

# 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.

## Central Ohio Chapter President's Article -- Sheri Nash

Over the last six months, I have tried to express the awe in which I see the people involved in our chapter who are touched, in one way or another, by Huntington's Disease. I've told stories, recounted heartfelt comments by others and basically tried to let each of you know that your interest and assistance matters. Your genuine concern for the HD community continues to make a difference. Our chapter continues to grow and expand.

I've bragged about the unwavering commitment of our Board as well as the dedicated volunteers who continue to fill in the gap and help us fit the puzzle pieces together. There is no doubt about it, I am very proud of the people involved in our organization. This includes most anyone who helps make the Central Ohio Chapter succeed...donors, volunteers, friends, family members, vendors, etc. How lucky we are!

The National Convention was held in Milwaukee this year. It was an exciting convention with great networking, presentations and research forums. New information was dispensed and older information was expounded upon. Once again, HDSA succeeded in educating and raising awareness. Each year, on Saturday evening, awards are presented to various chapters or

individuals for their successes and continued battle in the fight against HD. This Gala has been my favorite part of the convention. Historically, Central Ohio has been blessed with more than a few awards: Chapter of the Year (more than once), Best New Fundraiser and recognition for a great Convention a few years ago. It's wonderful to learn about the successes of others and see their happiness. I find the awards exciting and inspiring.

This year, inspiring is simply not a good enough word to express the awards ceremony. A very special person in our Chapter was recognized for "what HDSA is all about. This award recognizes an individual whose courage, dignity and fighting spirit honors others living with HD." This year, Gary J. Nash, MAI was honored as the HDSA Person of the Year! So much was said about Gary that I couldn't possibly go into it here. Yet, I will share a few excerpts from the speech given by the Chairman of the Board... "Gary does not deserve this award simply because he has HD. He deserves this award because he exemplifies true passion and courage. He is a leader and an example to all of us. Gary has always wanted to teach others and make a difference; he is still trying to make that difference. Yet, the most special thing about Gary Nash is that, without realizing it,



HE ALL READY HAS." Also, "Gary has another, more illusive, accomplishment. He has the ability to make people feel hope. His impact is in the support he offers to all. Gary has helped make Central Ohio a better and stronger chapter because he embodies courage and grace. Gary inspires others- not just those living with HD."

Many people have congratulated Gary on his recognition as HDSA Person of the Year. One gentleman from Louisville said he had no idea he had shared an evening with "Royalty." Others simply hugged Gary and thanked him for his courage and example. It was an honor to watch Gary Nash accept congratulations, dance the night away and continually stick his thumb up in the air in a "way to go" sign. So, as we were leaving the dance or leaving the hotel - people would stop him to talk or give him the "thumbs up" sign. Lots of people would say, "There's the HDSA Person of the Year..." I know I'll always hold the excitement of that night in my heart and I'll remember everybody's words. But, while others might call him the HD Person of the Year, I think I'll continue to call him something even better... I'll continue to call him Dad.



Photo: Gary Nash, HD Person of the Year! Way to go Gary!! Also pictured, Mary Anne Nash



## Exciting Research News from HD Coalition for a Cure

I want to report exciting news that was recently released. HDSA Coalition for the Cure Researcher Michael Hayden announced that his team has found that by blocking the action of a key enzyme (caspase-6) in the process that causes the cleavage of mutant huntingtin protein, they have been able to prevent symptoms of Huntington's Disease from developing in a mouse.

There are many steps ahead to

determine how this model of prevention in a mouse can be implemented using drug inhibitors. If promising substances are identified they would be moved along the HDSA Research Continuum to clinical trials which could yield potential treatments.

Dr. Martha A. Nance, member of the HDSA MSAC (Medical and Scientific Advisory Committee) on Dr. Hayden's work:

*"After over 25 years of research on Huntington disease, Dr. Hayden and his group in Canada have made a remarkable discovery, that they can prevent the symptoms of HD from occurring in a genetically-engineered HD mouse by altering the huntingtin protein so that it cannot be "snipped" into pieces by the caspase-6 enzyme. Although this finding, by itself, is not a cure for HD, it activity of the caspase-6 enzyme in*

*suggests that treatments to block the ability to "clean themselves up" if the production of the abnormal huntingtin protein is stopped, this should give renewed hope to HD-affected persons and their families. There is no better time than now to support HD research efforts, as we move ever closer to treatments for the disease!"*

Dr. Hayden's work is an example of how HDSA's funding of research is opening doors that will lead to treatments for HD. While today's excitement is very promising we still have a lot of work ahead of us. I hope this motivates you to continue your efforts to support HDSA Research and Care programs, and to helping us achieve our goal of making this the last generation with HD.

