



Huntington's Disease Society of America



Central Ohio CHAPTER

OUR VOICE

SPRING 2017

President's Letter

Dear Families,

Greetings from the Central OH chapter of HDSA!

I hope the conclusion of this mild winter finds you and your families well. For those of you who weren't able to join us for our year-end activities (our Annual Dinner at Der Dutchman, the OSU Tailgate Party at our Celebration of Hope and our Music for Hope events), I hope you will be able to attend one of our upcoming events this spring or summer. In this edition of our newsletter, you will see dates for most of our events for 2017! I look forward to seeing you!

As you know, the success of our fundraising helps our families affected by Huntington's disease in numerous ways and would not be possible without our extraordinary event chairs! I would like to take time to thank those who have given so generously of their time in organizing these fantastic events & fundraisers – Wendy Vaughan/Celebration of Hope, Ron Ioia/Music for Hope, Marilyn Hixson/Amaryllis Sale, Craig Baldwin/Swim Against HD, Katy Simon & Steve Hammond/Hoop-a-thon, Jaclyn Hindel/Team Hope Walk – Zanesville, and Lenae Tunila/Team Hope Walk - Hilliard. If you are interested in helping us at one or more of the aforementioned events, please contact me or the chair of the event.

And I want to wish a heartfelt thank you to YOU – our families – for supporting us in our quest for a cure. If you haven't visited our national HDSA's website recently <http://hdsa.org/>, there are some exciting news & research information that might be of interest. While you are there, you can register for the HDSA Annual Convention that takes place June 23 – June 25 in Schaumburg, IL.

I recently saw the following and thought some of you would enjoy seeing the trailer to this newly produced documentary *Her Mother's Daughter* that is by Rae Maxwell and produced by HDSA. The documentary introduces the world to Kathi O'Donnell and shows the devastating impact that Huntington's disease (HD) & juvenile Huntington's disease (JHD) has had on the O'Donnell family. As mentioned on the HDSA website, the film is a window into Kathi's inspiring journey as a caregiver as we see the different stages of HD & JHD (a rare form of HD that progresses more rapidly than adult onset.) *Her Mother's Daughter* is a powerful documentary of family, love and hope – across generations and against all odds.

I've put in a request to our national organization to see if any of our chapters can have access to watching the documentary too. Here is the link to the trailer: <http://hdsa.org/HMDfilm/>. I'll keep you updated if we are able to gain access to the documentary to host a chapter/group viewing.

Looking forward to the bright colors of spring & the more seasonable temperatures that will arrive shortly! Hope to see you at our first fundraiser on April 22nd at our Annual HDSA Hoop-a-thon!

Fondly,
Daphne Hess
Chapter President

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?

- <http://en.hdbuzz.net/> is a website covering research news, written in plain language, by scientist, for the global HD community.
- The most basketball free throws in one minute is 52 and was achieved by Bob J. Fisher (USA) in Blue Rapids, Kansas, USA, on 4 January 2015. Fisher took 75 shots during the record attempt.

guinnessworldrecords.com



Shoot for a Cure!

The 32nd Annual Hoop-a-Thon will be held on Saturday, April 22nd from 11am to 4pm at [St. John's Lutheran](#), 3220 Columbus St., Grove City, Ohio, 43123.

Fun, raffles, music, and food will be on hand. Shooters take pledges to see how many free throws they can make in 5 minutes. Come and enjoy a time of fellowship while supporting this important event.

To volunteer talk to KATY SIMON at (614)589-2845 or email her at khammond912@gmail.com.

You can also download a pledge sheet or make a donation at:

<http://centralohio.hdsa.org/about/hoop-a-thon>

5TH ANNUAL SWIM AGAINST HD IS APRIL 1st

The 5th Annual Swim Against Huntington's Disease is being held on Saturday, April 1, 2017. This event is at the McCorkle Aquatic Pavilion at The Ohio State University, 1847 Neil Avenue, Columbus, Ohio 43210.



