



# Huntington's Disease Society of America



## Central Ohio CHAPTER

# OUR VOICE

FALL 2016

### President's Letter

*The following is a letter we would like to share with you from Louise Vetter, HDSA Chief Executive Officer. Thank you for your commitment to finding a cure! Daphne Hess, Chapter President*

"In September of last year, something truly incredible happened – the start of a clinical trial for a drug with the potential to *silence* the huntingtin gene.

This is the first drug designed specifically to target the gene that causes HD to be tested in humans!

No doubt, the IONIS-HTTRx trial is one of the biggest advances since the discovery of the huntingtin gene 23 years ago. And not just because of its potential to halt the progression of HD.

This trial is part of an exciting new era of drug development specifically aimed at treating – and, ultimately, *curing* – Huntington's disease. Never before have so many pharmaceutical companies been pursuing HD therapies in the clinic. And the reason for that is truly profound:

*Companies are making this investment because they believe that success is possible.*

It's taken a long time to get to this point – decades of research and discovery aimed at unlocking the mysteries of Huntington's disease. **None of today's results would be possible without that, and none of that would have been possible without people like you!**

To date, our HDSA family has invested more than \$20 million dollars in HD research. This research has helped to create a foundation of knowledge upon which today's discoveries and advances are being made. But that's not all, Your support has also helped HDSA generate incredible passion and commitment within the research community.

Speaker after speaker at Convention, expressed incredible determination to beat this disease. It's given me hope that the work won't stop until this disease is stopped.

*(letter continues on page 9)*

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, interested friends, and supporters.

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**HUNTINGTON'S DISEASE SOCIETY OF AMERICA'S,  
CENTRAL OHIO CHAPTER VOLUNTEERS PROUDLY PRESENT:**



"The Tailgate for Hope" will be an indoor tailgate event at the local sports bar, King Avenue 5, to watch the Ohio State Football Buckeyes take on the Oklahoma Sooners, which will be one of the biggest games of the season!

This fun event will start at 7PM with music, buffet dinner,  
2 drink tickets per person and a silent auction.

The game starts at 8PM and will be shown on multiple screens.

*See Silent Auction Items top of page 3!*

To purchase tickets or donate online, please go to

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

For more information please contact Wendy Vaughan,  
HDSA Central Ohio Chapter Volunteer at: [wendy@cd1025.com](mailto:wendy@cd1025.com)

Call or text to [614-783-6757](tel:614-783-6757)

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

## SILENT AUCTION WILL INCLUDE ITEMS SUCH AS:

- 2 tickets to see "Hamilton" on Broadway in NYC, Saturday, November 12 or Sunday, November 13. \$500 towards airfare included.
- 4 tickets to see the filming of the new Harry Connick Jr. Show in NYC. Dates to be determined by winner.
- Ohio State football helmet autographed by Coach Urban Meyer. 2 tickets to the OSU vs Michigan Football Game on November 26 in Columbus, Ohio.
  - Summer cottage in Northern Michigan, and more!!!

If you would like to bid on an item but cannot attend event, please contact Wendy Vaughan [614-783-6757](tel:614-783-6757) or [wendy@cd1025.com](mailto:wendy@cd1025.com)

## TEAM HOPE WALK IN ZANESVILLE RAISED OVER \$12,000!

*Submitted by Jaclyn Hindel*

The Team Hope Walk in Zanesville, Ohio took place on May 21, 2016! It was a rainy day but we still had over 100 participants and raised over \$12,000. Our raffle items totaled over \$1000 in value and we had \$2000 in sponsorships!



It was a great event and we again just want to thank everyone for all their support in making this event so successful!

A big thanks to Team Mandi for coming and donating over \$5000!

You can view images from the walk here: [https://drive.google.com/folderview?id=0B7JjezLR9-m1RHgyZEI5dWctQUU&usp=drive\\_web](https://drive.google.com/folderview?id=0B7JjezLR9-m1RHgyZEI5dWctQUU&usp=drive_web)

### OFFICERS AND BOARD

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Ron Ioia  
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Keith Jones  
Dr. Sandra Kostyk  
(Medical Advisor)  
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Lindsay Williams

WEB Site Manager:  
Hal Hixson  
614-563-4460  
[halhixson@gmail.com](mailto:halhixson@gmail.com)

HD Helpline  
614-292-9960

## MONTHLY SUPPORT GROUP

2nd Thursday of every month

1621 Francisco Rd.  
Columbus, Ohio 43220

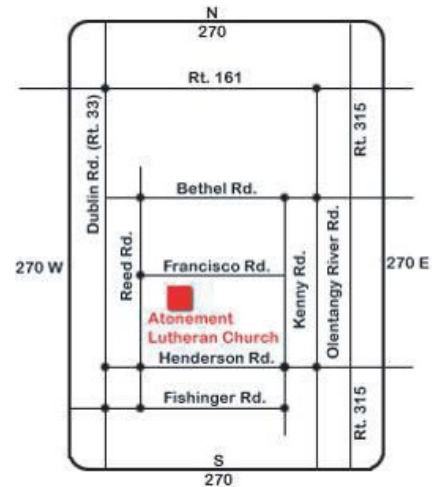
Barb Heinman  
Social Worker and  
Group Facilitator  
614-390-8009

“There are no problems we cannot solve together and very few that we can solve by ourselves”

– Lyndon Johnson

## Join our Monthly Support Group

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!



## What is a Support Group?

A support group is a small group of individuals who meet regularly to provide caring and support for those who participate in it. What most members consider important is the information gained, the interpersonal interactions of the group, and the supportive atmosphere.

Common questions may be: How is the group going to help? What does all this have to do with solving my problems? How much do I have to reveal or give of myself? Will everything that is shared in the group stay confidential?

