



Huntington's Disease Society of America



Central Ohio CHAPTER

President's Letter

Dear Families & Friends,

You know the summer is coming to a close when it's time for the Ohio State Fair and we start getting fired up about hosting our **Celebration of Hope – Stand Up for Hope** event! And new this year, the Central Ohio Chapter of HDSA has been selected to be the recipient of the **Annual Old Hilliardfest** Car Show being held on Saturday, September 9th! Don't forget to take the family to this fun-filled day of events!

This year's CoH **Stand Up for Hope** is on Friday, September 29th from 7:00 – 10:30 pm and is being held again at King Avenue 5. We are excited to announce this year that Dino Tripodis from WSNY/Sunny 95 will entertain us with two additional comedians! Also this night, we look forward to honoring The Ohio State University's Center of Excellence Physical Therapist team of Dr. Anne Kloos and Dr. Deb Kegelmeyer for their tireless work and research as they assist our family members with Huntington's disease! We hope to see you there! Watch your mail and email for registration information! Also, if you know of or work at a company or place of business who wishes to sponsor or donate gifts in kind, please contact me at dhess5556@yahoo.com or wendy@cd1025.com (Wendy Vaughan).

This year's HDSA National Convention in Schaumburg, IL had a tremendous turnout with over 950 conference attendees! Also exciting was the National Youth Alliance's awarding of over 50 scholarships for our youth and young adults to attend the conference! Donors representing Central Ohio provided items for this year's silent auction to help the scholarship opportunity. During the convention there were a plethora of convention sessions offered again this year that were categorized (youth, caregiver, at risk, etc) for those who wished to focus on a specific strand. I, of course, jumped around and attended different types of sessions. For those HD families who wish to look at resources or video broadcasts of chosen sessions, please visit <http://hdsa.org/about-hdsa/annual-convention/2017-2/>

Additionally, our OSU Center of Excellence is hosting an **Education Day at the OSU Fawcett Center on Saturday, August 26th from 10:00 am to 2:00 pm**. There will be multiple sessions offered and a special track for youth with the NYA's help! The day is FREE and lunch is provided! RSVP to Erica Wright at 614-688-9438 or erica.wright@osumc.edu

Have a wonderful fall! Please turn the pages to see more information about upcoming events and exciting announcements!

Fondly,
Daphne Hess

OUR VOICE

FALL 2017

Our Voice, a newsletter of the Huntington's Disease Society of America, Central Ohio Chapter, is published twice a year to provide information and to relay items of interest to individuals with HD and their families, health care professionals, friends, and supporters.

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Note our Website Change!

The Central Ohio Chapter Website address has been changed due to an issue with the old address. The new address is <http://centralohio.hdsa.org/> Members who have the old address stored in their “favorites” should note this change. Those using a search engine should not have a problem as the new address is listed as the first choice. Those going through the National website will have no problem, since it connects to the new Chapter address. Thanks to Hal Hixson and Craig Baldwin for their work in making the Chapter website a great site. *Check it out.*



Did you know?

The 33rd Annual HDSA Convention will be held in Los Angeles, California, June 7—9, 2018. The convention is a perfect place to learn new things, be encouraged, and enjoy some time with friends!

Watch convention videos. Click [here](#).

We attended the National Convention in Schaumburg, Illinois in June!!



L to R: Abby Reynolds, Kylie Hess, Eric Hess, Roger Vaughan, Daphne Hess, Dave Hess, and Syd Dalton

17TH ANNUAL CELEBRATION OF HOPE



Stand up For Hope!

WHEN: September 29th, 7—10:30pm



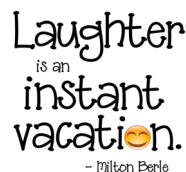
WHERE: [King Avenue 5 Bar and Restaurant, Columbus Ohio](#)

WHAT: A night of comedy and entertainment with Dino Tripodis from WSNY/Sunny 95 and friends, buffet dinner, and silent auction. The Celebration of Hope has raised a combined total of over \$750,000

since its inception. We anticipate another great evening with a sold out crowd of 150 attendees.

WHY: To raise funds for research and a cure, to honor Dr. Anne Kloos and Dr. Deb Kegelmeyer, to enjoy good food, and to stand up to HD!

The \$75 ticket includes a buffet dinner, 2 drink tickets per person. HDSA Honoree Presentation at 8PM and stand up comedian Dino Tripodis and friends starting at 8:30PM. Your tickets are tax deductible minus the fair market value of the event which we estimate to be \$25.00. Therefore, your ticket includes a \$50.00 donation to HDSA Central Ohio Chapter. Our goal is to raise \$20,000 at this event.