This particular event is open to members of the United States Masters Swimming (USMS) to compete in. This is a swimming competition with all the proceeds and donations going to find a cure of HD. Swimmers can range from 18 to 100 years old. The swimmers can select up to 5 individual events and 2 relays in which to race. Each race is seeded according to the times the swimmers provide with their registrations. The fastest swimmers regardless of sex or age swim against each other in the race heats. The races are scored based on gender and age brackets (each age bracket covers 4 years). This meet has also been designated as the OHIO LMSC short course championship meet. This designation gets more swimmers from around the state excited about competing at this pool with their fellow teammates.

We make our money by charging a registration fee for each swimmer to compete in the meet. The swimmers are also given the option of making additional donations and are given the tools to create a website to solicit friends and relatives for donations.

Warm-ups for the meet begin at 10:30 AM. The races start at 11:30 AM. The meet usually ends between 3:30 and 4:30 PM. The after party event will be held at the 'Chop Shop' a gourmet burger restaurant located at 2159 North High street. Pricing is around \$7 per head, which is a great deal. Everyone with a ticket will be able to order one of their delicious burgers and a fountain drink. A supply of sides including fresh cut fries, battered onion rings and salad are also available. There is a full bar which will have special event pricing. Free parking is available at 'The Little Bar' a few doors to the north. The Chop Shop is a 4 minute drive from the Neil Avenue Parking Garage. Tickets for the after party are available at the event registration table or see Craig Baldwin.

To register to swim and for more details, contact Craig Baldwin at ncbaldwin@zoho.com or 740-605-4785

To register or donate, click <http://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=1136>

Link to 'Chop Shop'
<http://www.chopshop614.com/about/>

OFFICERS AND BOARD

President:
Daphne Hess
dhess5556@yahoo.com

Past President:
Norm Baldwin
normbaldwin@frontier.com

Vice President:
Jaclyn Hindel
jmhindel1213@gmail.com

Treasurer:
Anne Kuschnerus
akuschnerus@yahoo.com

Secretary:
Debbie Ioia
daioia022@yahoo.com

Board Members:
Norm C. Baldwin
Justin Ford
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Tom Ioia
Keith Jones
Dr. Sandra Kostyk
(Medical Advisor)
Katy Simon
Lenae Tunila
Wendy Vaughan
Kelvin 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!



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, at 614-390-8009)

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](#).

Watch a research webinar from national, click [here](#).

Thank you from Norm Baldwin

Daphne Hess and I served the past year as “Co-Presidents” with Daphne being the lead officer. She is now the official president and I am officially a past president. The Chapter is in good hands, I thank her for work already done and that yet to be done.

I would also like to thank all who have worked so hard to advance the cause. As the saying goes, it has been an honor and a privilege to work with all of you. I especially appreciate the friendships that we have built over the years; something good from a battle against something so difficult.

If you will allow me one observation. The search for care and the cure can be defined with three essential parts. First the research facilities are necessary. No labs, no research people, no cure. Second is money. No funding, no cure. Third and also vital, volunteers in the trials. No volunteers, no trials, no cure. The Central Ohio Chapter is blessed in our efforts to do all three. The Center of Excellence provides the facility and the research people. Our Chapter raises money to fund the care and the cure. And many of our people with HD are and have been participants in research. Thanks to all of you for your efforts, especially those who are and have been in research programs. These programs lead the way to care and cure.



CENTER OF EXCELLENCE

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

Clinic nurse:
Kate Ambrogi
614-293-4969

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

HD Helpline
614-292-9960

NATIONAL YOUTH ALLIANCE

“Dedicated to making ours the last generation with Huntington's disease.”

Update from the National Youth Alliance!

Hello everyone! My name is Melissa and I am the Youth Services and Recruitment chair for the NYA board. I happen to live right here in Columbus! If you have any questions or would like to chat or meet up, feel free to reach out to me at anytime at mryant@hdsanya.org.

