



Our Voice

Letter from the Central Ohio Chapter President, Sheri Nash

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.

This is not the first article I have written for this issue of the newsletter. I wrote another one about 3 weeks ago and turned it in to our trusty editor. As I wrote that first article, I was filled with emotion. At times, the emotion was raw honesty and at other times, it was insecurity and nerves. I suppose, in a very true way, that article had been sitting in me for a very long time. "It" was an integral part of me and it was the first time I had put it to paper. Essentially, anybody that knows me in any real way would/will be able to read that first article and say, "Yep, that's Sheri- I understand what she's saying..." Yet, I wasn't sure if the article was "appropriate." It was the first time I was unsure about what I had turned in; I shared my insecurity and nerves with Theresa, our Editor and my dear friend. "T", as I call her, said it talked about a piece of my life and how it relates to the HD world, as usual. All right, I trust her, she knows me... all is okay with this article.

Ultimately, we decided this article might be too controversial. We all know what the word means, but the actual definition is, "marked by controversy; debatable." I thought and thought about that word, **Controversial...** The topic I wrote about was controversial, even now, I struggle with the right and wrong of that topic. So, here I sit, still writing about that topic, but now you just don't know what it is ...

Then, I realized that it's okay that I haven't named this particular topic yet, because so, so much of the HD world can be considered controversial. Let's consider a few items... dollars to family services versus research, caregiving at home versus skilled

nursing, to tell or not to tell, to test or not to test, to have children or not to have children, confronting the person with HD's actions or forgiving everything because they're "sick." Or, asking our friends/family to donate to the cause, disclosing your gene status to a potential partner, Pre-implantation Genetic Counseling, the list can go on and on. For some, these topics aren't bothersome at all, for others, they fiercely "defend" their choice and want others to bow to the same. We are a group of people who believe, who passionately care. We have our opinions- and none of them is more right than the other. In the end, we all want the same thing, to uphold our Mission of education, service and research.

So, I've effectively danced around the topic of my previous and unpublished article... maybe I listed it above, maybe I didn't. Right now, it really doesn't matter. What matters it that we have an incredible, committed and talented group of people involved in this chapter. What matters is that over 3000 people will read this newsletter at some point and each will be touched by something different. What is important is that we meet the needs of anyone touched by this disease- be it friend, family or dedicated donor.

Right now, I am confident that I can say, without controversy or debate... We are meeting these needs. We are growing, we are helping and we are making a difference. Actually, I'm going to change those words- *You are making a difference!* Your support, your understanding and your continued commitment to our cause... You are the force that



has made us an organization that is recognized and effectively working toward a cure. As we head into our fundraising season, please put one or two of our events on your calendar and make a commitment to attend. Our volunteers and leaders make a commitment daily thru the support group, outreach programs, fundraisers, speaking engagements, various mailings and constant research. We cannot do this without YOU. You are the Central Ohio Chapter of HDSA and for that we are grateful... that is anything but controversial.

Sheri L. Nash
Central Ohio Chapter President



Texas Hold 'Em

1st Annual Tournament in May.

Interested players or volunteers can contact Larry Brown at 614 208-8699.

The HDSA Center of Excellence at the Ohio State University Announces New Physical Therapy Services

Physical therapy consultations are now being offered for patients who attend the Huntington's Disease Clinic at the Ohio State University Medical Center on Thursdays. Faculty members Anne Kloos, PT, PhD, NCS and Deborah Kegelmeyer, DPT, MS, GCS from the Physical Therapy Division will evaluate a patient's balance and gait, recommend exercise programs, prescribe assistive devices, and offer safety tips to help prevent falls and accidents in the home. Drs. Kloos and Kegelmeyer both have over 20 years experience working with patients with neurological disorders and are excited to be able to extend their expertise to patients with Huntington's Disease. They will also conduct research and plan to recruit patients for a gait study in the coming months.

New Ways to Give Through the Web!

1) Thru the chapter website. From our home page at: <http://www.hdsacentralohio.org/index.php> click on "Donate".

On the donate page click on "Make a Donation" this will take you the Paypal website where you can make donations to the chapter from your Paypal account or by credit card. Once you have made a donation, you can print off a receipt for your tax deduction

2) Occasionally the chapter will placing items that didn't sell at an earlier silent auction for sale on Ebay. You can do a search for items listed under the chapter's Ebay User Id "cenohiohdsa"

3) For all the avid sellers on Ebay. The chapter is registered thru Mission Fish on Ebay as an official charity on Ebay. This means that when people sell items on Ebay they have the option of donating a percentage of the sale profits directly to our chapter. Instructions are below:

Log onto Ebay website.

