



# HAPPENINGS

SPECIAL EDITION – SPRING 2009

HUNTINGTON'S DISEASE SOCIETY OF AMERICA

NORTHEAST OHIO CHAPTER

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## **PRESIDENT'S MESSAGE FROM WES JOHNSTON, PRESIDENT**

Thanks to everyone who is participating in our Chapter's 2009 HDSA Open Forum: Research, Clinical Care and You in Memory of Maddie Waltermire On Saturday, May 16. I want to thank David Waltermire and his committee for organizing this year's meeting and bringing such a wonderful program to our HD families, caregivers, and health care professionals.

We also want to thank our corporate friends for their support: Lundbeck, Inc. (formerly Ovation), october design, Liggett Stashower, ZYMK Productions and Embassy Suites.

Please enjoy this issue of Happenings and read all about our upcoming events. As always, volunteers are needed to help us succeed in all of our endeavors. Two such talented individuals, Jeanie Chresos and Ed Skuza, have donated countless hours to Chapter activities over the past several years working on every event. This year they are the top sponsor for our Team Hope Walking for HD Walk-a-Thon, and Jeanie is the Chairman. We all owe them a huge debt of gratitude for their generosity. If you have time to contribute to serve on a committee or help out at an event, please call the Chapter Office at 330-998-6600

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### **MARK YOUR CALENDARS!**

SATURDAY JUNE 27 – TEAM HOPE WALKING FOR HD  
WALK-A-THON – AKRON - AT THE AKRON ZOO

SATURDAY AUGUST 1 – BLUE JEAN BALL – A CELEBRATION OF AMERICAN MUSIC WITH SPECIAL  
GUEST, DRUMMER TREY GRAY FROM BROOKS & DUNN – NO NECKTIES PLEASE!

SATURDAY SEPTEMBER 5 – GOLF OUTING

SATURDAY SEPTEMBER 12 – TEAM HOPE WALKING FOR HD  
WALK-A-THON – CLEVELAND – WENDY PARK ON WHISKEY ISLAND

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### **THE NORTHEAST OHIO CHAPTER HAS MOVED**

#### **NEW ADDRESS**

**BARBARA KAISER – DEVELOPMENT DIRECTOR**

**10176 LUMAN LANE**

**TWINSBURG OH 44087**

**PHONE: 330-998-6600**

**FAX: 330-998-6677**

**[bkaiser@hdsa.org](mailto:bkaiser@hdsa.org)**

**[www.lkwdpl.org/hdsa](http://www.lkwdpl.org/hdsa)**



## TEAM HOPE WALKING FOR HD WALK-A-THON

This year our Chapter will be participating in two Walks, one in Akron and one in Cleveland.

On Saturday, June 27, 2009 the Northeast Ohio Chapter will hold its Team Hope Walking for HD Walk-A-Thon at the Akron Zoo, 500 Edgewood Avenue, Akron, OH. Registration begins at 8:00 a.m.

Enjoy a fun-filled day of Prizes, Awards, Refreshments and Entertainment, and have fun with the animals!

The \$25.00 registration fee includes Admission to the Zoo, a tee shirt and lunch. Special discounted rates are available for families. Start forming your teams now! Sponsor a signpost in honor of or in memory of a friend or a family member. Corporate signposts are also available. If you want to join Team Hope, (as a Sponsor or as a Walker) call the Chapter Office 330-998-6600 or Jeanie Chresos at (216) 351-3932. You can download a registration form at our website at [www.lkwdpl.org/hdsa](http://www.lkwdpl.org/hdsa)

Donations are being accepted on [www.firstgiving.com/hdsa-oh-ne](http://www.firstgiving.com/hdsa-oh-ne)

We will be partnering with the Vizion Group, which is part of the national walk initiative. Laura McCaskey is our Site Coordinator for both walks. Laura has seven years of experience working in the nonprofit industry here in Northeast Ohio. Her experience encompasses fundraising, marketing and special events. She has worked for organizations such as PlayhouseSquare, The Catholic Diocese of Cleveland Foundation and West Side Ecumenical Ministry. She is a graduate of John Carroll University where she currently serves as an adjunct instructor. She holds a BSBA in Business Management from John Carroll University and an MBA from Cleveland State University.

