



Huntington's Disease Society of America



Central Ohio CHAPTER

OUR VOICE

FALL 2015

President's Letter

The Central Ohio Chapter of the Huntington's Disease Society of America (HDSA) is seeking candidates to serve on its Chapter Board of Directors. The Central Ohio Chapter is dedicated to improving the lives of people with Huntington's Disease and their families. Directors are responsible for leading the organization in contributing to the development of the HDSA mission and leading the governing of the organization by implementing the mission.

We are committed to building an increasingly diverse and representative Board. To do this, we are seeking candidates who meet the following criteria:

- A strong passion for the mission of HDSA with a commitment to hands-on involvement.
- A strong commitment to serving people with HD and their families.
- Professional expertise or interest in a least one of the following areas: Accounting, Financial Management, Fund Raising, Marketing & Communications (including public relations, website development and social media), Social Services, or Government.

Interested persons should contact Norm Baldwin at normbaldwin@frontier.com or Katie Boysen at kboysen@hdsa.org no later than Sept. 30th. All individuals will be contacted by a member(s) of the Nominating Committee to review their candidacy. Elections will take place October 13th at the Chapters Annual Meeting.

We look forward to welcoming new members to the Central Ohio Board and thank you in advance for spreading the word and helping to identify our new leaders.

If you have any questions, please contact me. Thank you for your consideration of this request.

Norm Baldwin
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, interested friends, and supporters.

Inside this issue

Chapter Annual Meeting.....	2
Celebration of Hope.....	2/3
Monthly Support Group.....	4
SUCCESSFUL WALKS... ..	4/5
Community Programs.....	5
HDbuzz.....	6
Support Group.....	6
Amaryllis Sale.....	7
Golf for a Cure.....	7
2015 Hoop-a-thon.....	7
Swim Against HD.....	8
Memorials/Honorees.....	9
Centers of Excellence.....	10
About HDSA.....	10



Chapter Annual Meeting, good food and fellowship!

The Central Ohio Chapter's Annual Meeting will be held on Tuesday, Oct. 13th at 6:00 pm at the Der Dutchman Restaurant in Plain City. There will be a report on the past year's activities and the election of board members for the coming year. Come meet Melissa Ryant, a board member of the National Youth Alliance.

To make a reservation contact Norm Baldwin at normbaldwin@frontier.com

***Celebration of Hope benefits the 29 HDSA Centers of Excellence,
including The Ohio State University Medical Center!***

Did you know?

- Maureen Nash chaired last year's Celebration of Hope, raising over \$15,000 to help fund the OSU Center of Excellence!

CELEBRATION OF HOPE

The Central Ohio Chapter Volunteers proudly present this year's theme: **ROCK LEGENDS, a tribute to John Lennon and Elvis Presley.**

The celebration is on Friday, October 2nd, at [King Avenue 5 Bar and Restaurant](#), 945 King Avenue, Columbus, Ohio 43212. Doors open at 7pm. *Come and enjoy!*

7 –8 pm Cocktails and Hors d'oeuvres
8—9pm Walt Sanders and the Cadillac Band
9pm Celebration of Hope Presentation
9:30—10:30pm Walk Sanders and the Cadillac Band

Tickets are \$75 per person of which \$40 is tax deductible. Hors d'oeuvres and 2 drink ticket are included.

Tickets can be purchased online; just click [here](#), or complete and mail in the form on the next page.



Mail reply to:

HDSA, Central Ohio Chapter
P.O. Box 1077
Westerville, OH 43096

CELEBRATION OF HOPE

SPONSOR LEVEL:

Please indicate your choice of sponsorship level:

- ◇ "HELP" (\$5,000 AND ABOVE)
- ◇ "BURNING LOVE" (\$2500 AND ABOVE)
- ◇ "IN MY LIFE" (\$1250 AND ABOVE)
- ◇ "COME TOGETHER" (\$500 AND ABOVE)
- ◇ "STRAWBERRY FIELDS FOREVER"
- ◇ "THAT'S ALL RIGHT" RAFFLE TICKETS
- ◇ IN-KIND DONATIONS

Description of In-Kind Donation: _____

I am unable to attend, but I am please to contribute: \$ _____

I authorize HDSA to charge VISA/MC/American Express in the amount of: \$ _____

Card #: _____ Exp. Date: _____ Security Code: _____

Name On Card: (Print): _____ Ph: _____

Signature: _____ Email: _____

Tickets are \$75 per person of which \$40 is tax deductible. Your generosity benefits the HDSA Center of Excellence Program and research for a cure. Our Tax ID number is 13-3349872.