Sign into your Ebay account.

Click on "HOME"

At the bottom of the "Categories" section, click "Giving Works"

Click on the "SELL NOW" button.

Go through the listing process for the item being sold.

Near the end of the listing page there will be "Donate a percentage of sale"

Below this is a pull down box with "No nonprofit selected"

Click on the check mark, then either select the our chapter's name, or "Select new non-profit". Search any part of the following "HDSA, Central Ohio Chapter".

Select our chapter.

Click on the "Select %". Enter the desired percentage.

Finish the listing as normal.



First Annual 2007 HDSA Sand Volleyball Tournery

Come on out to the first annual Sand Volleyball tournament at Flannagan's Dublin on July 21st! Bring friends and co-workers out to raise money for HD and to have fun in the sun! The \$200 entry fee will cover teams of 10 (with six on a court). Register by July 1st to get a \$25 discount on your registration. Prizes to the top four teams. The team that raises the most money will get free entrance into next years tournament and receive an individual prize for each team member.

Any interested participants or volunteers, or if you would like to register your team for this event please contact Theresa Hanson at 614.539.0055 or email theresa_hanson@sbcglobal.net.

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. 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.



*"Through my illness I learned rejection. I was written off. That was the moment I thought, Okay, game on. No prisoners. Everybody's going down."
-- Lance Armstrong*

Teen Support Group

We are planning to reestablish the Teen Support group. Any teenager between the ages of 10 – 18 are encouraged to attend. Meeting time is 2:00 p.m. on Sunday afternoon every other month at Atonement Lutheran Church on Francisco Blvd. Parents are welcome to stay and meet with each other while the teen group is in progress, approximately 1 ½ hours.

This is an important group in our HD family. We want to meet the needs of our young people through group support, information, education, and socialization with other teens who understand.

This group is facilitated by Barb Heiman, Social Worker. Please call 614-292-9960 if you have questions or are interested in attending.

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.lkwdpl.org/hdsa

Thank You to Safelite for sponsoring our first teen event at the Fort Rapids Water Park!

Five chapter teens had a great time at their overnight stay at the water park. The following day, they toured the OSU HD research lab where they received a personal tour from Dr. Kostyk and Raeann Carrier, a PhD candidate, also known as "The Keeper of the Mice!" Thanks Gary Nash for organizing this fun event!

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.

Chapter Memorials and Honorees

In Honor of...

 Sarah Morrison
The Columbus Foundation, J. Anthony
Kington, Esq.

Gary Nash 
Terry & Bev Oetzel
Appraisal Institute Cardinal Ohio
Chapter

Dennis B. Pell Company 
Mary E. & Rick Naumann

Robert Vaughan Family
The Columbus Foundation, W. Arthur
Cullman, Jr.

Janet Haney
Brad & Mary Haney 

Gayle Hornbeck
-William & Theresa Hanson

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Marlene Luce
The Earl & Eileen Family
The Terry & Kathy Newman Family 
The Christopher & Molly Ruth Family
Dennis & Anne
The Lindy & Sue Jackson Family
The Jonathan & Sarah Jackson Family
Kevin & Anna Seesholtz

 Lonnie Prince
Bernie & Kelly Kanney

Denise Dee Rhinehart
Jennifer Narramore
Barb & Gary Heiman
Geoff Hornbeck
Gerald Mosko
Damon Goodwin
Pat Meeker 
Greg Baker
Marty Vaughan

Norman & Bonnie Baldwin
Frank Fraas
Judi & Bob Timmons
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Roger & Wendy Vaughan 
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Arlington Court Nursing & Rehab
Center
Richard & Jean Griffith
Ted & Candyce Adams
Brian & Connie Wagner
Kevin & Kelli Schneider
Columbus Clippers Staff
Norm & Barb Emmets
The Capital University Basketball
Scorer's Table
James & Lynn Hamilton

In Memory of...

 Mary E. Adams
William & Janice Smith

Thomas Downing
Mr. & Mrs. Scherbauer

 Ronald Fowler
Co-Workers of Elyse Jones

Cynthia Yinger
Barb & Gary Heiman 
Ralph & Linda Richter
Trina & Vince Vannicelli 
Robert & Cheri Davidson
Paul & Janet Kerscher
ARC Industries South
Clifford Thomson

National Research Roster for HD Patients & Families

The HD Roster has been funded by the National Institute of Health since 1979 and is a unique nationwide information resource dedicated to facilitating scientific research on Huntington's disease. The goal of the HD Roster is to act as a link between patients and families affected by Huntington's disease and scientists interested in gaining a better understanding of this disorder.

