



Huntington's Disease Society of America



Central Ohio CHAPTER

OUR VOICE

FALL 2018

President's Letter

Dear Families & Friends,

Happy Fall!

I have more hope than ever that the researchers across the world will find a way to slow the progression or to find a cure for Huntington's disease! These past 6 months have been exciting in the research arena. I encourage you to sign up to receive notifications from HDBuzz, <https://en.hdbuzz.net>. They have a tremendous knack for explaining what can be difficult to understand in an easy to read format for those of us who are not familiar with scientific jargon.

To help our families who deal with HD, you can support us by attending our [Annual Celebration of Hope](#) on October 12th at King Avenue 5 (see pg 3).

Also our Annual Meeting with dinner at Der Dutchman is on Tues, Nov 13th!

ANNUAL MEETING

Tuesday, November 13, 2018

Doors open @ 6:00pm

Dinner @ 6:30pm

Der Dutchman

Plain City

Cost \$25/person

RSVP to Daphne Hess

dhess5556@yahoo.com

Or 614-519-6468

If you'd like to make a difference and get involved in a committee or help with any future events or fund-raisers, please contact me. There is something you can do to help fight HD and support those finding a cure.

Feel free to reach out to me at any time! I look forward to seeing you at one of upcoming events! Have a wonderful Fall & holiday season!

Daphne Hess
President
Central Ohio Chapter of the HDSA

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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NEW MAILING ADDRESS FOR HOME OFFICE

Please note the new address for the Central Ohio Chapter.

Central Ohio Chapter
HDSA
P.O. Box 2213
Columbus, Ohio 43216

HDSA CENTER OF EXCELLENCE AT THE OHIO STATE UNIVERSITY

CENTER OF EXCELLENCE

Wexner Medical Center
Martha Morehouse
Tower
2050 Kenny Rd. ,
7th floor
Columbus, Ohio 43221
614-293-4969

Director: Sandra Kostyk,
MD, PhD

Clinic Coordinator
Kate Ambrogi, RN
614-688-6685

Social Worker:
Erica Wright
614-292-9960

The HDSA Centers of Excellence provide an elite multidisciplinary approach to Huntington's disease care and research. Ohio is home to 2 of the 39 Centers of Excellence across the United States. The one closest to Columbus is located at the Wexner Medical Center on the campus of The Ohio State University.

At these world-class facilities, patients benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have deep experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease.

Monthly Support and Fellowship Group

We know it's hard to make a monthly commitment and we know that you're facing lots of challenges and changes that come with a loved one who has Huntington's Disease.

If you'd like to catch a cup of coffee at a time that's convenient for you, let us know. We have a small group that gets together once a month when it's convenient for all.

For more information contact Erica Wright at 614-293-4969 or erica.wright@osumc.edu or Norm Baldwin at normbaldwin@frontier.com.

18TH ANNUAL CELEBRATION OF HOPE



Please Join Us for the 18th Annual HDSA Central Ohio Chapter Celebration of Hope Acoustics Jam '18.

It'll be on Friday, October 12, 2018, at the King Avenue 5, 945 King Avenue, Columbus Ohio.

RESERVE YOUR SPOT TODAY!!!

Tickets are \$75.00, which includes a Buffet Dinner and 2 Drink Vouchers.

Entertainment will be by the Mama Drama Acoustic Duo, whose cover songs include various decades & genres from the 60's thru 2000's.

We will be recognizing our 2018 Honorees, Roger & Wendy Vaughan and Marty Vaughan.

For Questions & Sponsorship Opportunities, contact Melissa Ryant at mryant@hdsanya.org or 216-280-7464



Limited Tickets are being sold, so PURCHASE YOUR TICKETS TODAY!

Link to the On-line Registration website:

<https://hdsa.us3.list-manage.com/track/click?u=5f749c4f8c982767aa06cb20a&id=90e60d4db9&e=2c85badb02>

Link to the Event Flyer:

<https://hdsa.us3.list-manage.com/track/click?u=5f749c4f8c982767aa06cb20a&id=b43ab51c14&e=2c85badb02>

Thanks For Your Support!
Melissa Ryant

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

National Youth Alliance:
Melissa Ryant
mryant@hdsanya.org

AMARYLLIS CAMPAIGN TO START SOON!

The Annual Amaryllis Sale will take place October through December.

The amaryllis is one of the easiest flowering bulbs to bring to bloom. Originating in South America's tropical region, these large flowers are very popular and come in many beautiful varieties, including various shades of red, white, pink, and salmon. It is a gift that is appreciated by many.

It is common for supporters to purchase one, two, three, or more cases (16 plants per case) and then give them away as Christmas gifts and/or sell them a few at a time to other people.

Order a case for you, your family and friends. They are shipped directly to the buyer at their personal address.

Cost for a flower is \$10 plus shipping. Or you can get a case for \$160 (shipping is free).

For more info, contact Daphne Hess at dhess5556@yahoo.com.



NATIONAL YOUTH ALLIANCE



Huntington's Disease
Society of America



The National Youth Alliance provides support and resources for those who are ages 9 through 29. It's an excellent resource. To become a member go to hdsa.org/nya.

If you would like to connect locally, contact Melissa Ryant at mryant@hdsanya.org.

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 are 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.

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.

*Help for Today,
Hope for Tomorrow.*

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.