



# Our Voice

Our Voice, a newsletter of the Huntington's Disease Society of America, Central Ohio Chapter, is published four times annually to provide information and to relay items of interest to individuals with HD and their families, health care professionals and interested friends and supporters.

## Letter from the Central Ohio Chapter President, Wendy Vaughan

Thank you to a great leader.

Thank you Barbara Boyle for your enthusiasm, passion, dedication, determination, tenacity, drive, compassion, empathy, concentration and the gift of hope you have given to all of the HD families over the past 14 years! That is a lot!

Not to mention the long list of accomplishments that are yours as well... here are a few: The Center of Excellence Program, the doubling/ tripling of our fundraising over the years, the accomplishments of the advocacy program, the Coalition for the Cure, the first ever FDA drug to treat HD and the numerous little things that have gone untitled like the personal phone calls, notes to HD families, board members, researchers and donors.

Barbra Boyle has done an amazing job with HDSA. She has built bridges, given hope and love to a very difficult disease and often times in fundraising, difficult situations.

I am so proud to know her personally. I admire her and look to her as a mentor of how I can be a better chapter leader. She has inspired me to define what my accomplishments will be with HDSA. Barbara has walked the walk and talked the talk. She lives by example of what we can do to cure HD. And isn't that what everyone wants? To cure HD?

So when you are reading this letter.... Think about what you can do to fight for a cure. What will you do to make the situation better for HD families who are dealing with this horrible, unbearable disease?

Please, help out a caregiver, volunteer at a fundraiser, participate in a fundraiser by playing golf, shooting hoops or soliciting a donation. We need to work as a team. NO ONE person can be expected to do it all. The cure is on all of us. Please, work with us to make a difference because you can make the difference.

Barbara Boyle has made a huge difference. I will miss seeing her at events but I



know I can contact her for help any time.

Barbara Boyle has shown us inspirational leadership. Thank you Barbara for everything!!!

Sincerely,

Wendy Vaughan  
HDSA Central Ohio President



## A letter from the Chair of the HDSA National Board of Trustees, Walt Johnston

In the thirteen years since Barbara Boyle joined the Huntington's Disease Society of America (HDSA) as National Executive Director/CEO, the Society has grown to become the major source of help and hope for the Huntington's Disease (HD) community. Under Barbara's leadership, HDSA created the Coalition for the Cure and expanded the research program to an entire Drug Discovery Pipeline; Twenty-one HDSA Centers of Excellence have been opened, providing comprehensive services for our families; HDSA has grown to 38 Chapters and Affiliates; More than 200 support groups have become active; HDSA has been the preeminent source of HD information through our publications and our website; built a strong advocacy program; and this year, we saw the first FDA-approved therapy for people with HD.

Clearly, Barbara has brought HDSA to a standing where it is recognized as a unique entity among single-disease non-profits, delivering on all three legs of our mission.

Barbara has decided that it is time to retire from her responsibilities at HDSA, knowing that the programs of research, care and education are moving forward, and the Society is strong.

To continue the Society's work and expand these programs, the Board of Trustees of HDSA has conducted an extensive search, for a leader who can maintain and build upon this foundation and expand the Society's services.

We are fortunate to have been able to recruit Louise Vetter, presently CEO of the American Lung Association of New York. Louise will join HDSA as our new CEO on Monday, March 16, 2009.

Louise's passion for making a difference in people's lives through non-profit healthcare organizations and her impressive leadership skills convinced the Board Search Committee that she would be an ideal fit for the Society. She is looking forward to meeting all of you and learning first-hand how she can best help HDSA move forward to achieve the objectives we have set, and we are confident that under her leadership our programs will continue to expand and thrive, and our services to the members of the Huntington's Disease community will continue to grow.

During the first week that Louise serves as HDSA CEO, there will be a live introductory webcast available to all.

Details will be forthcoming. There will be many opportunities to meet her in person soon thereafter.

I know that each of you will join me in welcoming Louise to the Society and continue to dedicate yourselves to help her build upon HDSA's strong foundation, and continue our efforts to expand our programs of cure, care and education through the years ahead. I'm sure that as you get to know her you will understand why the Board is so enthusiastic and assured that the Society will be in good hands as we move ahead.