The HD Roster contains information on over 2,300 families consisting of over 140,000 family members. Since its inception, the HD Roster has facilitated hundreds of research studies by fulfilling two types of requests from researchers. Researchers can request data without any identifying information for statistical analysis to search for trends or symptoms that patients have in common; or, researchers can ask the registry to help them recruit subjects who have certain

characteristics or symptoms that might qualify them to take part in clinical or treatment studies. In this instance, the registry would identify those individuals who meet the criteria, then inform them of the study. If the individual signs a written consent to have their information shared with the researcher, then their name and contact information would be shared with the researcher.

It is important to understand that under no circumstances would any identifiable information ever be released to a researcher without the explicit written permission of the registry participant. All requests from researchers are reviewed by a scientific advisory committee prior to being fulfilled. If you have any questions, please call the Roster at (317) 274-5744 or email us at slcraig@iupui.edu.

HDSA National Convention

MARK YOUR CALENDARS!! This year HDSA is celebrating its 40th Anniversary June 15-17 in Oklahoma City, Oklahoma to honor the memory of Woody Guthrie.

This is a wonderful opportunity for all HD families to come together for education, socialization and the newest research information. Whether you are new to the HD community or a "seasoned" family member, the convention will provide encouragement and support as you walk the road of HD.

Topic areas on this year's agenda include but are not limited to:

- Understanding the Progression of HD
- Changing roles in the HD family
- Managing the HD household
- Partnership issues
- Caregiver issues
- Managing challenging symptoms
- Potential new therapies

Sharing sessions for caregivers, at risk and new to HD will be available. The National Youth Alliance will be in full swing with

workshops for teens and young adults as well as numerous social activities. Challenges facing families with Juvenile HD will also be addressed.

Please check the www.hdsa.org web site for more information and for registration details. The Central Ohio Chapter offers some assistance with convention expenses to area members. Please call 614-292-9960 (Social Worker) or 614-460-8800 (Downtown Office) for application information.



Hoops Bring Hope: Columbus Locals "Shoot for a Cure"

Columbus, OH (March 2007) – Spring is in the air and all of Columbus is buzzing with basketball fever. With both OSU women's and men's basketball teams as Big 10 Champs and the NCAA Tournament quickly approaching, visions of layups and jump shots are in everyone's heads. On April 14th, 2007 anyone can become a "shooting" star by participating in the Columbus Chapter of the Huntington's Disease Society of America's (HDSA) "Shoot for a Cure" Hoop-a-Thon, which is open to all ages and guaranteed to be fun for all.

This year, Upper Arlington High School (UAHS) senior, Zach Vaughan, is chairing the event as part of his senior thesis. Vaughan has set his sights on a lofty goal of raising \$25,000 for Huntington's Disease (HD) research and family services. The event will be hosted at UAHS gym from 9 a.m. to 3 p.m. at 1650 Ridgeview Road in Upper Arlington. Shooters will compete by shooting as many free-throws as they can in five minutes with chances to win premium prizes.

Again this year, the annual hoops event promises to be a slam-dunk with celebrity appearances from some of the players from OSU's Big 10 Championship men's and women's basketball teams. The event is open to the public and all shooters with pledges will receive a t-shirt for their participation. There will be a special raffle for shooters with pledges over \$50. Each shooter's name will be entered to win a \$200 Digital Camera for every \$50.00 in pledges turned in by May 1st. Refreshments will be provided on-site by George's Coney Island.

At the end of the day, a drawing will be held for the 2007 raffle prize, which is a 55" rear projection flat panel HD-TV donated by Digital Interiors in Dublin. Tickets for the raffle prize are \$5 each or six for \$25. For more information about registration, pledge sheets and raffle tickets call Zach Vaughan at 614-487-9711, or email at uazvon@yahoo.com. Information and pledge sheets can also be found on the chapter's website at www.hdsacentralohio.org.



"Shoot for a Cure!!!"

"Hoop A Thon"

April 14, 2007

9:00AM to 3:00PM

Upper Arlington High School Varsity Gym

1650 Ridgeview Rd.

Upper Arlington, Ohio 43221



HUNTINGTON'S
DISEASE SOCIETY OF
AMERICA
CENTRAL OHIO
CHAPTER

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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.

Name _____

Address _____

Phone number _____

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