. Some teams brought their own pop-up shelters. This year, US Representative Bill Foster (D-11th) from Illinois, a co-sponsor of the HD Parity Act, joined us at the start/finish line to speak about the importance of research to find a treatment for HD. The Walk committee this year honored Dr. Kathleen Shannon for her years of dedicated work and care at our Center of Excellence at Rush University Medical Center. After the plaque presentation, Dr. Jennifer Goldman, Dr. Shannon's successor, was introduced. After the Walk, participants were treated to a hotdog lunch and music from EliteDJ's. The Chapter Walk committee would like to thank all the volunteers who helped to make this year's Walk a huge success. Additionally, thank you to all of our sponsors

and their generous donations. You can view the sponsors here: <http://illinois.hdsa.org/sponsors>. This year, it appears that the Walk donations will gross over \$90,000, an all-time high! Visit HDSA-Illinois Chapter on Facebook to see some of the pictures from this year's Walk. If you missed the fun and excitement of this year's Walk, mark your calendar now for the 13th Annual Team Hope Walk on Sunday, May 21, 2017. We hope to see everyone next year!



For more info about Huntington's Disease:
<http://illinois.hdsa.org>

Family is EVERYTHING!

Team Hope Walk: <http://hdsa.org/thwnaperville>
Like us on Facebook
<https://www.facebook.com/HDSAllinoisChapter>





NEW SUPPORT GROUP AT NORTHWESTERN MEMORIAL HOSPITAL, CHICAGO, ILLINOIS

Huntington's Disease Support group for At Risk (non-symptomatic) patients and family members.

Parking Passes Available

Contact person:

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

7/13/2016, 7:00pm to 8:30pm

Northwestern Memorial Hospital, Chicago, IL
Prentice Women's Hospital, 250 East Superior Street
Conference room J

9/10/2016, 1:00pm to 2:30pm

Northwestern Memorial Hospital, Chicago, IL
Feinberg Building, 420 E Superior Street,
NM Academy #2-715

11/7/2016, 7:00pm to 8:30pm

Northwestern Memorial Hospital, Chicago, IL
Prentice Women's Hospital, 250 East Superior Street
Conference Room N

1/7/2017, 10:00am to 11:30am, Room TBA

3/21/2017, 7:00pm to 8:30pm, Room TBA

5/6/2017, 10:00am to 11:30am, Room TBA

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Hopes & Dreams

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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.

We  Volunteers



Mary Classen Born, the ex-wife of long-time board member Daniel Born, passed away on May 27th.

Mary Classen Born, MSW, ACSW

2/17/1956 – 5/27/2016

Mother, wife, friend, therapist, and fighter in the cause to end Huntington's disease.

We love you and miss you.

Donations remembering Mary can be made to HDSA Illinois Chapter.

Mary Classen Born, a social worker and family therapist, died in Niles, Illinois at Generations at Regency nursing center on May 27, 2016. She was sixty years old. After her diagnosis with Huntington's disease in 1996 at the age of forty, and retirement in 2000, she valiantly continued to live an active life that included travel, food, art, and the exploration of her own spiritual journey. Since 2009 she lived at Regency under full-time nursing supervision.

She is predeceased by her parents, George and Lydia (Wiens) Classen; her stepmother, Theresa Classen; her father's twelve siblings; two cousins, Jan and Cindy Wiens; Uncle Pete and Aunt Lenora Wiens; Aunt Martha Groening; Aunt Hilda Friesen; Aunt Marge Wiens. She is survived and mourned by her daughter Elizabeth Born, ex-husband Daniel Born (both of Chicago), siblings Vern Classen (Littleton, Colorado), Naomi Classen Krause (Martinez, California), and Phil Classen (Valley Center, Kansas). She is also survived by her Uncle Waldo and Aunt Alvina Wiens (Hutchinson, Kansas), Uncle Rolly Wiens (Meade, Kansas), Uncle Mick Friesen (Meade, Kansas), her cousin Gwen Wiens Blum (Lawrence, Kansas), as well as more cousins, nephews, nieces, and many friends.