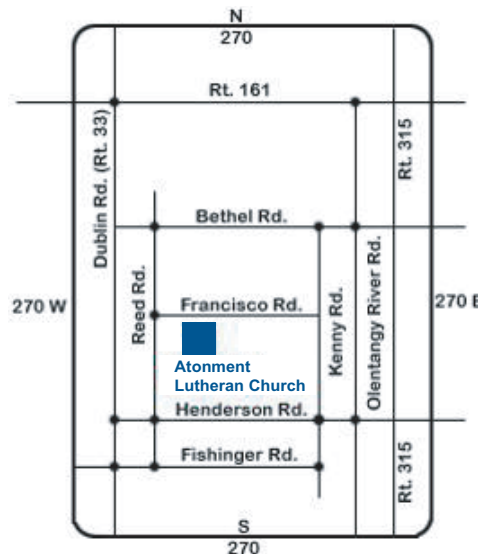
Barbara T. Boyle National Executive Director/CEO

## Central Ohio Chapter Meeting Time & Place

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.



## 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.

**The Cure Starts Here...  
The Caring Never Stops!**



## Updates on the HD Gift Certificate Program!

As we are aware, our chapter has been "selling" Kroger and Giant Eagle gift cards at cost. These cards require the stores to give 5% of your purchases back to our chapter! Until now, we have used these cards for our groceries, stamps, prescriptions and flowers. Our chapter received 5% of your purchases from the stores and you benefited from fuel purchases! It's a win-win situation!



Recently these stores began selling gift cards that you can purchase with your HD gift cards! Now you can buy gift cards to businesses like Home Depot, Kohls, AMC Movie Cinemas, and restaurants such as O'Charleys and Olive Garden. You can even purchase American Express, Mastercard, and Visa gift cards that you can use anywhere! Each time you buy a gift card, Giant Eagle or Kroger will donate 5% to HDSA and you will earn fuel points! This opportunity opens numerous possibilities of donating to HD!

Please send your checks or money orders and the type of gift card you prefer to:

Sheri Nash, 1751 Ramblewood Avenue,  
Columbus, Ohio 43235.

Phone: Please call if you have any questions 614.457.8480

### Would you like to participate in an Huntington's Disease research study?

Researchers are looking for participants in COHORT – Cooperative Huntington's Observational Research Trial. This study's purpose is to collect information in order to learn more about HD, potential treatments, and plan future research studies of experimental drugs aimed at postponing the onset or slowing the progression of HD.

For more information contact the HSG at 1-800-487-7671 or [www.Huntington-Study-Group.org](http://www.Huntington-Study-Group.org) or visit the Huntington Project web site at [www.huntingtonproject.org](http://www.huntingtonproject.org).

## 2006 Hoop-A-Thon Raised \$23,000 for Research

This past spring Columbus was all a buzz about basketball with both the OSU Women's and Men's Basketball teams in NCAA Tournament. Everyone knows that games can be won or lost on foul shots alone; But the Coalition for the Cure Research came out a winner with 75 participants in the HDSA "Shoot for a Cure" Hoop A Thon!

We hosted our annual "Shoot for a Cure" Hoop-A-Thon event on April 8th at the Hastings Middle School in Upper Arlington. At the Hoop-A-Thon, shooters obtained pledges from friends, neighbors and family members for the total number of free throws made in a 5-minute period. The money pledged per basket and collected will go to help support research for a cure to HD.



"Shoot for  
a Cure!!!"

At the last buzzer of the day, we pulled the winning ticket for our 2006 RAFFLE PRIZE. This years raffle prize was a 20' Toshiba LCD-Flat panel TV with a built in DVD player retail value at \$899.00 donated by Digital Interiors at 6570 Riverside Dr. in Dublin.

