



Huntington's Disease Society of America



Central Ohio CHAPTER

OUR VOICE

SPRING 2015

President's Letter

When asked "What does the Central Ohio Chapter of HDSA really do?", it could honestly be said that we raise money. Sometimes in frustration that may seem to be the only answer. To answer the question "What do we do?", we need to look at where the money that we raise is spent. A portion is spent locally and a portion goes to our National organization. which in turn provides funding for activities to fulfill our goals: Education, Care, and the Cure.

Following are listed some of the activities that are funded by the money and time you donate in support of HDSA.

Education: 1) Literature produced by national providing information about HD to the public and to those of us affected by HD. 2) The National Web Site at www.hdsa.org. Check it out; it has a wealth of information. 3) Our Central Ohio Web Site at www.hdsa.org/cohch. 4) Our Facebook page (Huntington's Disease Society of America, Central Ohio Chapter). 5) The National Convention. 6) Our Bi-Annual HD Educational Day program. 7) Advocacy programs.

Care: 1) National helps fund our Center of Excellence at OSU. The Center provides the best of medical care to HD patients. The Center provides genetic counseling, genetic testing, counseling for physical therapy, occupational therapy, speech therapy; counseling by a social worker, and training to area nursing homes to provide the best care possible for HD patients. 2) Our local support group provides information and support to those in need, as well as sharing with those who have and those who are walking the path of HD.

Cure: 1) National provides funding to several cutting edge research programs. Check the [National Web Site](http://www.hdsa.org) to see all that is going on; progress is being made! 2) Research programs are ongoing at our Center of Excellence at OSU. Programs that you may participate in and help find the cure.

Perhaps, what may be the best service of all, is the making of new friends and the fellowship enjoyed at all of our activities. What you do for HDSA in

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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Special point of interest

- Sat. March 28th is Education Day, 10:00 am to 12:30 pm, at the Martha Morehouse Pavilion, 2050 Kenny Road, Columbus, Ohio.



Maureen Nash chaired another successful Celebration of Hope last year at the Rife Center in downtown Columbus. The lobby of the Capitol Theatre with a view of downtown Columbus and the Capitol Building provided a beautiful setting and was enjoyed by all who attended. **Over \$15,000 was raised to help fund the OSU Center of Excellence.**

The Central Ohio Chapter extends our thanks to all who supported the Celebration and to Maureen for her leadership. Plans are under way for this years Celebration of Hope, to be held the first week in October.

*The 2014 Amaryllis sales surpassed our goal, thanks to the leadership of Marilyn Hixson.
Net receipts exceeded \$3300! Ron Ioia's Music for Hope raised over \$1700!
Thanks to Marilyn and Ron for their efforts for HDSA.*

Did you know?

- The Central Ohio Chapter received the National Award for the Best New Fund Raising Event of the Year in 2014. Thank you Norm C. Baldwin for the Arnold Swim Meet.
- You don't have to swim to enjoy the Annual Swim Against HD. Come cheer on the swimmers, volunteer to be a time, pass out ribbons...there's so much you can do. Talk to Norm C. Baldwin today!

3RD ANNUAL SWIM AGAINST HD IS APRIL 11th!

Article by: Norman Craig Baldwin

The 3rd Annual Swim Against Huntington's Disease is being held on Saturday, April 11, 2015. 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 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)

There are 19 events to chose from:

- | | | |
|--------------------------|---------------------------|-------------------------|
| 1. 500 Freestyle | 8. 400 Individual Medley | 15. 200 Backstroke |
| 2. 100 Breaststroke | 9. 50 Breaststroke | 16. 100 Freestyle |
| 3. 200 Individual Medley | 10. 100 Backstroke | 17. 200 Breaststroke |
| 4. 50 Backstroke | 11. 200 Butterfly | 18. 50 Butterfly |
| 5. 50 Freestyle | 12. 200 Freestyle | 19. 200 Freestyle Relay |
| 6. 100 Butterfly | 13. 200 Medley Relay | |
| 7. 400 Freestyle Relay | 14. 100 Individual Medley | |

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. The first two years we had around 120 swimmers, and netted ~\$8000 each year from the Swim Against HD events. I'm a member of the Columbus Sharks Masters Swim Team. My team has given a generous cash donation in the first two years.

This year the OHIO LMSC has added a twist. Hopefully we'll end up with more swimmers. They have agreed to pay the first \$25 of the \$50 registration fee for the first 100 swimmers who are members of the OHIO LMSC. This will hopefully encourage more swimmers to attend the meet.

Warm-ups for the meet begin at 10:30 AM. The races start a 11:30 AM. The meet should end between 3:30 and 4:30 PM. There is an after meet social that is held on High Street, at The Big Bar. We hand out VIP cards at the meet. People present the cards at the [The Big Bar](#). Once there they pay \$5 to get access to a buffet that runs about 2 hours and get to buy drinks at Happy Hour pricing.