Mary Ellen Classen was born in Huron, South Dakota on February 17, 1956. Raised in the Mennonite tradition, she claimed conversion in her early years at the Ebenfeld Mennonite Brethren Church in Kansas, where she was also baptized. She was an active member of the Manhattan Mennonite Fellowship in New York City, serving as part of its leadership team in the mid-1980s, and later joined Judson Memorial Church in Greenwich Village, New York. She was an active member of the Unitarian Universalist Society of Marietta from 1993 until 2001.

She attended Tabor College in Hillsboro, Kansas, where she met Daniel Born, whom she married in 1977. In 1978 she graduated with her bachelor's degree in social work. That year she also received the Social Sciences Divisional Award at Tabor and was listed in Who's Who in American Colleges and Universities. In 1980 she received her master's in social work from the University of Kansas, with a clinical concentration in community mental health, before taking her first job with Illinois Masonic Hospital in Chicago as part of the hospital's stroke rehabilitation unit.

She would do further postgraduate study at Grant Hospital in Chicago, Rutgers University in New Jersey, and the New School for Social Research in New York City. In New Jersey, she worked as a family therapist at the Dumont Community Center for Mental Health; as director of residential services for the Pequannock Valley Mental Health Center; and as a private practice family therapist in Wayne and West Caldwell. Later, in Marietta, Ohio, she would also have a private practice.

During her career she worked with individuals suffering from addictions and mental illness; served as a clinical and administrative supervisor for chronically hospitalized adults; and consulted with community boarding homes for the mentally disabled. Her last full-time position was as a family therapist with St. Joseph's Hospital, Center for Behavioral Medicine, in Parkersburg, West Virginia.

She was active in the fight against Huntington's disease before her own symptoms appeared. From 1987 to 1991 she was a member of the board of the New Jersey chapter of the Huntington's Disease Society of America, serving with Thomas Kean, the governor of New Jersey, and Dr. Samuel Bailly, the first president of the national HDSA organization. She was active in HDSA support group activities after her diagnosis, and also spoke at the Illinois state conference about her struggle with the illness. She did not lose hope. She had great confidence in the scientific research to find a cure, and enjoyed an especially close relationship with her neurologist, Dr. Kathleen Shannon, at Rush University Medical Center in Chicago.

Mary had a radiant smile and knew how to switch on the charm. She liked to work out, and while she was raised in a tradition that emphasized the inner light and spiritual formation, she appreciated making a fine appearance. Her friends recall her verbal facility, wit, and laughter. She was as comfortable talking about her evolving theology as she was sharing her quest for the perfect bread pudding in New Jersey diners. She loved nice restaurants in big cities. She liked the movies, and could bake an excellent apple pie. She was fond of New York, Paris, and Chicago. She thrilled to see her daughter graduate from the Art Institute of Chicago, and despite her failing health and compromised ability to walk, attended Liz's senior show.

She was not a complainer, but neither was she a one-dimensional positive thinker. She knew how to express her grief and rage against the disease that was stealing her life, while always seeking the higher ground. Ten days before she died, on oxygen and morphine, she uttered the final words that Dan would hear her speak: "I'm doing pretty well."

An open house memorial will be hosted at Hoofprint Workshop gallery (2433 S. Oakley Avenue, Chicago, Illinois 60608) on Friday, August 19, 2016, from 10 am until 5 pm. There will also be an online memorial at <https://www.flickr.com/photos/rememberingmary/>

Those who knew Mary and have photos or written memories for this site can send them to lizborn@gmail.com or mail them to Liz Born, 2433 S. Oakley Avenue, Chicago, Illinois 60608.

Memorial gifts in honor of Mary can be made to the Huntington's Disease Society of America (make checks payable to HDSA Illinois Chapter) and mail to HDSA Illinois Chapter, P.O. Box 1883, Arlington Heights, IL 60006.

