



# 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



**"Until all of us have made it, none of us have made it." —Rosemary Brown**

I am writing today to tell you some good news. After serving as a full-time volunteer for the chapter for 10 years, I have accepted a position to be the chapter consultant as a part-time employee. I am very excited to take this opportunity and hope my organization skills, determination and passion will lead our chapter to the next level of success. Elyse Jones has stepped in as the new president, but we still need to fill the vice president position as well as other positions on the board.

**So, I am writing to you today trying to find something inspirational for all of us.** I went to the Internet to find some ideas. I selected the quote above because to me, and from my perspective, it applies to HD. Until a cure is found, we must keep trying to do our best to find the money for research, and we must find the compassion to care for our families. We must not give up.

**My goal is to increase the number of individuals who donate money and who are willing to serve on a chapter committee.** Here is the situation as I see it. Most of us don't like HD. Or at least, I am not sure I have ever met anyone who was happy to have HD or have HD in their family. This disease is devastating in every way imaginable. If you are reading this newsletter, you probably already know that. But

my question is: What can each of us do to make the situation better?

The only thing I know to do is to aggressively seek a cure for HD—to be the best advocate for HD families I can be, plan the best events, ask everyone I know for money, be a good listener for families and stay active in HDSA. I am asking you to do the same, because if we all do just a little, we can raise enough money to fund research in hopes of making life with HD better and securing a future free of HD for the next generation.

But one drop in the bucket is not going to fill up the bucket. So I challenge you: For each NEW family who donates to HDSA or emails me to become an active volunteer by Oct. 1, 2009, the end of the HDSA fiscal year, I will donate \$25 of my salary back to HDSA! So, if you are not active in the chapter or donating to HDSA, please become active and donate what you can.

If you are active, thank you. Lately we have had a lot of new faces at our events and people willing to volunteer. A special thanks goes out to all of the NEW volunteers at the golf outing. You were great! Thank you so much.

Our chapter is made up of caring, understanding people who have their own stories with HD. As with all volunteer organizations, we do understand the ebb and flow of

volunteers. But this is clearly an organization that needs the help of all its past, present and future members to cure HD. We have lots of positions to fill and are always looking for new leadership. Help be the change you want to see.

**What is the easiest thing you can do to help the HDSA of Central Ohio right now?** Invite all your friends to buy a ticket to the "Celebration of Hope—Casino Night." We are responsible for raising \$60,000 net to keep the doors of the clinic open another year, so we need to get as many people there as possible. I know the economy is bad and funds are tight, but HD will NOT yield to the economy.

**We need you now more than ever.** Please make your reservations to come to the "Celebration of Hope—Casino Night" Sept. 25, 2009 at the Makoy Center in Hilliard, Ohio. If you make your reservations by Sept. 1, we will give you six additional free raffle tickets valued at \$50 to win some fabulous prizes.

Comments, suggestions or donations? Email me at [wvaughan@hdsa.org](mailto:wvaughan@hdsa.org).

*"Because unless all of us make it, none of us will make it."*

## Creatine and CoQ10 have additive effects in the R6/2 mice

Coalition for the Cure researcher Dr. M. Flint Beal and colleagues have found that creatine and CoQ10 each exert neuroprotective effects in a mouse model of HD and that neuroprotection increases when both are administered.

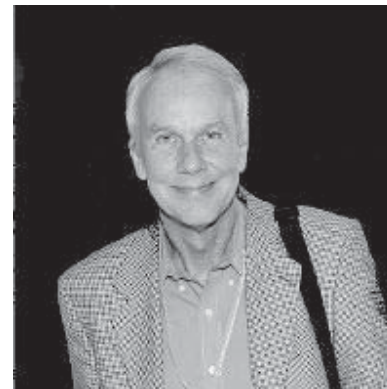
Both supplements boost energy metabolism which is known to be impaired in HD patients. In addition, both are antioxidants and oxidative damage is known to be a problem in HD. Creatine and CoQ10 are each in Phase III (final) clinical trials conducted by the Huntington Study Group as a result of promising results in mouse models and Phase I and II trials.

Should both be found effective, doctors and patients will need to know whether they should be taken in combination or whether there is no additional benefit to taking more than one of the supplements.

Creatine and CoQ10 affect cellular energy through different mechanisms. Creatine plays a key role in energy buffering between the mitochondria and the cytosol of the cell, which is especially important in cells with a high demand for energy. CoQ10 is a cofactor in the electron transport chain, which is part of the process by which energy is produced in the mitochondria. CoQ10 accepts electrons from Complex I and II and transfers them to Complex III.