This year the Hoop-A-Thon was a slam-dunk with celebrity shooters from CD101, ABC6/FOX28 Sportscasters, The Dispatch, WSNY95, and more. The highlight play of the day was the awesome appearance of the 6 players from The Ohio State University Big 10 Championship Women's Basketball Team. The OSU women were fantastic! Each of the girls took turns shooting free throws and signing autographs. Their basketball skills were amazing. They made between 87 to 102 baskets in a five-minute time span!!!

We had wonderful TV coverage from both ABC6/FOX28 and Sports Reporter Joe Weasel from NBC4. No one went home hungry due to the refreshments donated by Georges Coney Island and tons of baked goods donated by volunteers. A great day was had by all!

Check out our website for updates on fundraising events, research trails, and COHIO meeting times!

## 4th Annual Dream Date Auction

If you weren't at Coaches Bar and Grill on Saturday, June 24th, you missed the hottest singles in town and a great opportunity to raise money and awareness for the Central Ohio Huntington's Disease Society!

30 single, attractive, successful men and women from the Central Ohio area worked with local businesses to create exciting Dream Date packages which included a 4-day houseboat trip to Lake Cumberland, private wine tasting at Camelot Cellars with a catered dinner at the Blue Door Gallery, and a plane ride around the city with horseback riding and a picnic lunch, just to name a few!

The highest bidder on each package had the pleasure of enjoying a wonderful Dream Date, and the satisfaction of knowing 100% of their donation went to research and care for those suffering with its side effects every day.

The event raised over \$10,000 for Huntington's Disease. Perhaps the biggest accomplishment, though, was the overwhelming participation of those who are not affiliated with HD. The Dream Date Auction provided exposure for this disease to people who had never heard its name, or seen its devastating effects. Sadly, HD affects as many people each year as Multiple Sclerosis or Cystic Fibrosis, it receives very little publicity or attention.



Our 2006 HDSA Person of the Year, Gary Nash even took the stage to relay his personal crusade to release the grip of Huntington's Disease on his family, to which he received thunderous applause from teary eyed guests. Gary proudly announced, "Parkinson's Disease has Michael J. Fox, Muscular Dystrophy has Jerry Lewis, and Huntington's Disease has Gary Nash."

Our next fundraiser is our biggest of the year. The Martini Blast is the year's most unique event, with a live band playing old time favorites from the Dean Martin / Frank Sinatra era, a variety of cold martinis shaken or stirred, an elegant sit down dinner, and an after party at Columbus' hottest nightclub, Spice. For more information on the Martini Blast please visit, [www.hdsacentralohio.org](http://www.hdsacentralohio.org).

Thanks to all of our coordinators, dates, volunteers, sponsors, and supporters. This event would not have been successful without you!

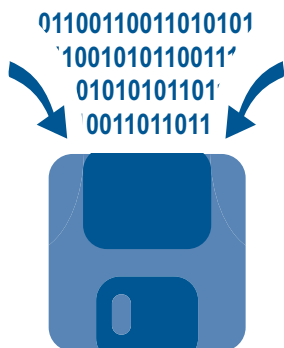
### Thank you to our new Sponsors!

**Safelite Group**  
2400 Farmers Drive, Cols. OH 43235, 614-210-9369

**Porter , Wright , Morris & Arthur**  
41 S. High St., Cols. OH 43215, 614-227-2000

Thanks to these sponsors for each donating over \$1000 to our chapter!

## Updating our Database—We Need Your Help!



We are currently updating our Central Ohio HDSA database and we would like your help!

It's fast and easy! All you need to do is visit [www.hdsacentralohio.org](http://www.hdsacentralohio.org) and click on update your contact information.

By verifying and/or updating your contact information, you can continue to receive our newsletters in the mail, or sign up to receive them by email!

Have you or a family member moved? This is a great way to let us know your new address!

You can also sign up to volunteer, get flash reminders about upcoming events, or to remove your name from the database contact list.

Don't have computer access? Call Theresa Hanson at 614-539-0055 and she will update your information for you!