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

Coordinating care for a loved one can be very time consuming and exhausting. Luckily, there are care managers within the community who provide assistance for you and your family/friend. This extra support can help you make decisions, find resources and help manage stress. A care manager can be a social worker, nurse, gerontologist, counselor or a different profession all together.

Care managers meet with families and help identify what services will benefit your family member/friend. She/he will assess each individual situation and identify a care plan that will meet your full healthcare, physical, social and emotional needs. There are many different care managers and it is important to find a person who has experience dealing with your specific needs. When looking for a care manager, it is important to interview several different people/agencies.

Connecting to a care manager will help you to identify your many needs and come up with a plan of action. Your initial meeting will be an in-person or phone assessment. After identifying the client's needs, a care plan will be created which includes recommendations and referrals to local and community services. Some additional services provided by a care manager include crisis intervention, support and counseling, education, advocacy, financial assistance, referrals for community services, advice on guardianship and power of attorney issues and/or act as a liaison for families who live far away.

Care Management services are billed privately or on a fee-for service bases. It is important to speak to the agencies directly to see if they will provide services on a sliding scale fee. These services are not billable by Medicare and Medicaid.

Some local care manager organizations in Illinois include:

Senior Bridge: <http://seniorbridge.com>, 1-855-627-3684
Liv Home: <http://www.livhome-chicago.com>, 847-805-8067
Charism Elder Living Services: <http://charism.net/>, 630-515-9223
Creative Care Management: <http://creativecaremanagement.com>, 847-869-5118

Memorials and Tributes

In Memory of Florence Alexander from Barry & Marilyn Kahn

In Memory of Ralph Short from Lois Short

In Memory of Henry Leck from Mrs. Rose M. Bleigh

In Memory of Pat Ross from Keith & Carrie McDonald

In Memory of Erwin Plavec from Josephine Jansky, Anthony & Carmella Jandacek, Paula Matzek, Marian Saydel

In Memory of Mary Classen Born from Bert & Dawn Haverkate-Ens, Todd & Sandra Vetrovsky, Wilbur & Vernelle Unrau, Michael & Rosanne Buell, Stephen & Janet Kozak, Evelyn King, Bruce & Michelene Fast, Bill & Shawna Born, Eric Ederer, Karen Fleming, Charles & Meegan Zickus, John & Ann Adamson, Bethene Trexel & Jonathan Tenney, Daniel Born, Charlotte & Steve Rybarczyk, Sara Shute & David Boyer, Brian & Cathleen Hall

In Memory of/In Honor of Ray & Karen Carter, Alice & Denise Stewart from Catherine Carter

In Memory of Mark Layer from the Earth Club at Lake Park High School

In Honor of Lucinda Pasley from Gary & Vallie Gould

In Honor of Jennifer, Michael & Richie Bilven from Zachary Bilven

In Honor of Teresa Srajer from Catherine Evers

A Tribute to Alan Plavec from Anthony & Carmella Jandacek





Planting trees together: The 2016 Huntington's Disease Society of America Convention

By Dr Jeff Carroll

Nearly a thousand HD family members converged on Baltimore, Maryland for the 2016 Huntington's Disease Society of America's Annual Convention. We normally don't write reports from patient and family conferences, but there was something special about the atmosphere of this year's Convention that compelled us to pen a brief update.

The Convention

This was the second-biggest convention in the HDSA's history, and HDBuzz co-founders Jeff and Ed were there to talk science. You can see a video of our presentation on YouTube and hear the audio in the latest edition of our podcast, *HDBuzzCast*. Many of the other talks are featured on the HDSA website.

Clinical trials

According to the Huntington Study Group's HD Insights Publication, there are currently thirteen clinical trials recruiting or in progress in Huntington's disease, some of which are testing treatments specifically designed with HD in mind, rather than drugs thought to be generally good for brains. This is an incredible time for HD families.

Two trials we've been watching closely had important updates. The Teva PRIDE-HD study of pridopidine, a new drug to treat movement problems in HD, is fully recruited. The same is true of Pfizer's Amaryllis study of their PDE-10 inhibitor drug that aims to improve communication between neurons. Delivering efficient trial recruitment is great news and a testament to the ability of the HD community to rise to the challenge.