Have you heard about the NYA Youth Retreats? We are hosting 4 of them this year and they are completely FREE! That's right- the retreat, hotel, and travel is all taken care of courtesy of TEVA and HDSA! The first one is taking place in Pittsburgh and we are thrilled to say that we are at capacity! If you didn't get your application in for the Pittsburgh retreat no worries because there are still 3 more for the year! Our next one will take place in Iowa City 7/28-7/30! Applications for Iowa are now available, for more information to sign up for retreats, click here: <http://nya.hdsa.org/nya-day-retreats>

The HDSA National Convention is only a few months away! Be sure to take advantage of scholarship opportunities- the NYA is dedicated to spending every last dollar to get YOU to convention! We grant full scholarships as well as partial scholarships. Whether you need help paying for just the hotel, airfare, or registration be sure to apply! EVERY NYA MEMBER IS ELIGIBLE. Not a member? Sign up at our website!

Applications are DUE April 12th. Note: Consideration will first be given



to those who did not receive a NYA Scholarship in 2016. <https://fs22.formsite.com/hdsa/form30/index.html>

The best way to stay up to date with NYA news is to sign up for our emails! You can do that at our website: <http://nya.hdsa.org/>. You will automatically receive a welcome email, so be sure to check your junk folder if you don't receive it!

Be sure to like us on facebook and follow us on twitter and instagram!

<https://www.facebook.com/HDSANYA/>

https://www.instagram.com/hdsa_nya/

<https://twitter.com/hdsanya>

 Huntington's Disease Society of America



32nd Annual HDSA Convention is June 22—24!

The convention will take place at the elegant Schaumburg Hotel and Convention Center near Chicago.

There will be three days of education, family, fun, and comradery!

To register for the convention, get scholarship information, book a room, look at airline information...visit the national website or click [here](#).



Celebration of Hope 2016, a wonderful event!

Our fall Celebration of Hope was a big win*! The indoor tailgate at King Avenue 5 was attended by many fans who saw the Ohio State Buckeyes make a sweeping win over the Oklahoma Sooners. Our offensive play for the evening was raising over \$22,000.

So grateful to our major donors:

John Dalton and Daphne Hess Family

The Cullman Family

The Vaughan Family

The Baldwin Family

Robert J Weiler Family

Dr. Sandra Kostyk

Teva NeuroScience

and the many many other friends and family who gave and attended this wonderful event.



*See page 11 for photos of Celebration of Hope 2016!

CENTRAL OHIO CHAPTER

HDSA
Central Ohio Chapter
P.O. Box 1077
Westerville, OH 43086-7077

Email:
cenohiohdsa@gmail.com

Phone:
614-360-1585

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

JOIN A WALK FOR THE CURE!

2017 Zanesville Team Hope 5K and Walk

Zane's Landing Park



The Team Hope Walk in Zanesville, Ohio is underway for the 2017 year!

We are excited to have Team Mandi as a honoree at our walk this year that will take place at Zane Landing Park on May 13, 2017!

Help us get started by registering for our walk here
<http://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=1093>.

2017 Hilliard Team Hope 5K and Walk



Washington Township Homestead Park
4675 Cosgray Road, Hilliard, OH 43026
Saturday July 22, 2017

Check-in begins at 8:00am
Walk begins at 9:00am

Contact: Paula Lintz
Phone: 614-207-9708
Email: Paula.Lintz@hsc.honda.com

To register and/or donate click [here](#).



MEMORIALS AND HONOREES

In Memory of...