Following is her contact information: Laura McCaskey - 216-704-0712 - [McCaskeyL@gmail.com](mailto:McCaskeyL@gmail.com)

And, don't let the dust settle on those walking shoes! The Cleveland Walk will be held on Saturday, May 12 at Wendy Park on Whiskey Island. Stay tuned for more details!



## GOLF OUTING - FORE A CURE HICKORY NUT GOLF COURSE - 23601 ROYALTON ROAD (ROUTE 82) COLUMBIA STATION, OH

**SHOTGUN START AT 2:00 P.M.**

**Save the Date—Saturday September 5, 2009**

Mackenzie Platten and her committee are hard at work organizing our first ever golf outing.

It promises to be a great time for a great cause. Besides playing golf, participants will enjoy side games, auctions, fabulous raffle items, and a steak fry. Start forming your foursome today. Foursome price: \$280. Individual golfer—\$75 per person. To sign up, volunteer, sponsor, or donate merchandise, contact the Chapter Office at 330-998-6600 or [bkaiser@hdsa.org](mailto:bkaiser@hdsa.org)

Spend part of your Labor Day weekend helping to fight HD – everyone knows that a bad day at golf is better than a good day at work!

## SOCIAL WORKER SPOTLIGHT

We invite all Huntington's Disease patients, their families, caregivers and individuals who are at risk to attend our monthly Support Group meetings. Monthly meetings are held in Cleveland and Akron and are facilitated by the Chapter's Licensed Social Worker Kristin Zverloff, LISW-S. You can contact Kristin via email at [kitzmiller27@yahoo.com](mailto:kitzmiller27@yahoo.com) or leave a message at the Chapter Office at 330-998-6600 and Kristin will return your call.

**CLEVELAND AREA SUPPORT GROUP MEETINGS** are held on the **Third Monday** of the month from 7:00 p.m. to 8:45 p.m. **2009 dates:** May 18, June 15, July 20, August 17, September 21, October 19, November 16, and December 21.

**Location:** Cuyahoga County Public Library Parma-Ridge Branch 5850 Ridge Rd., Parma 44129.

**AKRON AREA SUPPORT GROUP MEETINGS** are held on the **First Monday** of the month at 6:45 p.m. **2009 dates:** June 1, July 6, August 3, October 5, November 2, December 7. *No September meeting because of Labor Day*

**Location:** Ellet Community Center, 2449 Wedgewood Drive, Akron, OH 44312.

On Monday, July 6, the Akron Support Group will host Attorney Cindy Mason who give a presentation on Medicaid. The program will begin at 6:30 p.m. at the Ellet Community Center, 2449 Wedgewood Drive, Akron, OH 44312.

If you have any questions, please call Wes Johnston at 330-922-3443 or email him at [pards3@yahoo.com](mailto:pards3@yahoo.com)

## FROM THE ADVOCACY DESK:

In 2008 the Northeast Ohio Chapter Board created an Advocacy Chairperson position, which is now held by Mike Prokop. During his first year he began working with other board members as well as members of other chapters to lobby Washington for the passage of The Genetic Information Nondiscrimination Act of 2008 (GINA) followed by the FDA's passage of Tetrabenazine (TBZ). TBZ became the first drug ever approved in the United States for the treatment of a Huntington's Disease chorea symptoms.

Additionally, the Advocacy Chair called on the late Stephanie Tubbs Jones to work on the passage of HR 6259 (The Huntington's Disease Parity Act) now known as HR 678 in the 111<sup>th</sup> Congress. Advocates throughout the country are joining together to stress the importance of this bill to the members of Congress. On Feb 9<sup>th</sup> letters with copies of 86 petition signatures were sent to Congresspersons Marcia Fudge, Steven LaTourette, Dennis J. Kucinich, Betty Sutton, Marcy Kaptur, John A. Boccieri and Tim Ryan. As advocates, our goal is to secure enactment of HR 678 legislation in Congress thus improving access to treatment and medical care through SSI for individuals suffering from Huntington's Disease. A petition drive and letter writing campaign in northeast Ohio is currently underway. All are welcomed to participate. You may contact Mike Prokop at [mprokop@ameritech.net](mailto:mprokop@ameritech.net).

