



PRESIDENT'S MESSAGE



HELLO SUNSHINE!!!

Hopefully this letter finds each of you out basking in the warm sun on the beach, camping in the great outdoors, vacationing with family and loved ones, or taking time to complete some much needed home improvements during this beautiful, although short-lived warm weather in Ohio. I would like to take this time to introduce myself as the new Chapter President of HDSA for North East Ohio. My name is Jesse Lis. I currently work at Huntington National Bank as a Vice President

in Mergers and Acquisitions and attended college at Baldwin Wallace, majoring in Finance. I was raised in Columbia Station, Ohio which is where I currently reside with my husband, three kids, two giant dogs, and four ducks. It's a mini farm....and I love it!

HD came into our family in 2008 when my father started to display symptoms that were out of his typical character. When he became diagnosed, my sister and I both decided to get tested and were unfortunately positive. It was at this time that we met Wes Johnston, the North East Ohio Family Services Support person for HDSA. He aligned us quickly with proper doctors and social workers and never allowed us to feel alone. I remember attending my first ever Team Hope Walk in Zanesville, Ohio. My sister and I looked at each other and said- "Hey, we can do this too!" And ten years later, I am proud to say that with the support of others from HDSA NEO we have chaired or co-chaired Team Hope Walks, Golf Outings, Celebration of Hope Gala's, and many more events that have contributed hundreds of thousands of dollars each year since we've come aboard.

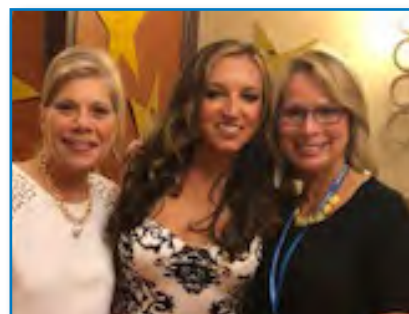


Surrounding ourselves with support is so important in these crucial times. My son, and I just returned from the 33rd Annual HDSA Convention in Los Angeles where there were over 1000+ people in attendance! This was HDSA's largest, most successful convention to date. We spent the weekend honoring the memory and love of Marjorie and Woody Guthrie. HDSA had very exciting news to impart and there were captivating research updates. A luncheon forum was held where we got to meet and heavily applaud all the key players as they spoke of their role in; "An On Going Story: Families and Researchers Come Together to Develop the First Huntingtin Lowering Therapy." The entire room felt progress on the horizon as we left with a plan to look after ourselves and remain healthy in this critical time. We were urged to sign up for www.enroll-HD.org and keep track of upcoming trials on www.hdtrialfinder.org. You can find many of the powerful convention tracks from 2018 at <http://hdsa.org/about-hdsa/annual-convention/2018-2/>. Check them out!

This was also an enormously successful convention for the National Youth Alliance (NYA)! They met and surpassed their goal of \$30,000 in fundraising efforts for next years' scholarship recipients. They danced the night away with friends and family at the reception gala. It is always so special to see that the youth within the NYA have each other to lean during convention and while listening to sensitive convention tracks. It is my hope that our local community will always reach out to the HDSA/NEO Board, specifically your NYA Regional Lead, Connor Lind at clind-NYA@gmail.com. Ask him about Scholarship opportunities or youth support groups if it is ever needed throughout the year. These opportunities can truly shape our young adults as they are dealing with difficult situations.



So before I leave you with this letter, I reflect back on our local HD event successes to date and I'm proud to state that it's been miraculous! Dr. Carrie Dudick served as our Chapter president for the past two years and has geared us up for a fabulous future. She served as chair for the Celebration of Hope Galas and will continue to provide the Chapter with excellent leadership and educational updates. Ven Lind chaired a very successful Golf Outing at Coppertop Golf Course. David Waltermire hosted HD families and Doctors at our Annual Education Forum in April where Jimmy Pollard gave a riveting speech about life as a Caregiver. We also had our highest attended Team Hope Walk at the Cleveland Zoo in June, raising over \$25,000! Now we are gearing up for the "Cleveland, Cleveland" Celebration of Hope Gala on Friday, October 19th at the Executive Caterers of Landerhaven. I sincerely Hope you can all attend and celebrate what is truly the crux of our decades of hard work- Instilling Hope. Hope for a cure, Hope for family, Hope for the next generation.



It is an absolute honor to meet you all and to serve as Chapter President for HDSA North East Ohio. Please know that what you endure with Huntington's, with us, you will never be alone. I learned that 10 years ago when I first met HDSA, and it is my promise to all of you now that you will always be made to feel at home.

All the best!

