



Huntington's Disease
Society of America



Northeast Ohio CHAPTER

40

Celebrating 40 years of Help & Hope in Northeast Ohio

SUMMER 2017

HAPPENINGS

PRESIDENT'S MESSAGE



Summer Greetings!

The past few months have been spectacular for HDSA of Northeast Ohio. We had our Team Hope Walk at the Cleveland Zoo with the highest attendance ever with over 400 people walking and running to support us. Our chapter was recognized at the national convention with the

Chapter Award for Advocacy. Jesse Lis and Connor Lind won the Woodie Guthrie Advocacy Award at convention. With this success comes the need for great thankfulness. I wanted to use this space to thank Jesse and Connor for heading the Team Hope Walk. Randi and John Zubin and Curtis Newton for helping to organize the day and promoting it. I wanted to thank all of the volunteers that helped make the day run smoothly. Thank you to Teva for our speaker and lunch. All of these people are what help make our chapter wonderful, successful and a supportive. And at a national level Jesse and Connor have done so much with traveling to Washington, we are lucky to have them.

The rest of this year is also looking bright. In September we will have our education day and a golf outing, and in October our annual Gala with a masquerade theme. I hope you consider attending, volunteering or supporting these events. What truly made the Team Hope walk was the sense of community that day. All of us walking, gathering, and talking that day. I hope these future events help to bring community to all of you as well. Thank you again!

Carrie Dudick, *President Northeast Ohio Chapter HDSA*



The Northeast Ohio Chapter Celebrates 40 Years of Hope!

This is a big year for the NEOH Chapter of the HDSA, as we celebrate our 40th Anniversary!

Over the years we have lost friends, family, and loved ones to this terrible disease, and we have helped each other cope with many factors that come with it.

However, our work and dedication to each other and the cause has also given back to us in many ways. The funds we have raised have lead to incredible leaps in the treatment of HD, we have learned more and more about this debilitating disease, and how we can comfort those stricken. In many ways, our advocacy has created lasting friends, and built enduring relationships.

So in so much as HD has effected us negatively, we should also embrace the positive moments that have come from the 40 years of hard work, dedication, and love that has brought members of the NEOH Chapter closer together, and given us hope that soon, a cure for Huntington's Disease may be found.

Thank you to everyone who has contributed, donated, worked, advocated, befriended, reached out, or comforted in an effort to help others and to ultimately end Huntington's Disease.

HDSA 32nd Annual Convention

The HDSA 32nd Annual Convention weekend was held this year on June 22 through the 24th in Schaumburg, IL. Researchers, Physicians, HDSA Chapter and Affiliate Leadership, families, and friends gathered at the Renaissance Convention Center inspired and energized by one mission; improving the lives of people with Huntington's Disease.

The National Youth Alliance had a fun-filled day of laughing, learning, and connecting at NYA day on Thursday! Then Convention kicked off in its' usual fashion with a Team Hope Walk, and flooded the Convention Center streets with a sea of blue. Guests were warmly welcomed at the "Game On" Reception by HDSA's Chairman of the Board, Dr. Arik Johnson, and provided with Chicago's best- deep dish pizza! This night was loaded with giant sport-themed blow up games for all ages and the most delicious funnel cakes!

On Friday morning, attendees were greeted by HDSA's President and CEO, Louise Vetter, who discussed the power of strengthening our strategic plan. We were then introduced to Keynote speaker, Shana Verstegen who provided her story of love and perseverance, and inspired us all to continue living our lives #HDSTRONG. We split off into Educational Tracks designed specifically for attendees in various stages of HD, or for Researchers and Caregivers impacted by the disease. Friday's Community Awards Luncheon was exciting for the NEO Chapter- We took home the Chapter of the Year Award for Outstanding Advocacy in 2017! It was great to watch and recognize all of the other Chapters and Affiliates for their efforts over the last year! The evening ended with a stoic and powerful documentary and special film screening of "Her Mother's Daughter." This film was beautiful and raw, and it was so great to meet so many of the "stars" of the film right there at convention.