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

OFFICERS AND BOARD

President:
Norm Baldwin
740-468-9081
normbaldwin@frontier.com

Vice President:
Devon Walker
740-962-2141
dnwalker02@hotmail.com

Treasurer:
Anne Kuschnerus
akuschnerus@yahoo.com

Board Members:
Craig Baldwin
Larry Brown
Steve Hammond
Barb Heiman
Deanna Henry
Marilyn Hixson
Dr. Kari Hoyt
Debbie Ioia (Secretary)
Ron Ioia
Tom Ioia
Dr. Sandra Kostyk
(Medical Advisor)
Maureen Nash
Katy Simon
Lenae Tunila
Robert Strausbaugh
Wendy Vaughan
Kelin Wheaton

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

HD Helpline
614-292-9960

What happens at Support Group?

A meeting usually has two groups. One is a typical sharing meeting offering information and support. The other group involves fellowship and making a craft.

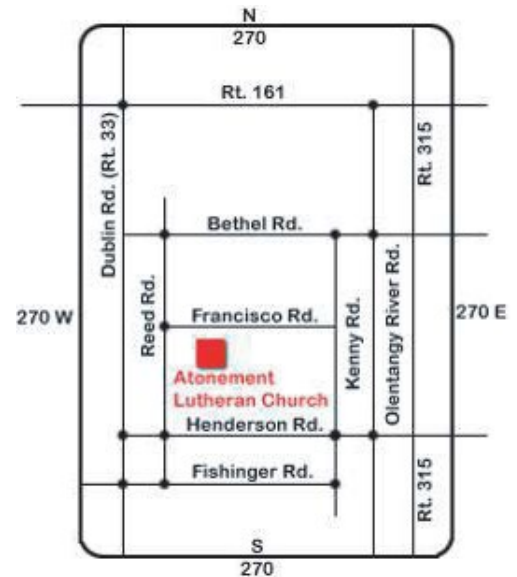
Periodically we have speakers on current topics and research.

There are two basic reasons to attend group meetings. One is to GET HELP. The second is to GIVE

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 and encouraged to attend. For more information contact Barb Heiman at 614-390-8009

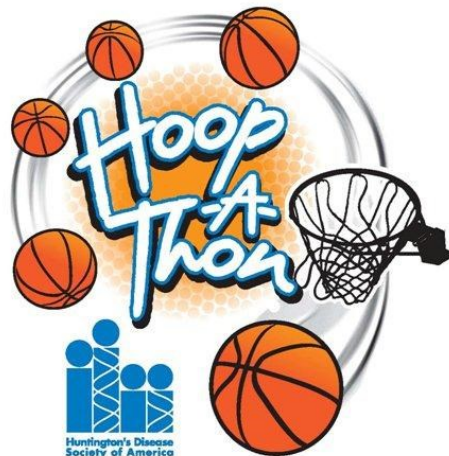


HOOP-A-THON

Would you like to make a direct donation to the Hoop-a-thon? [Click here to donate for a cure!](#)

The Hoop-a-thon will be at [St. John's Lutheran](#), 3220 Columbus St., Grove City, Ohio on Saturday, April 25th.

For more information about the Hoop-a-thon, see the next page!



30TH ANNUAL HOOP-A-THON is APRIL 25th!

The 30th Annual Hoop-a-Thon will be held on Saturday, April 25th from 11-4 at St. John's Lutheran Church, Columbus Ave. Grove City, Ohio.

This year the shooters are encouraged to shoot in memory or honor of a loved one. Materials will be available to personalize your Hoops t-shirt. A table will be available to display pictures of those being remembered. Please share in this endeavor.



All of the other fun, raffles, music, and food will be on hand. Come, enjoy a time of fellowship and support this important event.

To obtain a Pledge Sheet, click [here](#).

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.

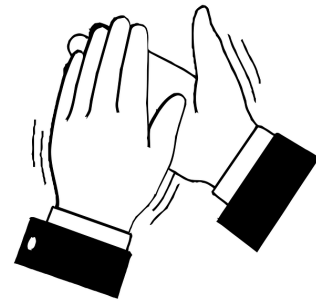
WE ARE SO PROUD

"HDSA is excited to recognize twenty-nine exceptional clinics in 2015 and directly support their comprehensive approach to helping families manage the challenges of Huntington's disease," said Louise Vetter, HDSA's Chief Executive Officer. "These awards are made possible by the incredible generosity of the HDSA community, who are united in their commitment to bring help and hope to more families, in every corner of the United States."

HDSA EXPANDS CENTER OF EXCELLENCE

HDSA announced on Feb. 29th, that it is expanding its support of Centers of Excellence from 20 to 29, an increase of 45% from 2014. For the complete news release, go to hdsa.org and click on NEWS article from 2/10/15. The OSU Center of Excellence under the leadership of Dr. Kostyk has been a Center of Excellence from the beginning of this program, celebrating its 15th year. The OSU Center of Excellence is recognized

as one of the highest rated Centers of Excellence. The Central Ohio Chapter is proud to support the OSU Center of Excellence with our Celebration of Hope event in October .



SIGN UP FOR NEWSLETTERS

You may have received this newsletter twice because you signed up for Mail-chimp and you're also on our old e-mail list.