Barbara will continue to serve as National Executive Director/CEO until Louise formally joins the Society, and will stay for an interim period to assist with the transition.

I'm sure that you may have questions, and that you will be contacted by members of the HD community in the days ahead. Please direct any questions you may have, or of any concerns that do arise to Fred Taubman (212 242 1968 x229, [ftaubman@hdsa.org](mailto:ftaubman@hdsa.org)), who will coordinate responses from the appropriate Senior Staff and Trustees.

Please feel free to communicate the following key points to anyone who may have questions about the transition:

- All programs of research, care, advocacy and education will continue as per this year's Plan of Work
- Barbara will continue her duties until Louise's arrival on March 16, and then will remain to aid with the transition for a period of time.
- If you have any requests or questions about events that are scheduled post-March 16, please contact Scotti Hutton ([shutton@hdsa.org](mailto:shutton@hdsa.org))
- Details of a live introductory webcast will be forthcoming. This will be held during the first week Louise joins HDSA (week of March 16)

While it may be difficult to think of HDSA without Barbara, thanks to her efforts we will be able to move forward with this transition from a position of strength. Our programs of research, care and education continue to evolve, our chapters and affiliates continue to expand, and the value of the Society to our families continues to increase.

Regards,  
C. Walt Johnston, Chair of the National Board of Trustees,  
HDSA

## Ohio Chapter Meeting Times & Places

### Central Ohio

Our meetings are held at 7:00 p.m. on the second Thursday of each month at:

The Atonement Lutheran Church  
1621 Francisco Road  
Columbus, Ohio 43220

Please join us at our next meeting. We first get together, discuss upcoming events and make announcements, then divide into 3 groups: caretakers, "at risk," and persons with HD. Caregivers meet for discussion and individuals affected with HD meet to do a craft or activity led by several volunteers. This arrangement has worked out well for the families to allow for open discussion with the caregivers and provide a fun activity for our HD individuals.

Each group has its own challenges and it is helpful to talk to others in the same situation. If we have a speaker scheduled, we stay together. There are two basic reasons to attend support meetings. One is to GET HELP. The second is to GIVE HELP. When you lose a loved one or they go into a nursing home, the usual feeling is that you want to distance yourself for a time. You really deserve some "time off" after care giving. But after awhile, please consider coming back--you can be a great help to people just starting on the road you have traveled. No teacher is as helpful as experience and the lessons you learn one by one can mean an easier time for new caretakers.



### Support Group Activities:

March: St. Patrick's Day Craft  
*Note: March 12th will be a speaker from Ovation Pharmaceuticals to discuss the use of Xenazine. They will be available to answer questions regarding Xenazine and talk about their support programs that are available for patients.*

April: Easter Craft

May: Mother's Day Craft

June: Guest Speaker

July: Pot Luck Picnic Dinner

**Akron:** Meetings are on a Monday or Tuesday, based on the availability of a meeting room. Ellet Community Center, 2449 Wedgewood Drive, Akron, OH 44312. For questions, contact Wes Johnston (Family Services Chairman) at 330-283-0109. Please see the website for more information: [www.lkwdbl.org/hdsa](http://www.lkwdbl.org/hdsa)

**Cincinnati:** This caregiver group meets every third Saturday at 11 a.m. in the Drake Hospital. For the patient and at-risk groups call Mary Beth Bialic at 513-741-4372.

**Toledo:** Toledo group meets every third Sunday from 2-4 p.m. in the fellowship hall at Our Savior Lutheran Church, 2820 W. Alexis Rd., Toledo, 43613. For more information, please call Robin VanGorder at 419-691-8940.

**Dayton:** This support group meets at 7:30 p.m. on the second Wednesday of every month at Fairview Methodist Church (on the corner of Fairview & Cataba). For more information please call Cincinnati Chapter Social Worker, Mary Beth Bialic at 513-741-4372.



### Information about Kroger Cards:

Currently we are enrolled in "Neighbor to Neighbor" Kroger Cares program. This program is a gift card program. The concept is this: for every purchase you make with a Kroger gift card purchased from HDSA, HDSA Central Ohio receives 5% money back donation.