## WRAP YOURSELF AROUND THIS

Wrap around events are an easy way for small groups to participate in large fund raisers. It's also a great way to build momentum leading up to the big event. Any family, club, church group, sports team, or group of friends can host a small event and direct the funds to the major fund raiser. A few examples are a car wash, garage sale, poker tournament, or bake sale. Or, wrap two into one – have a bake sale at your garage sale!

So, if organizing and being in charge of a major fund raiser scares you (and it scares us), please consider a wrap around event. If it doesn't scare you, please call our Chapter Office at 330-998-6600.

## **THIS IS WHAT WE'RE TALKING ABOUT:**

Social Worker Kristin Zverloff has arranged for our chapter to have booth space at WKDD's One Day Indoor Yard Sale at the Summit County Fairgrounds (229 E. Howe Road – Tallmadge) on Saturday, May 30 from 10:00 a.m. to 3:00 p.m. All money raised will be directed to the Team Hope Walking for HD Akron Walk. Clean out those basements and garages and call Wes Johnston at 330-283-0109 to arrange for drop off of items at his house. More information on the Indoor Yard Sale is available at WKDD's website, [www.WKDD.com](http://www.WKDD.com)



## **YOU HAVE A FRIEND ON THE WEB**

Be sure to take advantage of all the information that is on our website. We have Support Group Information, Chapter News, and details on Chapter Events. Our website address is [www.lkwdpl.org/hdsa](http://www.lkwdpl.org/hdsa).

The website of the National Organization is [www.hdsa.org](http://www.hdsa.org). There you will find information on Research, Living with Huntington's Disease, Events and How You Can Help.

There are hundreds of publications available for download. Click on the tab "Living with Huntington's Disease," then click "Family Care," then "Publications." There you will see the list of publications you can download for free.

Our website is maintained by the Lakewood Public Library. We are grateful to the library's director, Ken Warren and his staff. They have provided this service at no charge to our Chapter for many years.

## **MAY IS HUNTINGTON'S DISEASE AWARENESS MONTH**

We are pleased to announce that HDSA will recognize and celebrate May as Huntington's Disease Awareness month with the debut of a new TV and Print campaign featuring Olivia Wilde, who plays "I3" on the hit show House, and her co-star, Peter Jacobson, ("Dr Taub"). They will appear in a 30-second PSA and Print Ad designed to build awareness of Huntington's Disease (HD) and how the value of HDSA research and care programs goes beyond those affected by HD. To view the new commercial, go to [www.hdsa.org/mayawareness](http://www.hdsa.org/mayawareness)

In addition to participating in one of the many local events scheduled this month ([www.hdsa.org/events/](http://www.hdsa.org/events/)), we encourage you to advocate on behalf of HR 678, the Huntington's Disease Parity Act of 2009. You can do this by visiting [www.capwiz.com/hdsa](http://www.capwiz.com/hdsa) to find your Representative and send a letter in two simple steps. At [www.hdsa.org/takeaction](http://www.hdsa.org/takeaction) you can learn about other steps you may take to advocate for the passage of this key legislation.

We encourage you to utilize the fact that May is Huntington's Awareness Month as a way to open up a dialogue with your friends and colleagues about Huntington's Disease, and the HDSA programs of research, care and education. Explain to them that the discoveries made by our scientists are valuable to researchers working to understand and treat many other diseases. Invite them to attend an event, participate in one of our upcoming walks, or to visit our website, [www.hdsa.org](http://www.hdsa.org) to learn more about HD and how the 40 HDSA Chapters and Affiliates are providing much-needed support to families facing the daily challenges of Huntington's Disease.

If you have any questions, or would like to request additional materials, please visit the HDSA website, or send us an email at [hdsainfo@hdsa.org](mailto:hdsainfo@hdsa.org)

## **HDSA NATIONAL CONVENTION – JUNE 5-7, 2009**

HDSA will hold its National Convention at the Hyatt Regency Phoenix from June 5 – 7, 2009. For further information, go to [www.HDSA.org](http://www.HDSA.org)