Jesse Lis, *President*
Northeast Ohio Chapter HDSA

Research Highlights from the 33rd Annual HDSA Convention

As we ease into the summer, enjoy some highlights from our research sessions at HDSA's 33rd Annual Convention in Los Angeles.

The Ionis/Roche ASO drug has gotten lots of press in the past year, but did you know there are additional strategies for lowering huntingtin? Multiple companies and academic laboratories are approaching this goal from other angles. We invited Dr. Pavlina Konstantinova to speak about her research at a company called UniQURE that is using a virus-based approach to deliver RNA therapies for lowering huntingtin: <https://vimeo.com/275140952> Watch the video starting at 20:45 to hear from Dr. Elizabeth Doherty, Director of Medicinal Chemistry at CHDI, who spoke about efforts to lower levels of huntingtin protein using a small molecule drugs.

The 2018 HDSA Convention also featured a Clinical Trials Showcase in which researchers and company representatives spoke about big ongoing clinical trials: <https://vimeo.com/274612855>. First up (0:22) is Jamie Levy who leads the clinical platform team at CHDI and runs the Enroll-HD study. Next (9:42), Dr. Ed Wild talks about HDClarity, a worldwide sample collection initiative.



Save the Date for the 34th Annual HDSA Convention in Boston, June 27-29, 2019!

Social Worker's Q & A:

What are Advanced Directives and should I complete them?

Advance Directives refers to legal documents including the Health Care Power of Attorney and Living Will that provide medical instructions for your care in the event you are unable to speak for yourself. The Health Care Power of Attorney document allows you to appoint someone to make medical decisions for you, while the Living Will documents your wishes for end of life care in advance if you are in a terminal or irreversible condition. These documents ONLY come into effect when you are unable to make your own decisions.

As HD progresses, communication and cognition can be affected therefore planning ahead with these documents allow you to plan your healthcare wishes for the future. You may choose to complete both or one and not the other or none at all. If you do not complete and become unable to speak for yourself, your legal next of kin will be contacted to make decisions for you.

If you choose to complete a Health Care Power of Attorney document, it is important to consider choosing an agent/ alternate agent that knows your values and healthcare wishes and can make medical decisions for you with those in mind. Your agent can be anyone you think would be best; it does not have to be a family member. While it might be difficult to talk about these issues, it can be helpful to have your family aware of your wishes ahead of time. You might consider discussing your wishes in regards to CPR, breathing tubes, feeding tubes, dialysis, pain management, hospice care and organ/brain donation.

If you have further questions about these documents or need help completing, please contact me.

Katie Dykman

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

Save the Dates 2018

October 19th, 2018 - 2019
Celebration of Hope Gala

June 2nd, 2019 (tentatively)
Team Hope Walk & 10K

June 22nd, 2019
Fore-a-Cure Golf Outing

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

HDSA Northeast Ohio Chapter

Special Guest Speaker & Support Group Session

July 18th, The Northeast Ohio Chapter of the HDSA hosted a special guest speaker and "Power Support Group Session" at the Brecksville Library.

Guest speaker Wendy Erler introduced to Wave's scientific approach and an overview of their current global clinical trial:

"Wave Life Sciences: Allele-Specific Selective Targeting of Mutant Huntingtin (mHTT)"

HDSA NEO had over 40 people in attendance. The evening consisted of refreshments and the opportunity to ask a bunch of questions about upcoming trial studies. Thank you to everyone who participated in this great event.

More about Wendy:

Wendy is the Vice President of Patient Advocacy and Commercial Market Insights at Wave Life Sciences. She is passionate about incorporating patient perspectives into the drug development process and corporate culture. Wendy is keenly aware that it is a privilege to engage with the Huntington's disease community and spends a great deal of time listening and learning from the people she meets. She loves a good Team Hope walk! Prior to joining Wave, Wendy spent over 15 years at Biogen and Shire gaining experience in commercial operations, program management and patient advocacy across a variety of therapeutic areas including oncology, ALS, MPS and SMA. She was a member of Biogen's first rare disease business team and led teams for commercial launches in Hemophilia for Biogen. Wendy and her husband Rick have three children and two dogs. Wendy earned her MBA from St. Joseph's University and her BA from Miami University.



Living with HD

At-Home DNA Kits Require Caution

At-home DNA kits like 23 & Me are growing in popularity, and claim to provide information about your health and ancestry. The Washington Post created an FAQ about what you can actually expect to learn – and who gets your info. These kits do not test for genetic disorders like Huntington's disease. For more information about testing for HD, please visit HDSA's webpage on genetic testing.