Support groups are designed to be safe havens for individuals who are being impacted by similar life circumstances. Members give encouragement to one another, hear other's points of view, and realize that they are no longer alone in their struggle. Sharing experiences often helps each member to understand what may lie ahead and how to limit the impact to themselves and to their family. There are no experts. The group is the focus, and individuals are what hold the group together.

No matter what the problem or concern, sharing with others who are in similar circumstances can provide knowledge, understanding and support to help meet the challenges that lie ahead.

(For more information on the Central Ohio HD Support Group call Barb Heiman, Social Worker and Group Facilitator 614-390-8009)

## THE 2016 HOOP-A-THON WAS A MAJOR SUCCESS!

*Submitted by Katy Simon and Steve Hammond*

We had a fantastic crowd and plenty of great food. First off we would like to thank St. John's Church for providing such an ideal place to hold our event. Next I would like to personally thank all of our volunteers for giving us their time. Last, but not least, I would like to thank our food sponsors: Little Caesars Pizza, J.P.s Barbecue Restaurant, Cameron Mitchell Restaurants, Krispy Kreme Doughnuts, The Brownie Lady, and Kroger at Silver Horn Center. Our raffle table was loaded with some very nice prizes, along with our food donations, both were very profitable. All in all, a great event, raising over \$15,000. ! Thanks to all it was a huge success!!



## AN EASY WAY TO SUPPORT HD AND IT COSTS YOU NOTHING!

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.



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.

#### 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

## 2016 HDSA CONVENTION, LEARN MORE!

Not able to attend the 31st Annual HDSA Convention in Baltimore, Maryland? Wish you could have heard some of the speakers, research, workshop speakers? You still can! Click on the link below. It will re-direct to the national site where you can view presentations.

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

## SAVE THE DATE!

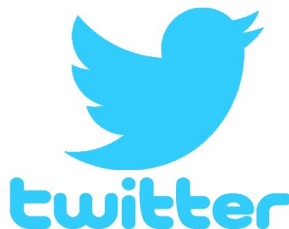
Join us for the 32nd Annual HDSA Convention right outside of Chicago at the elegant Renaissance Schaumburg Hotel & Convention Center. It will be

*June 22–24, 2017*



in Schaumburg, Illinois. Stay tuned for more details at [HDSA.org](http://HDSA.org).

## FOR THOSE WHO LIKE TO TWEET...



Click here to follow [@hdsa](https://twitter.com/hdsa) on Twitter!





## Volunteer Inspiration

*Volunteers do not necessarily have the time; they just have the heart.*

Elizabeth Andrew

*If you want to lift yourself up, lift up someone else.*

Booker T. Washington

*Volunteers are love in motion.*

Unknown

## Hilliard Walk, a great success!

The Hilliard Team Hope Walk/Run was a great success!

There were hundred plus participants on one of the hottest days this summer. The net receipts exceeded \$7,300.

The top fund raisers for the walk were Daphne and Kylie Hess. *Way to go Daphne and Kylie!*

And a big thanks to thanks to Paula Lintz for her hard work!

## Annual Meeting at Der Dutchman

The Central Ohio Chapter's Annual Meeting will be held on Wednesday, Oct 12th at the Der Dutchman Restaurant at [445 S. Jefferson Avenue, Plain City, OH 43064](#). Doors open at 6pm. Dinner will be at 6:30pm

The cost for this delicious home-cooked meal is \$18 per person.

There will be a report on the past year's activities, election of board members for the coming year, and sharing of the most recent news in Huntington's research.

RSVP to Daphne Hess at [dhess5556@yahoo.com](mailto:dhess5556@yahoo.com) call 614-519-6468 for the Der Dutchman Annual Dinner!





## Louise Vetter letter continued...

With so many promising leads for researchers to pursue, there's never been a better time to invest in research that has the potential to provide real help now – and real hope for tomorrow.

The IONIS-HTTRx trial may be one of the most exciting developments to date, yet it's only one of many exciting huntingtin lowering strategies researchers are pursuing. One of the big challenges is to find the easiest and most effective ways to deliver huntingtin lowering agents to the brain. Researchers are currently testing a number of different ways to do this – and the results of these trials will be critical to uncovering the best way to reduce levels of the huntingtin protein and, with it, the devastating symptoms of the disease.

There's also a lot of new buzz about “gene editing” techniques that could enable scientists to simply delete all of those C-A-G repeats. Right now, it's still more like science fiction than science fact, but it could just be the key to wiping out HD.

We really have come a long way. Jeanette Garcia has seen that firsthand in the eight years since she discovered she was gene positive.

Back then, doctors told her there were no treatments available for Huntington's disease. Today there are at least 13 drug trials currently underway for HD, and more on the horizon.

Early on, Jeanette became a champion for research – but it was frustrating to her that there was no simple place people could go to find out what HD trials they might be eligible for. In 2015 HDSA launched the HD Trial Finder, an important one-stop-shop tool for trial enrollment.

Like you, Jeanette hasn't just witnessed this progress; she's been a part of it. And today she's an inspiring voice for the power of research – and the HD community. She's adamant: “I believe the only way that we'll find a cure is through our participation in clinical trials.”

Jeanette is determined to do everything she can to combat HD and to create hope for herself, for her three siblings who are HD positive, and for her three children who are at risk.

Thanks to people like you, we've turned a corner in this fight. And with your gift today, we'll take the next critical steps toward defeating this awful disease ... for good.”

With Determination & Hope!

Louise Vetter  
Chief Executive Officer

PS: When it comes to HD, you and I know that time is not on our side. And, unfortunately, the reality is that scientific breakthroughs take an enormous amount of money – and time. That's why it's critical that, together, we invest in the most promising research now.