It is our goal to establish our e-mail list in the Mail-chimp program. The benefit with Mail-chimp is that you can sign up directly and choose the type of mail you wish to receive. You can even update your own e-mail address ensuring you get your newsletter in a timely fashion!



If you have not already done so, please sign-up for Mail-chimp. **Click on the green check button above and complete the information requested** or go to www.hdsa.org/cohch/ and click on "Newsletter", then click on "Subscribe to our newsletter".

It doesn't take long to sign up. When we have a substantial number of subscribers , we will discontinue the old e-mail list.

FBI SUPPORTS HD



The FBI will again be supporting HDSA at their annual golf outing. This year's tournament will be held on Thursday, June 25, 2015, at The Golf Club of Dublin, Dublin, Ohio.

The FBI will continue to recognize Special Agent John Karnemaat who lost his battle with Huntington's Disease on November 5, 2007. John's daughter attended last year's tournament shared a moving presentation.

The Central Ohio Chapter is grateful for the support of the FBI.

If you would like to donate door prizes to the FBI outing contact Norm Baldwin at normbaldwin@frontier.com or for more information about the FBI outing go to <http://www.tonychristymemorial.com>

We are united by a common experience, purpose, and hope. Together we can!

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/>

CENTER OF EXCELLENCE

Davis Center
480 Medical Center Drive
First Floor
Columbus, Ohio 43210
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

JOIN A WALK FOR THE CURE!



2015 Hilliard Ohio Team Hope 5k and Walk

Washington Township Homestead Park
4675 Cosgray Road Hilliard Ohio 43026

Saturday July 25, 2015

Registration begins at 8:00 am

5k begins at 8:30 Walk begins at 8:40

\$25 5k \$20 Walker

Click [here](#) for registration form or contact chairperson Paula Lintz.

DONATE by clicking [here](#).

JOIN TEAM HOPE TODAY!

And Support The Huntington's Disease Society of America



Every Step Takes Us Closer To Our Goal. You can help the Huntington's Disease Society of America find a cure for HD and provide help to the 30,000 Americans with HD and the 250,000 who are at risk.

All proceeds support HD SA's fight to improve the lives of people affected by HD and their families.





This year's chairperson, Jaclyn Hindel, is leading the way with Phyllis Shoemaker.

Team Hope Walk For Huntington's Disease

May 23, 2015

**Zane's Landing Park
Zanesville, OH
8:00 AM**

Make a donation and/or get forms at:

www.hdsa.org/thwzanesville

Or donate by clicking [here!](#)

Contact: Jaclyn Hindel

Phone: 740-221-5359

Email: jmhindel1213@gmail.com



MEMORIALS AND HONOREES

In Memory of...

Ron Purdy

Norm and Bonnie Baldwin
Marilyn Hixson
Michael C. Summers and
Cathy A. Boring

David Vaughn

Gary and Barb Heiman
Norm and Bonnie Baldwin

Paul Dorrow

Joseph and Clara Dorozowski

Chip Hixson

Judith K. Castle

Lawrence and Verna Meyer

Michael and Christie Meyer

Russell Meyer

Michael and Christie Meyer

Jim Meyer

Michael and Christie Meyer

Phil Hess

John Dalton

William B. Peterson

The Peterson Family Trust
Holly L. Trask
Scott D. Gill, CPA, INC.
M.H. and C. Riggs
Brian and Beth Robinson
James and Valerie Schmitt

Carol Nolan

Shelly Edwards, Kara, Val, & Mo
Valerie L. Whitton

Tracy Allman

Paul and Carol Minshall &
family

Bud and Nesha Gibson

Michael and Betty Obert

Linda Ferguson

Hazel Kohbarger
Jewel Taylor

Carol Hennessee Kennedy

Beverly & John Stockdale
Phyllis A. Martin Disbrow
Patricia M. & James A. Crager

In Honor of...

Dave Hess and Family

John Dalton

Jean Johnson

Juania J. Ball (Pecan Plantation
Women's Club)

Gary and Laurie Pecuch

Barry and Nancy Fisher

“Walk on with
hope in your heart,
and you'll never
walk alone.”

Shah Rukh Khan

DEEP IN THE HEART OF TEXAS THERE IS HOPE

The 30th Annual HDSA Convention will
be held on June 25-27, 2015
Hyatt Regency at REUnion in Dallas, TX.

[REGISTRATION FORM AND DETAILS](#)

[HOTEL ACCOMODATIONS](#)

[TRAVEL TO CONVENTION](#)

[CONVENTION SCHOLARSHIP](#)



HUNTINGTON'S DISEASE CENTER OF EXCELLENCE EDUCATION DAY

On Saturday, March 28, from 10am—12:30pm, there is a free event for individuals, families, and friends touched by Huntington's Disease.

This event will be held at the [Martha Morehouse Pavilion](#), 2052 Kenny Rd., Columbus, Ohio 43221.

To RSVP, please email shaver.56@osu.edu

A light breakfast will be served. Topics include accessing community resources, driving evaluations, research updates, and a time for questions and answers. (Please visit the research table for information about current clinical trials.)