There is no room for complacency though. We need to recruit all active trials as quickly as possible. Teva's Legato-HD study of laquinimod, for example, is testing a drug that it's hoped will slow the progression of Huntington's disease but still needs more volunteers. The same is true of several other trials.

Good news from the 'gene silencing' trial

Ed Wild gave an update on the trial of Ionis-HTRx, the first 'gene silencing' or 'huntingtin-lowering' drug that's ever been tested in human HD patients. Speaking on behalf of the sponsor, Ionis Pharmaceuticals, Ed reported that the trial began in September 2015 and that 5 clinical sites are now up and running. In an exclusive HDSA update, he announced that there have been no safety issues with the drug so far, and the trial's independent safety committee had just approved the start of the third of four dosing levels. This is the best news we could have expected at this stage in the trial, and we eagerly await further updates.

Where do I sign up?

How can HD-impacted people get into a clinical trial? In the US and Canada, the answer is HDSA's TrialFinder system. You enter a few basic details and within a minute you will see a customized list of what studies you may be eligible for in your area, with links to the research teams.

What if I'm not eligible?

Clinical trials can be hard to get into because each one has strict criteria for who's eligible and who's not. If you find there's no drug trial near you that you're able to take part in, don't lose heart. Here's our 3-step plan for finding the silver lining.

- Sign up for Enroll-HD, a platform for understanding HD and a database for recruitment into future clinical trials. Virtually all HD family members are eligible, even people who haven't had a genetic test.
- Be a trial wingman: spread the word about trials and research on Social Media and in person to your friends and family. Can you volunteer to help someone else be in a trial, by accompanying them to appointments or helping them complete trial activities?
- Take part in observational studies – that's HD research that doesn't involve testing new treatments. These studies are essential because they help bring about the next generation of treatments and trials.

Innovation

Although the HDSA convention isn't a science meeting, we were surprised by the amount and quality of innovative new projects we heard about there. Our personal highlights were:

- CHDI Foundation linking up with IBM's Watson supercomputer platform to understand HD, like modeling the huntingtin protein and how it's affected by the HD mutation
- Hearing directly from Teva Pharmaceuticals' Dr David Stamler that they remain committed to getting SD809 licensed for HD. SD809 is a slow-acting form of tetrabenazine for HD movements that the FDA recently requested more information about. Stamler was unequivocal: "The FDA did not reject the application ... they asked for additional information and analyses ... There were no safety concerns that were raised by the Agency ... Teva is doing everything in its power to bring this medicine to the market as quickly as possible."

- Azevan Pharmaceuticals' STAIR trial, investigating whether their drug SRX246 can help with the common and very challenging symptom of irritability in HD.
- Wave Life Sciences, engaging early with the HD community to talk about their programs to develop new 'gene silencing' drugs to lower production of the mutant huntingtin protein. Wave's approach aims to take advantage of a quirk in chemistry. Most drugs are actually a mixture of 'regular' and 'mirror-image' versions of the same drug that have the same basic structure but can behave slightly differently. Wave hopes that by eliminating the mirror-image versions, their silencing drugs will be more powerful. If this works it'll be pretty cool.

Planting trees

In our regular research roundup, we compared Huntington's disease research to a tree, rather than the 'pipeline' you may have heard about before.

The roots of the tree are the global HD community; the trunk is the 'basic' laboratory research that happens every day and helps to keep new drugs coming; the branches are the observational research involving human volunteers that helps us understand HD and develop new drugs; and the leaves are the clinical treatment trials that let us test those drugs.

We like this image because all parts of the tree are interconnected and depend on each other to produce the fruit we all need: effective treatments for Huntington's disease. Everyone in the HD community has a responsibility to look after each bit of the tree if we want those treatments as soon as possible.

Our presentation ended with a Chinese proverb:

The best time to plant a tree is twenty years ago. The second best time is today.