Saturday was a day filled with Research talks by the brilliant Dr. Elena Cattaneo, and a witty HD timeline discussion by our favorites- Dr. Ed Wild and Dr. Jeff Carroll. We also received exciting upcoming news about Clinical Trials for HD. Education Tracks continued and the NYA hosted a lunch honoring the youth with special awards for 2017. Our own NEO Junior Board Member, Connor Lind, was recognized as an All-Star Advocate, and honored for all of his hard work this year. The Gala Reception and Awards dinner was beautiful and a bitter-sweet ending to the fantastic weekend. Families and friends gathered, sharing stories and the knowledge that they gained over the last few days. Amazing contributors were recognized for all of their efforts and achievements and candles were blazing blue in the night sky as a symbol of the hope and commitment that we all share with each other.



Living with HD Food Tips

Tips to Maintain Food Intake



1. Eat smaller, more frequent meals (i.e.: 6 instead of 3 times a day).
2. Eat favorite foods in a relaxed, pleasant atmosphere.
3. Keep snacks available at all times, such as candy, cheese, cookies, ice cream, sandwiches, or mini-pizzas.
4. Use other cues to remind yourself to eat, such as a clock with a timer, a beeping wristwatch, or the commercial breaks on television.
5. Avoid drinking liquids with meals because you will fill up too quickly and not have enough room for the food.
6. If you drink a supplement or shake, drink it between meals.
7. Avoid drinking beverages without calories (i.e.: diet soda, seltzer).
8. If you drink coffee or tea, add sugar and whole milk or cream for extra calories. Or, try a cafe latte or chai tea.

Why should I attend a support group?

There are a lot of great reasons to attend our wonderful support groups. One reason to attend is to build up your support system before you need it; be proactive instead of reactive. It is great to have supportive family and friends and the support group will not replace this, but it will provide an opportunity for you to share and/or ask a question outside of family/friends. Get to know fellow support group members and learn about their challenges and successes. You might hear some great advice by someone whose been in a similar situation as you are. If things are going well for you, please come share your experiences, ideas, and resources – you never know who will benefit!

If you are not comfortable talking to “strangers”, don’t worry since no one is forced to talk or share with the group. You can attend to listen to the group. Over time, you’ll likely feel comfortable and might choose to share.

Attending a support group may be a difficult decision, but it also might be one that may provide the emotional support and connections to help your fight against HD. Your involvement is important; consider joining us!

For questions about our support groups and/or any other concerns, please do not hesitate to contact Katie Dykman (440) 742-1284 or kdykman@hdsa.org.

AREA SUPPORT GROUP MEETINGS

Cleveland Area:

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

Jan 9	May 8	September 11
Feb 13	June 12	October 16
Mar 13	July 10	November 13
April 10	August 14	December 11

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

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!***

Caregiver's Corner Webinars

Caregiver's Corner is designed to provide information, resources and support for caregivers so they are better able to face the daily challenges of living with HD. Go to:

LIVING WITH HD | CAREGIVER'S CORNER WEBINARS

<http://hdsa.org/living-with-hd/caregivers-corner-webinars/>



Shana Verstegen's HD Workout Tips

In collaboration with the Huntington's Disease Society of America, Shana Verstegen has volunteered her time & expertise to provide valuable tips to help HD families live a healthier lifestyle. Check out the videos for motivational workout tips designed for a healthier you.

HD WORKOUT TIPS

<http://hdsa.org/hd-workout-tips/>



Shana Verstegen is the former president of the HDSA Wisconsin chapter (2007-2013) and has served as a Huntington's Disease Society of America national spokesperson since 2002. She received her bachelor's degree in kinesiology and exercise science at the University of Wisconsin in 2002, and went on to earn the Log Rolling World Champion title in 2006, 2007, 2008, and 2012, and the Boom Run World Championship in 2008 and 2009.

Verstegen currently travels the country as a trainer for the American Council on Exercise – San Diego, TRX Training San Francisco, and Supreme Health and Fitness based in Madison, Wisconsin. She has helped raise public awareness about HD by making numerous television appearances on programs including the Tonight Show with Jay Leno, the Wayne Brady Show, Girls Behaving Badly (Oxygen Network), and a special ESPN feature about Huntington's disease. In print she has been featured in venues including Oxygen, Women's Physique World, Muscle & Fitness, Wisconsin Woman, and Newsweek magazine. While she says she has many things to be proud of, her work with HDSA in honor of her mother will always top that list. Her mother, Debby Martin, died from complications of Huntington's disease in March 2013. Verstegen says that watching her mother lose her ability to move independently inspired her to live every day to the fullest with a focus on movement—from being the first female pole vaulter at the University of Wisconsin to winning a half dozen lumberjack titles. Verstegen is passionate about raising awareness toward finding a cure for Huntington's disease, and fundraising to make that research and cure possible.