It does add up if everyone used the card. So if you have a gift card that you have purchased from HDSA continue to use it and ADD money on to when you need to up to \$500 in one transaction. IF you do not have a Kroger Gift Card, contact Sheri Nash at 457-8480 or email her at [terrysash@sbcglobal.net](mailto:terrysash@sbcglobal.net) to purchase one. This program will continue until the end of April. At that time this program will change. We will keep you informed of what it will change to at that time. In the meantime..... Go KROGERING!!!!

## Chapter Memorials and Honorees

### In Memory of...



Thomas A. Downing:  
Nathan K. Burr  
Dale and Rebecca Louderback  
Judy K. Minton

Daniel Alan Hamppp:

Joan Neeb  
Barb Heiman  
Allen, Yurasek, Merklin &  
Owens-Ruff LLC  
Wilma McClaskie  
Tara Depuy  
Megan and David Hunter



John Karnemaat:  
Susan J. Pfeiffer



Dorothy Douglas:  
Bonnie Douglas Davis



Wayne Erlandson:  
Dolores P. Meeker

Richard Lowry:  
Dolores P. Meeker



Eugene Neff:  
Dolores P. Meeker

Mark Wilkins:  
Dolores P. Meeker



Michael and Stacey  
Znamenacek:  
Dolores P. Meeker



### In Honor of...



Dave and Daphne  
Hess & Family:  
John Dalton

Sarah D. Morrison:  
Chester Willcox & Saxbe LLP

Phil Meeker:  
Lori Love



### OSU Researchers Presenting to the European HDA in Wales

Drs. Anne Kloos and Deb Kegelmeyer from the Ohio State University Division of Physical Therapy were invited to attend and give a presentation to the European Huntington's Disease Association Physiotherapy Working Group in Cardiff, Wales on February 27, 2009.

This group is comprised of physical therapists from around the world who are conducting clinical research in Huntington's disease. Drs. Kloos and Kegelmeyer will present preliminary findings from their on-going research project that investigates the use of the video game "Dance Dance Revolution" to improve balance and gait in patients with Huntington's Disease.

This project is supported by a 2008-2009 Clinical Research Award from the Huntington's Study Group and the Huntington's Society of Canada.

### HDSA National Youth Alliance Scholarships

HDSA's National Youth Alliance is pleased to announce that they will have Convention Scholarships available again this year. We ask everyone to please encourage anyone 9-29 years of age to please apply for this scholarship and take advantage of this great opportunity.



Wendy Vaughan, HDSA COC president has the Convention Scholarship forms as well as National Youth Alliance membership forms. Eligibility for the scholarship is to be part of the National Youth Alliance.

For questions regarding this or other NYA matters please contact the NYA at [NYA@hdsa.org](mailto:NYA@hdsa.org) or Mynelly Perez at [mperez@hdsa.org](mailto:mperez@hdsa.org).

## Shoot for Cure "Hoop a Thon"

Saturday April 18, 2009 from 9AM to 2PM  
at Upper Arlington High School,  
1650 Ridgeview Rd. Columbus, Ohio 43221

What is a Hoop a Thon? Shoot for a Cure "Hoop a Thon" is a basketball free throw event to benefit HDSA. 100% of the funds raised go directly to research to find a cure to HD. Anybody can shoot hoops and have fun. No talent is required. Just a desire to help raise money to cure HD. We ask each shooter to go out to get donations to HDSA based on the number of baskets they may make at the Hoop a Thon or just a flat donation just for shooting hoops. Each shooter stands at the foul line and shoots free throws for 5 minutes. The goal is to make as many baskets as possible. Pledges can then be collected based on the per basket donation. Flat donations collected before the event are very welcome.

Goal: to raise \$20,000 for HD Research. Every dollar counts!



**WE NEED SHOOTERS and VOLUNTEERS!!!** Challenge your friends and neighbors to come and shoot Hoops with you. For more information, registration or more raffle tickets call Wendy at 614-487-9711 or email at [wvaughan@columbus.rr.com](mailto:wvaughan@columbus.rr.com). Go to our website at [www.hdsacentralohio.org](http://www.hdsacentralohio.org) To download a brochure.

**Raffle Prizes!!!!** The raffle tickets are \$5.00 a piece or 6 for \$25.00. The winner does not need to be present to win. The drawing will be made at 2PM on Saturday April 19th.