## How to Cope with Stress

- 1. SET REALISTIC GOALS AND PRIORITIES** and identify those things you must do first.
- 2. ORGANIZE YOUR TIME** in accordance with those priorities.
- 3. LEARN TO SAY "NO"** when asked to do something stressful.
- 4. RECOGNIZE THAT SOME STRESS IS UNAVOIDABLE** – it's part of life.
- 5. MAKE A LIST OF STRESSFUL SITUATIONS** in your life.
- 6. DIVIDE THE LIST** into things you can't avoid or control and things you can hope to influence.
- 7. USE YOUR TIME AND TALENTS EFFECTIVELY** to address those stressful situations you can change.
- 8. DON'T WASTE YOUR ENERGIES** in a frustrating attempt to conquer what you cannot control.
- 9. DON'T BE AFRAID TO ASK QUESTIONS**, solicit suggestions, and share your problems with others.
- 10. DO ALLOW YOURSELF TIME OUT** to enjoy personal interests or just to smell the roses.

*Paul J. Rosch, MD*

*President of the American Institute of Stress*

## Chapter Memorials and Honorees



### **In Honor of Norm and Bonnie Baldwin**

*Alice M. Katterhenrich  
Barb Heiman  
Loren & Jean Plassman  
Allan & Rose Campbell  
Jim & Lois Meyers*

*Ken and Barb Honemann  
& Family*

*Dorothy Honemann  
Craig & Candy Franz*

*Theresa & William Hanson*



### **In Memory of Margaret Devault South High School class of 44**

*Norm & Bonnie Baldwin  
Barb Heiman*

### **In Memory of Richard Fligor**

*Walter Wellstead & Family  
Ray & Luella Grummel  
Jim & Debra Thomas & Family  
Robert & Rita Burkhart  
James & Paula Davis  
Pamela Wellstead*



### **In Memory of Gayle Hornbeck**

*Katherine O'Connor  
Campbell, Hornbeck,  
Chilcoat, & Veatch LLC  
Robert & Nancy Palma  
Dave & Sheree Tata  
Patricia Meeker  
Barb Heiman*

*Robert & Cheryl Sickafoose  
Becky & Ray Watts*

*Myrna Clark*



*Donald & Mary Louise Shipley*

*John & Debbie Faust*

*Ed & Donna Fry*

*Norm & Bonnie Baldwin*

*Lum D. Brock Jr.*

*Tim McDuffee*

*Brad and Colleen Schwartz*

*Theresa & William Hanson*

*William & Patricia Youngs*

### **In Memory of Orville W. Miars**

*Mrs. Jessalyn L. Miller  
Mary A. Longemeyer  
Damon Goodman  
James & Linda Sachs*

### **In Memory of Lela Wollum**

*Mrs. Mary Young  
Herschel Haulman  
Frank & Rosa Giampetro*

### **In Memory of Lisa Williams**

*Howard & Judith Williams  
Ruth Streib  
Thomas & Shirley Williams  
A.J. Sniadowski &  
Carol Sniadowski*



### **In Memory of Dale Meyers**

*Ralph & Dolores Verhoff*

### **In Memory of Tom Bustin**

*Sandra Carvajal Bustin and  
Michael Joseph Reyes*

### **In Memory of Janet Haney**

*Brad & Mary Haney  
Memory H. Makad*



## Goodsearch.com Donates Money to Fight HD!

Have you heard of Goodsearch? This search engines goal is to donate millions of dollars to good causes each time people search the web! How to they do this? Each search will generate approximately \$0.01 each time you search for information.

Huntington's Disease Society of America and the Central Ohio Chapter has just signed up, so you can help donate money to HD with just a click of a mouse!

We know \$.01 does not seem like a lot of money , but with 1,000 supporters searching twice a day,

HDSA will receive approximately \$7,300 per year! The sky is the limit, though the more people search, the more money we have to find cure! So get searching!

In order for our cause to earn as much money as possible, we need your help in spreading the word. Send an email out to all of your family, friends and supporters and tell them to sign up today! Don't forget to set all of your browsers at work and home!

<http://www.goodsearch.com/>



**What:** Golf for a Cure

**Date:** Sunday, October 15, 2006

**Time:** 1:00 pm

**Where:** Willow Run Golf Course, Alexandria, Ohio (At State Route 310 & State Route 161)

**Format:** 4 person, best ball scramble

**Cost:** \$100.00/golfer

**Meals:** Lunch at the turn & Dinner after the tournament

**1st Place Prize:** A one day spring fishing charter on Lake Erie

**Hole-in-One Competition:** Chance to win a 2007 Ford Fusion

**Raffles:** Additional prizes will be raffled off!

**Registration:** Larry Brown at (614) 208-8699

## Girl Scout Troop #2250 has Car Wash Fundraiser

Special Thanks to Kali Basenback, Ali Wiggall and Jackie Barnhart of Girl Scout Troop #2250 for raising \$200 for HD research. The car wash was held on August 20, 2006 from 12 to 4 p.m.