If you weren't able to attend the 2016 HDSA National Convention in Baltimore, MD, you can watch some of the presentations from the convention by navigating to this URL:

<http://hdsa.org/about-hdsa/annual-convention/2016-convention/>



At the National Convention, the Illinois Chapter won the Award for Outstanding Fundraising Event - 2015 for our Team Walk.

HOT RODS FOR HUNTINGTON'S DISEASE CAR SHOW – SATURDAY, SEPTEMBER 17TH Volo Auto Museum, 27582 Volo Village Road, Volo, IL

It's that time of year again. We're beginning to plan your favorite annual charity car show, **Hot Rods for Huntington's Disease**. We have big plans for the 2016 event and wish to invite you to play a part. 'Hot Rods for Huntington's 2016 has partnered with the world famous Volo Auto Museum to bring you, yet again, an amazing car show for a worthy cause.

Live bands, silent auction, hot looking cars and award ceremony. Registration for those showing their car is \$20 if done before July 29, 2016 and includes free event shirt and two tickets to the Volo Auto Museum.

After July 29th you can contact **hotrods4hd@gmail.com** where registration will be \$20 without an event shirt, but will still include two tickets for the museum. You can also pay at the car show gate the day of the event which includes two tickets into the Volo Auto Museum. Reminder...Registration is for only those that will be showing their car in the car show. All other spectators must pay general admission at the museum entrance.

Sponsorships and Donation items for Silent Auction welcomed. For more information, please contact Danielle Karlson-Perrott at **hotrods4hd@gmail.com**.

Donor drive link is: **<http://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=1003>**

Electron beam snaps best images yet of Huntington's disease protein

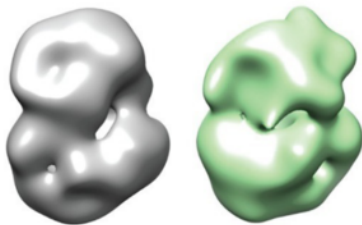
Electrons enable huntingtin protein, the cause of Huntington's disease, to be visualized at highest resolution ever

By [Tom Peskett](#) on June 21, 2016; Edited by [Dr. Ed Wild](#) - Originally published on June 20, 2016

Figuring out the shape of a protein can help scientists understand how it works and what goes wrong in disease. Huntingtin, the protein that causes Huntington's disease, has been an elusive target. A recent study using electron microscopes offers a striking glimpse of huntingtin, paving the way for future work.

Seeing is believing

Proteins are the machines that perform all the important day-to-day jobs that our cells need to carry out. The precise 3D shape or **structure** of a protein gives it the ability to perform its specialized job.



These images from the research paper show the 'normal' huntingtin protein (left) and the subtle differences in structure of the mutant huntingtin protein (right).

Huntingtin, the protein that causes Huntington's disease, has a 'tail' made up of a chemical called glutamine, one of the protein building blocks. When the tail is excessively long, due to a mutation in the DNA blueprint for huntingtin, it causes HD. We don't yet understand exactly how the extra glutamines change huntingtin from a normally functioning protein to one that causes harm. So far, scientists have tried to work this out by studying mainly what huntingtin does, but perhaps if we could **see** huntingtin, this would give us some important clues.

Why do we want to know what huntingtin looks like?

There are two main reasons for trying to figure out what huntingtin looks like.

First, if we knew huntingtin's structure, it is likely this would give us hints about how normal huntingtin works and how this goes wrong in HD. This information could be used to direct future research and speed up the discovery process.

Second, if we had very detailed information about the structure of huntingtin, it might be possible to design drugs that would target the toxic 'mutant' huntingtin.

Why's it so hard?

Proteins are too small to see using straightforward methods. If you could expand a single molecule of huntingtin protein until it was easily visible, say to the size of a watermelon, which would be like expanding a watermelon until it was as wide as the USA. Even the best light microscopes available are nowhere near powerful enough to see a single huntingtin molecule.

"It seems that huntingtin is flexible - it likes to jiggle around and adopt different shapes."