Prizes include:

- A certified LeBron James Autographed and Embroidered Cavaliers Away Red Jersey. Value: Priceless
- 2 tickets to 2 Cleveland Indian Sunday Games. Valued at \$150 (dates available to choose are 4/26; 5/31; 6/1; 7/19; 9/6)
- A Gift Certificate to Nukur the Salon and Aveda Salon on Lane Ave., Cols. OH. Valued at \$100

### HOW to RAISE MONEY and AWARENESS!

Shooters can go online to [firstgiving.com](http://firstgiving.com) and make up their own individual webpage to get pledges. It is easy to do! Please go to [www.firstgiving.com/hdsa-coh](http://www.firstgiving.com/hdsa-coh)

- Click on "get started"
- Select event you wish to participate in
- If you are a returning member enter your e-mail address and password.
- If you are a new member please enter your e-mail address and select "I am new to this site" and click continue.
- Then fill out all the information (i.e. name, address, etc.)
- Create a name for your page and enter it on the yellow box under web address.
- Then design your page, you can customize it any way you would like.
- You may add your own text and upload your own pictures.
- You can customize your thank you e-mail to all donors and have to option to receive an e-mail when someone donates.
- Once you are finished designing your page send it out to friends and family!

### How do I promote my page?

Show your fundraising efforts on your social network pages (i.e. face book, myspace, etc. ) to do so follow the instructions below.

To add a widget to your blog or website:

1. Visit your or your friend's fundraising page
2. In the upper right corner, click "Share this page"
3. Click "Grab a fundraising widget"
4. Select the widget code displayed in the yellow box and copy it.
5. Next, go to the editing section in your blog or website, and paste the widget code where you would like it to display.
6. Encourage your friend's to do the same!

## 24th Annual HDSA National Convention

The convention will be held at the Hyatt Regency in Phoenix, AZ from June 5-7th, 2009. Please email Wendy Vaughan to have a convention registration form mailed to you ([wvaughan@columbus.rr.com](mailto:wvaughan@columbus.rr.com)). For more information about the convention visit the website at: [www.hdsa.org/convention](http://www.hdsa.org/convention). See you in Phoenix!!



## 10 Easy Ways to Help an HD Family

From the Spring 2000 issue of Hopes & Dreams, newsletter of the Illinois Chapter, Huntington's Disease Society of America.

1. **Keep in Touch** - A card, call, or visit, mean a great deal and each family member benefits from your efforts.
2. **Do Little Things - They Mean a Lot** - Make extra portions and drop them off. When running errands, check whether there's anything that the family needs.
3. **Give Them a Break** - Offer to stay with the HD person so family members can run errands, attend meetings or take a short trip. Even if the caregiver doesn't leave the house, this will provide some personal time.
4. **Be Specific When Offering Assistance** - Many caregivers find it hard to ask for something specific, so prepare a 'to do' list (e.g., laundry, dusting, etc.). Dedicate some time each week to helping the family tackle some of these tasks.
5. **Be Alert** - Learn about HD and how it impacts the family. Know how to recognize a problem and respond. Learn about common behaviors and helpful care techniques.
6. **Provide a Change of Scenery** - Plan an activity that gets the whole family out of the house. Be sure to include the person with HD if the caregiver feels it's appropriate.
7. **Learn to Listen** - Ask family members how they're doing and encourage them to share. Be available when the caregiver is free to talk without interruptions. You don't need to provide all the answers, just be a compassionate listener.
8. **Care for the Caregiver** - Encourage caregivers to care for themselves. Pass along helpful tips and information. Offer to attend a support group meeting with them. Contact the HDSA (800-345-HDSA) for support groups in your area.
9. **Remember All Family Members** - The person with HD appreciates your visits. Spouses, adult children and even young grandchildren are all affected in different ways by a relative's HD, so be attentive to their needs too.
10. **Get Involved** - There are many things you can do to help families today that may help to prevent further devastation tomorrow. Make a contribution to HDSA or volunteer at your local chapter. Ask your legislator to support funding of research and programs to help HD families. You can make a difference.

## Living and Learning: Along the Continuum of Huntington's Disease

Date: Saturday April 4th 2009

Time: 9:30AM to 4PM

Place: Ashland, Inc. , 5200 Balzer Parkway, Dublin, Ohio 43017

Cost: \$15.00 that includes a box lunch

Join us for this educational seminar! We will be discussing topics pertinent to anyone with Huntington's Disease: Updates on research, care, drug treatments and more.