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.

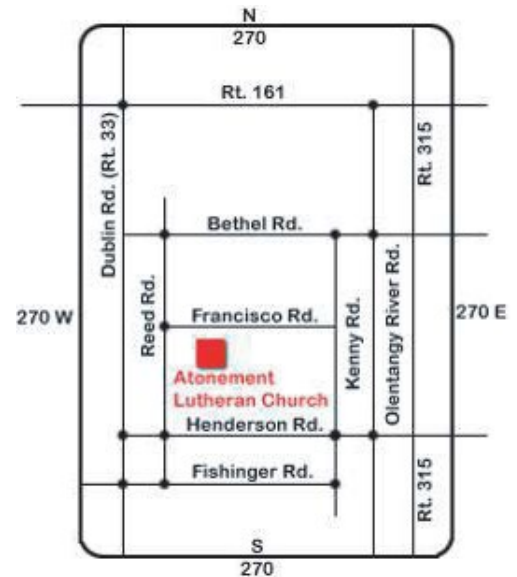
Periodically we have speakers on current topics and research.

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, in the northwest corner of Columbus.

All are welcome and encouraged to attend. For more information contact Erica Peacock at 614-293-4969.



SUCCESSFUL 5K!



The 5th annual Team Hope Walk in Zanesville, Ohio took place on May 23, 2015. Jaclyn Hindel and Phyllis Shoemaker, who expressed their thanks to sponsors and generous supporters, reported that over \$12,000 was

raised for HDSA and that nearly 100 people were at the event. They stated, "We are extremely excited about the overwhelming success of the event and eager to get started planning the 2016 walk!" ***HDSA appreciates the efforts of Jaclyn and Phyllis....THANK YOU!***

ANOTHER SUCCESSFUL TEAM HOPE 5K!

The fourth annual Hilliard Team Hope 5K and Walk was July 25 at the Homestead Park. This year we had a record attendance with 104 registered runners and walkers for HD. We raised \$7,500 and are still expecting a check from Kohl's for an additional \$500. OhioHealth was our sponsor again for the third year. We also had gift cards and other raffle donations from Roosters, The Rusty Bucket, Donatos Pizza and a Team Hope organizer from Pennsylvania. Our top fundraiser was Team Smouter, raising over \$2,800.

Special guests at the event were Dr. Janet Bay System Vice President and Physician Leader OhioHealth Neuroscience, Dr. Sandra Kostyk, Melissa Ryant from our National Youth Alliance, board member, as well as our Lundbeck representative.

We are currently planning our fifth annual Team Hope 5k and Walk for July 23, 2016.



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.

"I first heard about HDBuzz at a support meeting that Dr. Kosytek attended. Now, I see it on the National website! It's brings hope to know that someone cares and is doing all they can to find a cure!"

FIND OUT THE LATEST IN RESEARCH



HDBuzz.net is the first internet portal for the rapid dissemination of high-quality Huntington's disease (HD) research news to the global community, written in plain language, by HD clinicians and scientists. It covers laboratory and clinical research, with the aim of helping HD people to understand the latest HD science, on their own terms. All content is disseminated from hdbuzz.net via free syndication to other HD community websites, blogs and social media platforms like Facebook and Twitter.

[CLICK HERE TO VISIT HDBUZZ.NET](http://hdbuzz.net)

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.



*You can
make A
Difference*

FALL AMARYLLIS SALE!

Huntington's Disease Society of America

The Amaryllis Sale will be coming up! Consider buying a case of flowers and to give as Christmas presents to family, friends, customers, co-workers. An idea: one person buys several cases and gives the flowers to employees; they then have a contest for the first plant to bloom and/or the number of blooms. The plants really are great gifts and help raise money for the HDSA mission, care, cure, and education. To let us know if you'd like to place an order, please contact lpecuch@stjohnsgsc.org.

