



Huntington's Disease Society of America



Central Ohio CHAPTER

OUR VOICE

President's Letter

Welcome to our Spring 2016 Newsletter! I am a new face to the Central Ohio Chapter of the Huntington's Disease Support Association Board and look forward to meeting you as I work with Norm Baldwin to transition to the role as your new president. Since some of you may not know me, I am a wife to Dave, mom to Eric and Kylie, a teacher of math at Beechcroft HS (Columbus City Schools) and the boys' and girls' tennis coach! I've never known a life that is not immersed in activities!

Our family is fairly "new" to Huntington's Disease. My father-in-law was diagnosed with HD in 2007. I've learned a lot since that time – as many of us have experienced since HD touches our families and friends. My husband tested positive in 2008. By participating in the HDSA, we've had the tremendous opportunity to meet many wonderful families whose loved ones are affected by HD.

I want to take the time to thank Norm Baldwin for all he has done to take our HDSA chapter to the next level. Norm, Bonnie and his family have been intimately involved in all the fundraisers for our chapter, participating in the monthly support group meetings, and his son was instrumental in starting the Columbus Swim Against HD event! I take this opportunity to thank you, Norm, for your generous gifts of leadership, support and time to the Central Ohio Chapter of the HDSA!

As with any new chapter leader I want get to know you – our membership – to help take our fundraising to support our Ohio State University Center of Excellence and support of our families to the next level. In order to accomplish this, our chapter needs YOU to volunteer to help at one of our fundraisers and/or help recruit volunteers and participants! Our chapter is only as strong as its members, and I know we've got an outstanding group who understands that we are always looking for additional help.

Our Spring/Summer activities include the following... won't you please consider volunteering and participating at one or more of the events? You will be among a great group of people who are helping us get closer to finding a cure for HD.

Saturday, April 2 nd	10:30 am	4 th Annual Columbus Swim Against HD (McCorkle/OSU Campus)
Saturday, April 16 th	11:00 am	Annual Hoop-a-thon (St. John's Church, Grove City)
Saturday, May 21 st	8:30 am	Zanesville Team Hope Walk (Zane Landing Park, Zanesville)
Saturday, July 23 rd	9:00 am	Hilliard Team Hope Walk (Homestead Park, Hilliard)

Also, don't forget about the 31st Annual HDSA National Convention! This year in Baltimore, MD from June 2 thru June 4.

If you have any questions, I can be contacted at dhess5556@yahoo.com Thank you for your assistance! I look forward to meeting you!

Daphne Hess
Chapter President

SPRING 2016

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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IMPORTANT UPDATES!

- See page 11, HDSA Center of Excellence at The Ohio State University Wexner Medical Center updates!

CELEBRATION OF HOPE, A SUCCESS!

This year's Celebration of Hope was held at King Ave 5 Bar and Restaurant.

It was a very successful, upbeat, and positive event, raising over \$14,000 net.

A big thanks for Wendy Vaughan for leading this year's Celebration of Hope.

Thank
You

***Celebration of Hope raised over \$14,000.
Thank you Wendy Vaughan and to everyone who contributed!***

Did you know?

- You don't have to swim to enjoy the Annual Swim Against HD. Come cheer on the swimmers, volunteer to be a timer, pass out ribbons...there's so much you can do. Talk to Norm C. Baldwin today!

4TH ANNUAL SWIM AGAINST HD IS APRIL 2nd!

Article by: Norman Craig Baldwin

The 4th Annual Swim Against Huntington's Disease is being held on Saturday, April 2, 2016. This event is at the McCorkle Aquatic Pavilion at The Ohio State University, [1847 Neil Avenue, Columbus, Ohio 43210](https://www.google.com/maps/place/1847+Neil+Avenue,+Columbus,+OH+43210/@39.954244,-83.000644,17z/data=!3m1!1e3!3m2!1s1847+Neil+Avenue,+Columbus,+OH+43210!8m2!3s1847+Neil+Avenue,+Columbus,+OH+43210!3s0x88255d77e0000000:0x88255d77e0000000). This particular event is open to members of the United States Masters Swimming to compete in. This 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 events in which to race. Each race is seeded according the times the swimmers provide with their registrations. The fastest swimmers regardless of sex or age swim against each other in the races. The races are scored based on sex, and based on 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.