Please register by March 27, 2009 by sending in your check for \$15.00 made out to HDSA. Mail it to 490 City Park Ave. Columbus, Ohio 43215

For more information go to our website: [www.hdsacentralohio.org](http://www.hdsacentralohio.org) or call the HDSA Help Line at 614-292-9960. Please leave a message and we will return it promptly.

Speakers, April 4th HD conference:

- Dr. Sandra Kostyk, M.D. PhD., The Ohio State University "HD Clinical and Research Updates"
- Dr. Robert M. Taylor, M.D., The Ohio State University, "End of life issues and Palliative Care"
- Anne Kloos, PT, PhD, NCS, "The Role of Physical Therapy in Huntington's Disease"
- Brenda Francis, Speech-Language Pathologist, "Swallowing Issues with HD"

### OVERVIEW:

Our professional speakers will be addressing a variety of issues important to the HD patient and family along the continuum of care. Breakout time for small group question and answer sessions will be available. Families, caregivers and patients will benefit from this day dedicated to Huntington's Disease.

Activity Room: Games, crafts and videos will be available for our HD patients throughout the day.



Help us save money!  
Sign up to receive the newsletter by email instead of snail mail!

Email Theresa Hanson at [tzhanon@gmail.com](mailto:tzhanon@gmail.com) to be added to the distribution list.

Thank you to ALL those who came and donated to "Touchdowns for Huntington's Disease" Sept. 13th 2008!!



### Successful Amaryllis Sale!

Thanks to all who supported HDSA's mission of care and research by buying amaryllis bulbs in our recent campaign. Our chapter made more \$2300 profit!



### HDSA - 2009 Drive Toward A Cure BMW Sweepstakes

Grand Prize: Model Year 2009 BMW 328i Sedan or \$25,000 Cash  
 Second Prize: \$5,000 Cash  
 Third Prize: \$2,500 Cash  
 Fourth Prize: \$750 Cash  
 Fifth Prize: \$500 Cash

Sweepstakes limited to only 2,500 tickets sold! For every two tickets you buy (or sell) at just \$100 each, you receive a third free! Winners will be drawn at HDSA's National Convention on June 6th, 2009 in Phoenix, AZ. (You do not need to be present to win). Visit [HDSA.org](http://HDSA.org) to purchase tickets.

## Golf, Rock and Bowl 2009!

When: Friday, June 19th, 2009

Where: Raymond Memorial Golf Course, 3860 Trabue Road, Columbus Ohio 43228.

Time: Registration is at 9:30AM. First group will tee off at 11:00AM

Format: 4 Man Scramble, Best Ball

Cost: \$75.00 per golfer

Meals: Lunch at the turn. Dinner, complimentary bowling and music will be immediately following at Ten Pin Bowling Alley, 5499 Constitution Blvd. Hilliard, OH 43026

Prizes: 1st, 2nd, 3rd, and last place trophies. Hole in one contest and many prizes to be raffled off!

Sponsorships Available: Contact Wendy Vaughan at [wvaughan@columbus.rr.com](mailto:wvaughan@columbus.rr.com)

Don't play golf? The just come for the party! For \$20.00 at the door anyone can enjoy a night of fun that includes 2 draft beer tickets, complimentary bowling, music and complimentary food will be served from 6-8PM. Cash bar, 50/50 raffle and more. Donations to HDSA accepted at the door.

Registration: The deadline is June 10th. Registration will be accepted by mailing your fee to HDSA 490 City Park Ave. Columbus, OH 43215. Please make checks payable to HDSA- Golf, Rock and Bowl. In your registration, please include: 1) Team Captain; 2) Team Captain's Phone Number and Email Address; 3) The Names of the Three Team Members.





HUNTINGTON'S  
DISEASE SOCIETY OF  
AMERICA  
CENTRAL OHIO  
CHAPTER

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Columbus, Ohio

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Would you like to send a donation in memory  
or in honor of someone close to your heart?

If so, please send your donation to HDSA,  
Central Ohio Chapter, with an attached note or letter.

Please fill out and return this certificate.

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Please direct this donation of \$\_\_\_\_\_ to: Care\_\_\_\_\_% Research\_\_\_\_\_%