## Volunteers Needed for the First Annual COHDSA Mud Volleyball Tourney

Contact Theresa Hanson at (614) 539-0055 if you are interested in getting involved with the planning for this NEW HDSA fundraiser.

## Amaryllis Sale



### Help HDSA/Central Ohio raise funds for patient and family support and research.

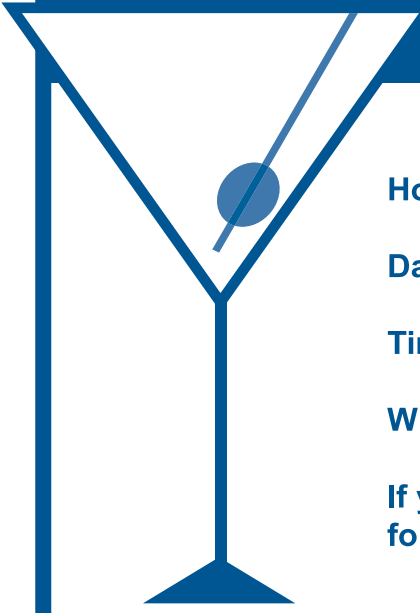
These bulbs sell for \$10 each and the Chapter earns \$4.80 on each one sold. These make great Christmas gifts, holiday party favors, and host gifts!

You can buy individual amaryllis bulbs in small quantities (less than 16) for yourself or to sell. Dave Fisher will deliver them or you can pick them up from his home or at an agreed upon place. Or if you would like larger quantities, order by the case of 16. These will be delivered by UPS to your address.

Cases may be all one color, or assorted. The colors available are:

- Ferrari (red)
- Apple Blossom (soft pink)
- Clown (red/white striped)
- Picotee (white with red edge)
- Pink Diamond (deep pink/white)

**Contact:** Sheri Nash at (614) 457-8480



## 2006 Martini Blast - A Celebration of Hope!

**Honorees: Mickey Halls of Rich Products, Elsie Znamenacek & Family**

**Date:** Friday, September 29, 2006

**Time:** 7 p.m. to 11 p.m.

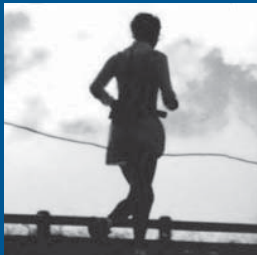
**Where:** The Vault 35 E. Gay St. Downtown Columbus

**If you have questions, would like to volunteer, or would like to register for this event, please contact: [dmartin@hdsacentralohio.org](mailto:dmartin@hdsacentralohio.org)**

### Silent Auction Items Needed

Contact Dawn Martin at (614) 430-8482 or [dmartin@hdsacentralohio.org](mailto:dmartin@hdsacentralohio.org) to donate items for the Martini Blast Silent Auction.

Suggested items: gift baskets, electronics, jewelry, gift sets, gift certificates, maid services, out of town trips, etc.



## Columbus Marathon

Rachael Margo and Laurel Helber are participating in the Columbus Marathon in honor of a family friend.

**Date:** Sunday, October 15, 2006

**Where:** Downtown Columbus

**If you would like to donate money in support of these ladies, contact the Central Ohio HDSA Chapter office at (614) 460-8800**

## Congratulations Sheri Nash!!!



Sheri Nash will be traveling to the Ronald Reagan Building and International Trade Center in Washington D.C. on Sept. 20th to receive a national award from the "Angels for Adoption" program. Sheri and her husband, Jeff, have welcomed four beautiful girls (all natural birth sisters) into their home --Elizabeth (14), June (9), Lisa (4), and Grace (20 months).

"The Angels in Adoption™ Program, CCAI's signature public awareness program, which provides an opportunity to all members of the U.S. Congress to honor the good work of their constituents who have enriched the lives of foster children and orphans. This program includes an annual event in Washington, D.C., the Angels in Adoption™ gala, which is geared toward highlighting ordinary people doing extraordinary things. These "unsung heroes" are selected by members of the U.S. Congress." (Source: <http://www.ccaainstitute.org/angels.php>)