That's where electrons come in. Electrons are almost inconceivably small particles that are found orbiting the edges of atoms - and they can be used in microscopes. While light passes around a single protein, barely noticing it, electrons feel a strong push from the protein, which can ultimately be detected and used to make an image. So an electron microscope was the instrument of choice for an international team of researchers led by Ihn Sik Seong of Harvard Medical School, who wanted to look at huntingtin's structure.

First, they genetically engineered insect cells to produce human huntingtin. They were then able to extract the huntingtin protein, removing all of the other proteins that it was mixed with in the insect cells. The huntingtin protein was then placed on a small metal grid and put in an electron microscope. They then took pictures of the grid using the electron microscope, which gave them grainy images containing small white objects: their first view of the individual huntingtin molecules.

Huntingtin likes yoga?

So far so good, but the researchers were faced with another problem. If you were to take the pictures of the individual huntingtin molecules and line them up side-by-side, they would all look slightly different. To put it another way, it seems that huntingtin is flexible - it likes to jiggle around and adopt different shapes.

To improve their view of huntingtin, they turned to a technique used by most electron microscopists, called 'averaging'. They used a computer to combine about 10,000 images of individual huntingtin molecules to bring out the features most common to all. This gave them a much better idea of what an 'average' huntingtin looks like. This would be similar to overlaying lots of pictures of peoples' faces – you would lose the detail of their individual expressions but would keep the really important features such as the fact that each person has two eyes, two ears and a mouth.

Their final 3D structure shows that huntingtin is probably made up of two 'arms', which are linked together by a 'hinge' that allows the arms to bend towards and touch one another, producing something that overall resembles a sphere. When the researchers compared the structures of normal and mutant huntingtin, they saw a small difference in shape, suggesting that the HD mutation affects huntingtin's structure in a subtle way.

In a different experiment, the researchers used a chemical to randomly link closely spaced regions of huntingtin to itself. Looking for the chemical links, they could tell which regions of the protein were likely to sit next to one another. They found that when they increased the number of glutamines in huntingtin's tail, the bending of huntingtin's two arms changed. The arm with the glutamines curled up less and the other arm curled up more. Exactly what this means is not yet clear, but it does suggest that a small change in one part of the protein can have consequences for the protein as a whole — a potentially important finding and one that may help explain how glutamine-lengthened huntingtin is altered in HD. Huntingtin apparently has a hinge that allows it to curl up on itself.

Limitations and next steps

Huntingtin turns out to be very difficult to work with so the researchers had to use a chemical to stabilize it, and another chemical to make it more visible in the microscope. These chemicals could have altered huntingtin's structure slightly and affected their interpretation of it. One way of overcoming this is to embed proteins in ice, eliminating the need for those other chemicals, and future experiments will likely address these issues.

It's also worth remembering that the huntingtin in this experiment was purified and put in a test tube, so the range of shapes huntingtin can make is probably even greater in the human brain where it interacts with other proteins.

What's the next step?

This study provides an exciting glimpse of huntingtin, but there is still a lot of work to do. The structure obtained by Seong and colleagues is certainly not detailed enough to be useful for designing drugs against HD. However, modern electron microscopes are getting better at capturing the structure of proteins, and future studies will aim to do just that with huntingtin. A detailed knowledge of huntingtin's structure could be crucial in understanding what goes wrong in HD. Now researchers are beginning to pull back the curtain on huntingtin.



Turn Chicago BLUE

During the month of May, the Illinois Chapter once again asked people to Turn Chicago BLUE for HD Awareness Month. This year we were able to convince 2 buildings to spotlight their building in blue lights, while the Blue Cross-Blue Shield Building spelled out the words, CURE HD. Thank you!!