Human Biology Project Applications

Researchers from around the world are submitting proposals this week to the HDSA Human Biology Project, which funds human-centric Huntington's disease research from around the world. Our scientific advisory board, comprised of expert HD doctors, researchers, and family representatives, will do an in-

depth review of proposals and meet this fall to select promising research projects to be funded by HDSA for 1-2 years. These researchers update us on their progress via regular scientific reports. To read about currently funded work, check out the pages for our 2016 and 2017 Human Biology Fellows.

Open Research Blog by an HDSA Berman-Topper Fellow

Dr. Rachel Harding was named the 2018 recipient of HDSA's Berman-Topper HD Career Development Fellowship. You can read about her latest experiments on her blog, Lab Scribbles, where she writes about her work in real time. This week she's replenishing her stocks of huntingtin protein and doing experiments to see what other proteins stick to it!

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





HDSA Celebration of Hope

Join us Friday, October 19, 2018
6:30 pm - 11:00 pm for

**Cleveland.
Cleveland.**

Celebration of Hope

The Huntington's Disease Society of America is dedicated to improving the lives of people and families effected by HD. From community services and education to advocacy and research, HDSA is the world leader in providing help for today and hope for tomorrow.


Thank you to our Presenting Sponsor Teva



For more information and to make reservations contact
Carrie Dudick cabdudick@yahoo.com
or www.hdsa.org/coh-cleveland

Sponsorship information available by contacting Deb Boyd
dboyd@hdsa.org





Huntington's Disease
Society of America

TEAM HOPE



**10TH ANNUAL
TEAM HOPE
WALK & 5K
June 3rd, 2018**

THANK YOU to all the runners, walkers, volunteers, and sponsors that made this year's Team Hope Walk/5K a success, which again this year broke attendance records!

518 Total Participants raised over \$25,000!

This year the walk was held again at the Cleveland Metroparks Zoo on June 3rd. The highly energized participants enjoyed the lush environment and exhibits while supporting our cause. Cleveland Indian's Slider was there to hang out and start the run. After the walk, participants were treated to a delicious lunch.

Great job fundraisers and teams! We are grateful to the Walk Committee, co-chaired by Jesse Lis and Connor Lind, and the many volunteers who helped with registrations, donations, raffles, set up, tear down and fund raising.



**SAVE
THE DATE!
Saturday
June 22, 2019**



Area Support Group Meetings

Cleveland Area:

Meets on the second Monday of every month

6:30p.m. – 8:00p.m.

Jan 8	May 7	September 10
Feb 12	June 11	October 15
Mar 12	July 9	November 12
April 9	August 13	December 10

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.

January 2	May 1	Sept. 4
February 6	June 5	Oct. 2
March 6	July 3	Nov. 6
April 3	Aug. 7	Dec. 4

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!**

Living with HD Food Tips

Brain Healthy Diet

Based on research literature for the general population, and other common neurological conditions, such as dementia, there are some dietary factors considered to be "brain healthy".

Three of the most important dietary factors in a brain-healthy diet are vitamin B-12 anti-oxidants and anti-inflammatory agents. There are many foods that provide these substances, so you can take your pick of these foods to incorporate into your diet. Try to include at least one at every meal.

Vitamin B12

Vitamin B12 is found in animal foods (meat, dairy, eggs, poultry, etc.). B12 keeps the body's nerve and blood cells healthy and helps make DNA. Studies have shown that prolonged deficiency of this vitamin may have neurological effects on the brain and can cause nerve damage, although these effects are not specific to HD. Most people in the US get enough B12 if they include animal foods in their diet.

Antioxidants

Antioxidants protect your cells from free radicals ("bad" cells) in the body. COLOR is important when choosing foods with antioxidant properties – foods with deep, rich color tend to be higher in antioxidants. Choose a variety of fruits and vegetables to get the most benefit. These nutrients are good for everyone, not just someone with HD. More research is required to determine whether there is a specific increase of antioxidants needed for people with HD.

Essential Fatty Acids- Omega 3 & Healthy Fats

Omega 3 fatty acids are helpful in reducing inflammation throughout the body. They also can reduce triglycerides (and have a blood thinning effect so check with your doctor before taking a supplement). Other healthy fats include olive oil, nut butters, and avocados.



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/nehdon.

DONATIONS TO HDSA NOW MADE EASIER THROUGH PAYROLL DEDUCTIONS

such as contributions through Community Health Charities.

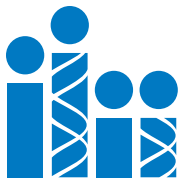
Contact Mike Ryan at mryan@healthcharities.org or at (614) 891-2566 for more information.



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



Huntington's Disease
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 **Northeast Ohio** CHAPTER

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