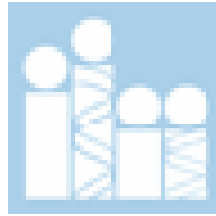


**“THE CURE
STARTS HERE...
THE CARING
NEVER STOPS.”**



Our Voice

OUR VOICE IS THE OFFICIAL PUBLICATION OF THE CENTRAL OHIO CHAPTER, HDSA

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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.

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&
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Volume 3, Issue 3

July 2006

Central Ohio Chapter President's Article

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



SHERI NASH,
CHAPTER PRESIDENT

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

Pres. Letter Continued on Pg. 3

Exciting Research News from HD Coalition for the Cure

I want to report exciting news that was released today. 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

Story Continued on Pg. 6

Central Ohio Chapter Meeting Time and Place

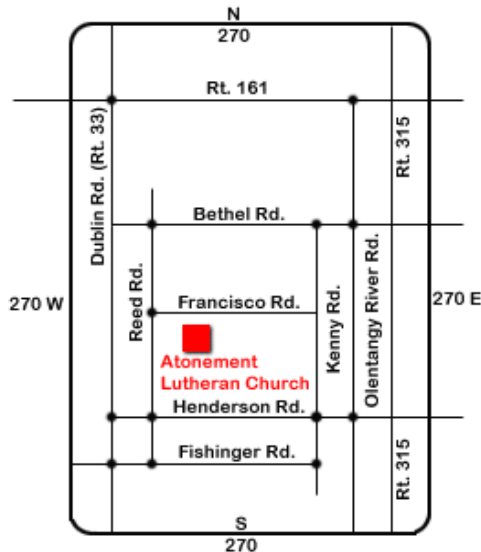
Our monthly meetings are held at 7:00 p.m. on the second Thursday of each month at:

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.



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 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 has received 5% of your purchases from the stores and you have benefited from fuel purchases! It's a win-win situation!

Now, these stores have begun 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

President's Message Continued....

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 re-



GARY NASH, HD PERSON OF THE YEAR! WAY TO GO GARY!! ALSO PICTURED, MARY ANNE NASH

member 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.



2006 Hoop-A-Thon, \$23,000 Raised 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 mem-

bers 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.

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!

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

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 that was tripled by an anonymous donor, for a grand total of over \$30,000! Perhaps the biggest accom-

plishment, 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.

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,



Pictured above, Marley Moorman and emcee Kelsey.

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

Spice. For more information on the Martini Blast please visit, www.hdsacentralohio.org.

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

✦ **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 or visit the Huntington Project web site at www.huntingtonproject.org.

Area Support Groups

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

CLEVELAND

The Cleveland Area support group will continue to meet on the third Monday of each month. at 7-8:30 p.m. Meetings are held at the Offices of Zion, Synek & Associates, 4141 Rockside Rd. Suite 150, Independence, OH 44131

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

TOLEDO

This support 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

Dayton area 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.

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.

MANSFIELD

Meetings are held at 7:00 p.m., on the first Monday of every month. Home of Charlotte Dourgherty, 671 Weller Ave, Mansfield, OH 44904. Call Charlotte at 419-

Save the Date!

If you have questions, would like to volunteer, or would like to register for this event, please contact:

dmartin@hdsacentralohio.org

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

Martini Blast!

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

When: Friday, September 29, 2006

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



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/ 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!

10 Ways 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 UN-AVOIDABLE – 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

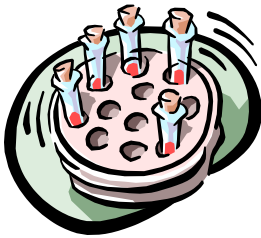
ENERGIES in a frustrating attempt to conquer what you cannot control.

9. DON'T BE AFRAID TO ASK QUESTIONS, solicit suggestions, and share your problems with others.

10. DO ALLOW YOUR-SELF TIME OUT to enjoy personal interests or just to smell the roses.

*Paul J. Rosch, MD
President of the American Institute of Stress*

Coalition for the Cure continued from page 1....



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 suggests that treatments to block the activity of the caspase-6 enzyme in humans would be a promising avenue for researchers to pursue. Combined with earlier reports that brain cells have 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



Huntington's Disease Society of America

Central Ohio Chapter invites you to

Help Us Celebrate, Gary Nash HD Person of the Year!



August 16, 2006, 6:30-9:00 p.m.

San Francisco Oven,
66 East State Street, Columbus OH 43215
614-220-5600



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 Horn-

beck

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

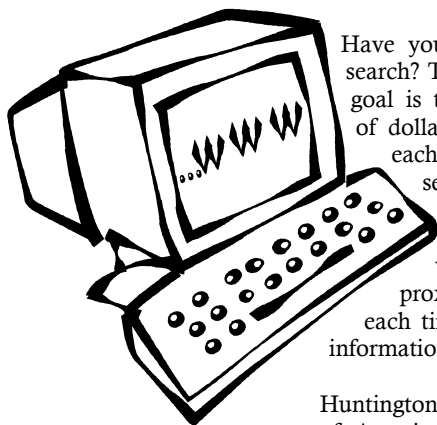
In Memory of Tom Bustin

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 would, HD SA 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/>



HDSA

**“THE CURE STARTS
HERE...THE CARING
NEVER STOPS.”**

**HUNTINGTON’S
DISEASE SOCIETY OF
AMERICA
CENTRAL OHIO
CHAPTER**

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HDSA

Non-Profit Organization

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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 including the name of the person to be remembered. Send your information to the address listed above.

Please tear out and return.

Name _____

Address _____

Phone number _____

Please direct this donation of \$_____ to: Care_____ % Research_____ %