Please help us achieve our goal by purchasing your ticket(s) or going online to donate at <https://hdsa.donordrive.com/event/ohcoh>

For more information please contact Wendy Vaughan, HDSA Central Ohio Chapter Volunteer at: wendy@cd1025.com. Call or text to 614-783-6757

RESERVATIONS FOR THIS PARTY WILL BE LIMITED, SO SIGN UP EARLY!

OFFICERS AND BOARD

President:
Daphne Hess
dhess5556@yahoo.com

Past President:
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Vice President:
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Board Members:
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Barb Heiman
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Marilyn Hixson
Dr. Kari Hoyt
Tom Ioia
Keith Jones
Dr. Sandra Kostyk
(Medical Advisor)
Katy Simon
Lenae Tunila
Wendy Vaughan
Kelin Wheaton
Lindsay Williams

WEB Site Manager:
Hal Hixson
614-563-4460
halhixson@gmail.com

HD Helpline
614-292-9960

MONTHLY SUPPORT GROUP

2nd Thursday
of every month

1621 Francisco Rd.
Columbus, Ohio 43220

Barb Heiman
Social Worker and
Group Facilitator
614-390-8009

All are welcome!

Our monthly support group meeting is held at 7:00 PM on the second Thursday of each month at the [Atonement Lutheran Church](#), 1621 Francisco Road, Columbus, Ohio 43220, which is in the northwest corner of Columbus.

All are welcome! Come get support, give support. All are needed.



When the diagnosis came back, it blindsided us. We had no idea that there was anything like this anywhere.

AMARYLLIS CHAIRPERSON NEEDED

The chapter is currently seeking someone to lead our amaryllis sales. A big thanks to Marilyn Hixson for her gracious leadership the past years. Last year's gross sales exceeded the goal of \$5,000, with sales being shy of \$8,000. Half of those monies went to research.



If you have a heart for finding a cure for Huntington's Disease and enjoy behind the scene organization, a few computer skills, and taking on an already established project, then this is the place for you!

Contact our Chapter President, [Daphne Hess](#), for more details.

There are now 41 Centers of Excellence!

“The 2017 HDSA Centers of Excellence program expanded to 41 Centers from 39 last year, 29 in 2015 and 20 in 2014 – a more than 100 percent increase in four years. The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington’s disease that share an exemplary commitment to bringing comprehensive care.” Read more by clicking [here](#).

Central Ohio’s Center of Excellence is on the 7th floor of the Martha Morehouse Tower at The Ohio State University Wexner Medical Center, [2050 Kenny Road, Columbus Ohio 43221](#).

Three Sites Worth Viewing...

HDSA National Website at <http://hdsa.org>

“Families bear the burden of HD in silence. Pope Francis embraced us.” **Read article by Mona Gable** at <https://www.statnews.com/2017/08/08/huntingtons-disease-vatican-pope-francis/>

HD BUZZ “Huntington’s disease research news. In plain language. Written by scientist. For the global HD community.”

Get the latest at [HD BUZZ](#).



CENTER OF EXCELLENCE

Martha Morehouse Tower
Neurology Clinics,
7th floor
2050 Kenny Rd.
614-293-4969

Clinic nurse:
Kate Ambrogio
614-293-4969

Research coordinator
and Genetics Counselor:
Allison Daley
614-688-8672

HD Helpline
614-292-9960

CENTRAL OHIO CHAPTER

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P.O. Box 1077
Westerville, OH 43086-7077

Email:
cenohiohdsa@gmail.com

Phone:
614-360-1585

Website:
<http://centralohio.hdsa.org/>



Walk for a cure in Hilliard



CONNECT TO THESE PROGRAMS! IT COSTS YOU NOTHING AND YOU'RE HELPING HD!

Two ways you can donate to HDSA and it costs you nothing is through the "Kroger Community Rewards" and "Amazon-smile".

Kroger allocates money each year and gives it to charities as their customers designate. To make HDSA as your charity designation, go to <https://www.kroger.com/communityrewards> and follow the prompts.



You MUST register after May the 1st, EVERY YEAR with the Kroger Community Rewards program. If you do not register each year, your designation will be dropped.



Amazon sets aside .5% of each sale for donation to charities. To designate HD as your charity go to <https://smile.amazon.com/> and follow the prompts.

Other business places have similar programs, watch for them and name HDSA as your choice.

*Help for Today,
Hope for Tomorrow.*

About HD

Huntington's disease (HD) is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities usually during their prime working years and has no cure.

Every child of a parent with HD has a 50/50 chance of carrying the faulty gene that causes Huntington's disease.

Today, there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

In approximately 10% of cases, Juvenile Huntington's disease (JHD) affects children or adolescents and JHD typically progresses more rapidly than adult onset HD.

The symptoms of HD are described as having ALS, Parkinson's and Alzheimer's diseases - simultaneously.

Together, we hope & work for a cure for HD.