Swim Meet (continue)

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 should end between 3:30 and 4:30 PM. The after event party will be held at the '[Chop Shop](#)' a new gourmet burger restaurant located at [2159 North High street](#). Pricing will be around \$6 per head, which is a great deal. Everyone with a ticket will be able to order one of delicious burgers and a fountain drink. A supply of sides including fresh cut fries, battered onion rings and salad will be 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.

Come and enjoy the party!

To donate, click [here](#).

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



thanks

to everyone
who purchased
amaryllis

flowers during the 2015 Amaryllis campaign.
The 2015 Amaryllis sales went very well this year, netting \$3,200.

Thanks to Norm Baldwin for his leadership in this endeavor. Special thanks to everyone who purchased a flower bringing hope for a cure.

OFFICERS AND BOARD

Co-President:
Daphne Hess
dhess5556@yahoo.com

Co-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

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Norm C. Baldwin
Steve Hammond
Barb Heiman
Deanna Henry
Marilyn Hixson
Dr. Kari Hoyt
Debbie Ioia (Secretary)
Ron Ioia
Tom Ioia
Keith Jones
Dr. Sandra Kostyk
(Medical Advisor)
Katy Simon
Lenae Tunila
Robert Strausbaugh
Wendy Vaughan
Devon Walker
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

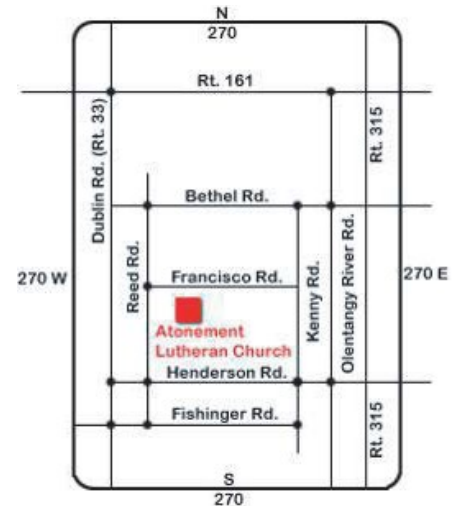
1621 Francisco Rd.
Columbus, Ohio 43220

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

CENTRAL OHIO
CHAPTER WEBSITE
[http://
centralohio.hdsa.org/](http://centralohio.hdsa.org/)

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.

"There are no problems we cannot solve together and very few that we can solve by ourselves" – Lyndon Johnson

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

31ST ANNUAL HOOP-A-THON is APRIL 16th!

The 31st Annual Hoop-a-Thon will be held on Saturday, April 16th from 11am to 4pm at [St. John's Lutheran](#), 3220 Columbus Ave. Grove City, Ohio.

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, enjoy a time of fellowship and support this important event.

To register and/or make a pledge, click [here](#).

For more information CALL KATY SIMON (614)589-2845 or EMAIL khammond912@gmail.com .



You can also get a pledge sheet at

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

Walk-ins welcomed!

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. 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.

HDSA AWARDED FOUR STARS

“HDSA outperforms most other charities in America.”

-Michael Thatcher

“At HDSA, Family is Everything.”

- Louise Vetter

2015 Year in Review from the National Office

“Every HDSA mission program grew in 2015. We now have 45 percent more HDSA Centers of Excellence, a total of 19 Human Biology research awardees, and support from more than half of the US House of Representatives for the HD Parity Act! This is unprecedented impact for HD families which is complemented by the HDSA Annual Convention and our networks of more than 30 local education events, 50 HDSA supported social workers, 170 HDSA support groups and our national helpline. Team Hope is now 18,000 volunteers strong and Huntington’s disease is featured in the news on a daily basis.

These extraordinary efforts have not gone unnoticed. In 2015, Charity Navigator, America’s largest charity evaluator, awarded HDSA four stars — its highest rating. “HDSA outperforms most other charities in America,” said Michael Thatcher, Charity Navigator’s CEO.

Our work is far from done, but every day more families are able to depend on the help and hope that’s made possible by your support.

At HDSA, Family is Everything. Thanks for being part of our family commitment to a world free of Huntington’s disease.”