Annual Fore-A-Cure Golf Outing

Good News! Ven Lind secured the venue for the "Annual Fore-A-Cure Golf Outing" for **Saturday, September 23rd at 2:00 at Coppertop at Cherokee Hills Golf Course**. More to come, but wanted you all to save the date, location and time for now. Contact Ven Lind for more info VenL@fontanini.com





Huntington's Disease
Society of America

**TEAM
HOPE**

9TH ANNUAL TEAM HOPE WALK & 5K

THANK YOU to all the runners, walkers, volunteers, and sponsors that made this year's Team Hope Walk/5K the most successful in chapter history, and one of the top walks in the country!

418 Total Participants, and over \$35,000 Raised!

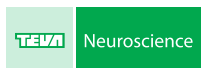
This year the walk was held at the Cleveland Metroparks Zoo on June 4th. The highly energized participants enjoyed the lush environment and exhibits while supporting our cause. Cleveland Indian's Slider was there to hang out and start the run. After the walk, participants were treated to a delicious lunch and guest speaker.

Congratulations to top Individual fundraiser Lauren Wiles, and our top team was Beth's Battalion. **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.



THANK YOU SPONSORS for your generous support.



Carolyn Leetch in loving memory of Jim Leetch
Wesley Johnston in loving memory of Millicent Johnston



Save the Dates

Saturday, September 9th, 2017

HD Education Day 9:00am - 1:00pm

Food is included. \$5 per person. For information as it becomes available, visit www.hdsa.org/neoh

St. Joseph Byzantine Catholic Church
Activities Center • 8111 Brecksville Rd

Saturday, September 23th, 2017

2:00pm

Annual Fore-A-Cure

Golf Outing

Coppertop at Cherokee Hills Golf Course

Friday, October 13th, 2017

Celebration of Hope

A Night in Venice Masquerade Ball

Landerhaven, Mayfield Heights

Research NIH & FDA

HDSA, along with partnering organizations, is constantly working to increase funding and streamline the approval process for new and novel therapies to treat Huntington's disease. One major way HDSA has been supporting this goal is through our staunch and steadfast support of the 21st Century Cures initiative.



21st Century Cures is a bi-partisan initiative which, through legislation, will advance the discovery and development of treatments, strengthen the patient voice in the regulatory environment, increase funding for the National Institutes of Health and Food and Drug Administration, and greatly improve our innovation ecosystem.

Visit https://en.wikipedia.org/wiki/21st_Century_Cures_Act to find out more about the 21st century cures initiative!

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.



facebook

HDSA on FACEBOOK!

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



Huntington's Disease
Society of America



Northeast Ohio CHAPTER

40

Celebrating 40 years of Help & Hope in Northeast Ohio

P.O. Box 14668

Cleveland, OH 44114

NON PROFIT
US POSTAGE
PAID
CLEVELAND OH
PERMIT NO. 498

HDSA NORTHEAST OHIO CHAPTER BOARD OF DIRECTORS

Helpline Number 440-742-1284

President: Carrie Bohenick Dudick, MD

Vice President: Jesse M. Lis

Treasurer: Cory A. Baughman, CPA

Secretary: Carolyn Leetch

Donald L. Barr

James H. Crawford

Daniel J. Hostetler, JD

Eric Hutchins, LNHA, CDP

Wesley G. Johnston, Jr.

Mackenzie Platten*

Connor Lind

Ven Lind

Mayur Pandya, DO

Alan M. Tartakoff, PhD*

David E. Waltermire* – Charter Member

** Past President/Life Director*

GREAT LAKES REGION

Deborah Boyd – Regional Development Director

PO Box 72

Richland, MI 49083

Phone: (269) 629 5452

Fax: (269) 629-4205

dboyd@hdsa.org

NATIONAL OFFICE HDSA

Louise Vetter – CEO

505 Eighth Avenue #902

New York, NY 10018

Phone: (800) 345-4372

Fax: (212) 239-3430

www.hdsa.org/neoh

NEOH HDSA Social Workers

Katie Dykman: 440-742-1284 kdykman@hdsa.org