SUPPORT groups

Date/Time	Additional Information	Contact Information
CENTRAL ILLINOIS		
2nd Sunday of even months TIME: 2:00 to 4:00pm <u>LOCATION:</u> St. Joseph Medical Center, Bus. Conf. Center – Room 2, 2200 E. Washington Street, Bloomington, IL	2016 Meetings: 02/14, 04/10, 06/12, 08/14, 10/09	Dave or Susie Hodgson (630) 386-3928 spiketdog@softhome.net
GENEVA		
Specific Sundays of odd numbered months (see dates in next column) TIME: 2:00 to 3:30pm <u>LOCATION:</u> Cadence Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot) * Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome.	Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left. 2016 Meetings: 01/24, 03/20, 05/15, 07/17, 09/18, 11/20	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
LAKE COUNTY		
2 nd Monday of every month TIME: 7:00pm <u>LOCATION:</u> Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville	Call for additional information and directions.	Marilyn and Barry Kahn (847) 975-2403 marilynkahn1@gmail.com
ROCKFORD		
TIME: 2:00pm <u>LOCATION:</u> OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room, Rockford, IL * Use the main entrance - second one back from the parking lot entrance. As you enter the building you'll see a counter staffed by volunteers. Turn right, before you reach the counter. The St. Anthony Room is straight ahead.	Open to people with HD, family members, caregivers, and interested professionals. 2016 Meetings: TBD (Planned for Quarterly)	Cheryl Sutton (815) 262-4889
SOUTH SUBURBAN		
2 nd Tuesday of odd months TIME: 7:00pm <u>LOCATION:</u> Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	2016 Meetings: 01/12, 03/08, 05/10, 07/12, 09/13, 11/08	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH UNIVERSITY MEDICAL CENTER		
4 th Tuesday of even months TIME: 7:00 to 8:30pm <u>LOCATION:</u> Rush University Medical Center, 1620 W. Harrison Street, Tower Resource Center, Tower, 4 th Floor, Suite 04527, Chicago, IL * Parking is available at the Rush garage on the southeast corner of Paulina and Harrison Streets. From the 4 th floor, follow the signs to the Tower.	Valet parking is available in front of 1620 W. Harrison. Parking at both of these venues will be validated in full.	For more information, please call 1-630-443-9876. Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD
CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL		
7/13/2016, 7:00 to 8:30pm <u>LOCATION:</u> Prentice Women's Hospital, 250 East Superior St., Conference Room J 9/10/2016, 1:00 to 2:30pm <u>LOCATION:</u> Feinberg Building, 420 E Superior St., NM Academy #2-715 11/7/2016, 7:00 to 8:30pm <u>LOCATION:</u> Prentice Women's Hospital, 250 East Superior St., Conference Room N	For At Risk (non-symptomatic) patients and family members. 2017 Meetings: (Room TBD) 1/7/2017, 10am to 11:30am 3/21/2017, 7pm to 8:30pm 5/6/2017, 10am to 11:30am	Emily Zivin (630) 443-9876 ezivin@hdsa.org Parking Passes Available
MUNSTER, INDIANA		
2 nd Tuesday of even months TIME: 7:00pm <u>LOCATION:</u> Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	2016 Meetings: 02/09, 04/12, 06/14, 08/09, 10/11, 12/13	Cindy Rogers (219) 680-6001 (cellular) (219) 836-2369 (home)

Sadie Foster, M.A., L.C.P.C., has a telephone Information & support call service for HD families. This call is held the fourth Sunday of every month at 7pm. To participate dial 630-300-6276 and when asked, enter code 702087#. You do not need to identify yourself on the call.

For additional support you may call:

Sadie Foster, MA, LCPC, at the College of Medicine Huntington's Disease
Clinic Tel: 815-271-7101 or E-mail: sadie@sfoster.com

Sarah Mitchell, Rush University Medical Center Social Worker
Tel: 312-942-6445 or E-mail: sarah_mitchell@rush.edu

 SAVE THIS DATE!

July 23, 2016	Team Run for HD: Amita Fitness for America Sunset Half Marathon
September 10, 2016	4 Paws 4 a Cause – Norwood Dog Park, Chicago
September 17, 2016	Hot Rods 4 Huntington's Disease – Volo, IL
October 8, 2016	Celebration of Hope – Lincoln Park, IL

<https://illinois.hdsa.org>



SUMMER 2016