— Louise Vetter,
HDSA Chief Executive Officer

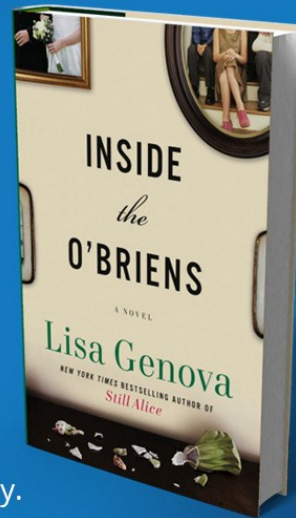


Read the entire [2015 Year in Review Report](#) on the National Website.

READ

Inside the O'Briens is a new book by **Lisa Genova**, the *New York Times* Bestselling Author of *Still Alice*.

Inside the O'Briens concerns the devastating impact that Huntington's disease has on an individual and his family.



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

ABOUT HD

Huntington's disease (HD) is an inherited brain disorder that results in the progressive loss of both mental faculties and physical control.

Symptoms usually appear between the ages of 30 to 50, and worsen over a 10 to 25 year period. Ultimately, the weakened individual succumbs to pneumonia, heart failure or other complication.

Everyone has the HD gene but it is those individuals that inherit the expansion of the gene who will develop HD and perhaps pass it onto each of their children.

Presently, there is no cure. Although medica-

tions can relieve some symptoms, research has yet to find a means of slowing the deadly progression of HD.

Current estimates are that 1 in every 10,000 Americans has HD and more than 250,000 others are at-risk of having inherited it from a parent.

Once thought a rare disease, HD is now considered one of the more common hereditary diseases.

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

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

CENTRAL OHIO CHAPTER

HDSA
Central Ohio Chapter
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Westerville, OH 43086-7077

Email:
cenohiohdsa@gmail.com

Phone:
614-360-1585

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

JOIN A WALK FOR THE CURE!



2016 Zanesville Team Hope 5K and Walk

Zane's Landing Park
Zanesville, OH 43701
Saturday, May 21, 2016

Check in at 8:00 AM
Walk begins at 8:30am

Contact: Jaclyn Hindel
Phone: 740-221-5359
Email: jmhindel1213@gmail.com

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

2016 Hilliard Team Hope 5K and Walk

Washington Township Homestead Park
4675 Cosgray Road, Hilliard, OH 43026
Saturday July 23, 2016

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

Contact: Paula Lintz
Phone: 614-207-9708
Email: lintzpj@gmail.com

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

31st Annual HDSA Convention will be held in Baltimore



For all the latest details on the 31st Annual HDSA Convention, visit the national website or click [here](#).

The convention will take place at the Hyatt Regency along the picturesque Inner Harbor.

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

The dates are June 2 - 4, 2016.

*Help for Today,
Hope for Tomorrow.*



MEMORIALS AND HONOREES

In Memory of...

Sherman Shoemaker

Frederick Seidler

Gary J. Nash

James & Verdale Metzger

Lawrence & Verna Meyer

Michael and Christie Meyer

James Meyer

Michael and Christie Meyer

Russell Meyer

Michael and Christie Meyer

In Honor of...

Bonnie & Norm Baldwin

Michael and Christie Meyer

In Honor of...

Elaine Meyer

Michael and Christie Meyer

David & Betty Meyer

Michael and Christie Meyer

Mark & Kathy Meyer

Michael and Christie Meyer

“If there ever comes
a day when we can’t
be together, keep me
in your heart. I’ll
stay there forever.”

-Winnie the Pooh

HDSA Center of Excellence at The Ohio State University Wexner Medical Center Updates

Submitted by Dr. Sandra Kostyk

On February 1, 2016, we received the news that we have been approved for Center of Excellence funding for the 16th year in a row. There are now 39 centers in the United States that meet different COE designation levels. We are grateful for the support of our community that helps us maintain our multidisciplinary team approach to HD.

At the end of 2015, we moved our HDSA COE clinic back to the 7th floor of the Martha Morehouse Tower at [2050 Kenny Road, Columbus Ohio 43221](#). There have been no changes in phone numbers or contact information. However, we have split the clinic into two half days rather than one full day and this seems to be helping keep clinic flow smoother. Clinic now meets on Mondays starting at noon and Fridays starting at 9:00 AM.

Our team continues to support the HD research efforts. Current trials include the observational trial ENROLL-HD and interventional trials including the Pfizer Amaryllis trial, the Vacinnex Signal Trial and Auspex ARC trial. We will soon be starting a phase two NeuroNext trial to study a potential new medication that may be helpful to treat the irritability that is sometimes associated with HD.

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