The **8th Annual Golf for a Cure** was held July 11th at the Glenross Golf Club in Delaware. It was a wonderful day, with many players, good food, great prizes and best of all it was a successful fundraiser. The chairperson, Devon Walker, is confident that our goals of \$5,000 will be reached. ***Thanks to Devon for her hard work and all who made this another success.***



The **2015 Hoop-a-thon** was held at St. John's Lutheran Church in Grove City. It was another festive day with lots of fellowship and fun. St. John's donated their Family Center and an individual donated all of the food, resulting in just \$1000 in expenses. We raised a net of \$12,500 toward our goal of \$15,000. **Steve Hammond and Katy Simon have agreed to chair the 2016 Hoops.** Norm Baldwin, the past chairman urges your support of Steve and Katy. We look forward to another wonderful event in 2016.



Thumbs up for the “winners” of the Hilliard Team Hope 5K!

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

SWIM AGAINST HD DOES IT AGAIN!



The Third Annual Swim Against HD was held on Saturday, April 11th, 2015 at the McCorkle Aquatic Pavilion on The Ohio State University campus. The Swim Against HD is a swim meet for members of the USMS. The swimmers range from 18 to 85 years old. This year we had 135 swimmers. 121 signed up on the website, 7 signed up by mail, and 7 were deck entries. The after-meet party was held at The Big Bar on

High Street across from The Ohio State University (OSU) campus. OSU is not allowed to provide free event space to non-profits, but they do give us a discounted rate on the facility. This year the Ohio LMSC helped increase the number of swimmers at the event. They covered \$25 of each swimmer's entry fee if that swimmer was also a member of the Ohio LMSC chapter of the USMS. There were swimmers from 20 teams. Ohio Splash was the team that scored the most points at the event and the Columbus Sharks was the team that raised the most money. The event netted \$7,681.31 with a gross of \$12,525.25 and expenses of \$4,843.95. A good time was had by all. We received lots of glowing feedback on the event and the cause for which we are raising money. 75% of the gross from this event came from outside the HD community. Thanks for everyone's help and support in putting on this event! **Norman Craig Baldwin, Meet Director Columbus Sharks Masters Swim Team**



MEMORIALS AND HONOREES

"It is often in
the darkest
skies that we
see the
brightest stars."

Richard Evans

In Memory of...

Phil Meeker

Patricia Meeker
Mark & Christy Sayers
E.K. & H.J. Mock
Kenneth & Lori Love
Richard Meeker
Richard Youmans
Karen Haberer
Janet Anderson & Margy Johnson
Roger & Connie Troyer
Betty Ferguson
Jean Daniels & Herman Howard
Esther Thompson
Jeanne Oesch
Miles & Kay Patton
Richard & Virginia Sparks
Ross Shipley
David & Carol Gibson
Norm & Bonnie Baldwin
Douglas Quinn
Stanley & Jean Carpenter Haycook
Micheal & Angelena Mounts
Maxine Kidwell
Jody Meeker
Barb & Gary Heiman
Marilyn Hixson
The Joe Howard Family
Richard Harris Family

Laura Marcum

Jewel Lykins

Chip Hixson

Judith Castle

David Scott Allman

Herron Financial Group
Ruth Skinner
Vic & Diane Skinner

Bob Meese

Barb and Gary Heiman
Norm & Bonnie Baldwin

Robert Cleveland Sr.

Rob & Laura Cleveland

In Honor of...

DaLeena Brown

Larry Brown
Jake Brewer

Jane Hess Family

John Dalton

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



The HDSA Centers of Excellence provide an elite multidisciplinary approach to Huntington's disease care and research. HDSA currently has 29 Centers of Excellence across the United States.

At these world-class facilities, patients benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have deep experience in 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.

ABOUT HDSA

*Help for Today,
Hope for Tomorrow.*

The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by Huntington's disease. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today, hope for tomorrow for people with Huntington's disease and their families.

What is Huntington's Disease?

Huntington's disease 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 during their prime working years and has no cure. HD is known as the quintessential family disease because every

child of a parent with HD has a 50/50 chance of carrying the faulty gene. Today, there are 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease. Many describe the symptoms of HD as having ALS, Parkinson's and Alzheimer's – simultaneously.

HDSA History

HDSA was founded in 1968 by Marjorie Guthrie, the wife of legendary folk singer Woody Guthrie. Woody died from HD complications in 1967 when he was only 55 years old, but the Guthrie family legacy lives on at HDSA to this day.

Together, we hope & work for a cure for HD. To learn more, go to <http://www.hdsa.org/>