Charlotte Kroner

Phillips Companies

Mike Morrison

Norman and Bonnie Baldwin

Elaine Meyer

Joseph and Jane Meyer

Norman and Bonnie Baldwin

Kenneth and Barbara

Honemann

Duff and Connie Jo Parker

Eldore and Jane Gerken

Benjamin and Lana Bostelman

Valerie Brewer

Scott and Jennifer Hehr

F. David and Shirley Gibson

Richard and Peggy Kennedy

Beverly Stockdale

Mark and Jan Barnes

Darrel and Mary Basinger

Thomas and Dorothy Newell

Bringman & Co., Inc

Daleena Brown

Norman and Bonnie Baldwin

Michael and Joyce Johnson

Roger and Wendy Vaughn

Robert Allman

Steven and Catherine Guess

Herron Financial Group

William and Shirley Koniewich

Mossbarger and Smithson

Certified

Paul R. and Carol Minshall

Campbell Concrete Construction

In Honor of...

Bonnie Baldwin

Joseph and Jane Meyer

Linda Christie

John and Janet Cleland



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.



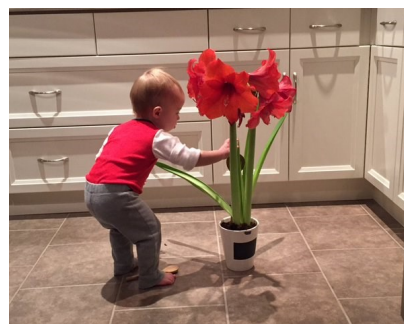
Amazon sets aside .5% of each sale for donation to charities. To designate HD as your charity go to <https://smile.amazon.com/> and follow the prompts.

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

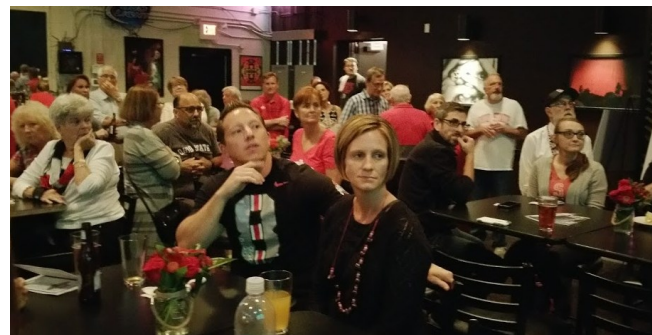
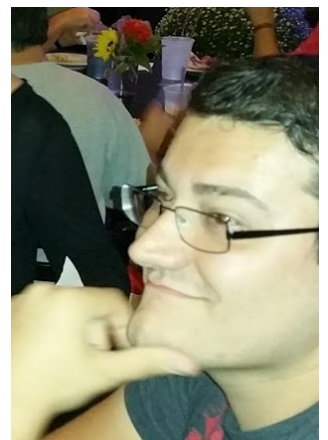
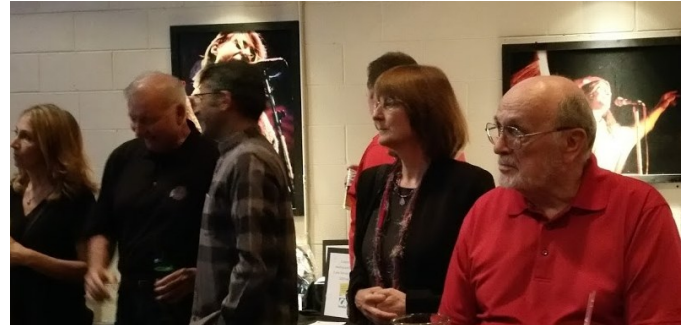
Amaryllis Sales bloom hope!

Marilyn Hixson lead another successful Amaryllis project to close out the chapter fund raising for 2016. Gross sales exceeded the goal of \$5000, with sales being just shy of \$8,000. Half of those monies will go towards research. Thanks to all who participate in this project. A good fundraiser and an excellent program educating the public about HD. One report of a pastor using the Amaryllis as

an example in her sermon of "new life" and citing hope to those afflicted with HD.



Celebration of Hope 2016 raises over \$22,000!



Thank you Wendy Vaughn for chairing this wonderful event!

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.

<http://hdsa.org/>

*Help for Today,
Hope for Tomorrow.*