Dr. Beal and colleagues provided the R6/2 mice with a diet which included two percent creatine or one percent CoQ10,

or both, and compared the results for the three groups with R6/2 mice that were fed a regular diet. The CoQ10 group did better on the rotorod test of motor performance and survived longer than the control group. The creatine group did better than the CoQ10 group, while the group that received both did best of all.



The results suggest that research into whether HD patients would benefit from taking both is worth pursuing. "If both CoQ10 and creatine show efficacy in ... HD trials, then future studies of the two compounds in combination may be warranted. A combination of the two compounds would also be a promising approach for treating pre-symptomatic individuals, since both compounds are natural products and are well-tolerated with few side effects," the authors conclude.

### Reference

Lichuan Yang, Noel Y. Calingasan, Elizabeth J. Wille, Kerry Cormier, Karen Smith, Robert J. Ferrante, and M. Flint Beal. "Combination therapy with coenzyme Q10 and creatine produces additive neuroprotective effects in models of Parkinson's and Huntington's diseases." *Journal of Neurochemistry* 2009 Jun;109(5):1427-39.

## Help HDSA Save Money—Provide your Email Address!

**As we all know, the money in our pockets is in short supply these days. HDSA is severely affected by this.** Therefore, we would like to run our operations as efficiently as possible.



We need your help keeping our database up-to-date. Please let us know if:

- You have moved or are planning to move.
- You are receiving this newsletter and would like to receive it via email.
- You are receiving this newsletter or other information from HDSA and you no longer want to receive it.

Please contact the Central Ohio office at 1-614-460-8800 or email Wendy Vaughan at [wvaughan@hdsa.org](mailto:wvaughan@hdsa.org).

## Ohio Chapter Meeting Times & Places

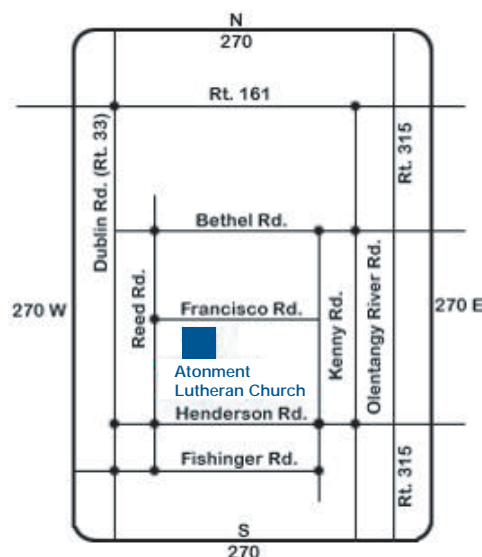
### Central Ohio

Our meetings take place at 7 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. First we get together to discuss upcoming events and make announcements, then we divide into three 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 by allowing open discussion between families and caregivers while providing fun activities for our HD individuals.

Each group has its own challenges and it is helpful to talk with 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 and the other 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 caregiving, but after awhile, please consider coming back—you can be a great help to people who are just starting down the road you have traveled. Sharing your experience and the lessons you've learned can help smooth the path for new caretakers.



#### Christmas Gifts:

Each December we sign Christmas cards and wrap presents for our HD family members who are homebound or in a nursing home.

If you have an HD family member, please make sure they are on our list. Contact Barb Heiman at [gheiman@juno.com](mailto:gheiman@juno.com).

**Akron:** Meetings are on Mondays or Tuesdays, based on the availability of a meeting room, at 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](http://www.lkwdpl.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 (Cincinnati Chapter Social Worker) at 513-741-4372.

**Toledo:** Toledo group meets every third Sunday from 2 p.m. to 4 p.m. in the fellowship hall at Our Savior Lutheran Church, 2820 W. Alexis Rd., Toledo, OH 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 Mary Beth Bialic (Cincinnati Chapter Social Worker) at 513-741-4372.

### Do you have ideas on how to improve the Family Services Committee?

We would like your input to help our support group and family services to better fulfill your needs. Please take a minute and share your ideas. Email Barb Heiman with suggestions at [gheiman@juno.com](mailto:gheiman@juno.com) or mail them to HDSA, Central Ohio 490 City Park Ave. Suite C. Columbus, Ohio.

*We are looking for feedback on things such as:*

**HDSA materials, brochures and newsletters:** How useful are they to you? Are they easily available to you?

**Support group meetings:** Are the dates, locations and times convenient? Do you attend one? If yes, which one? Comments or suggestions on content? Topic areas you would like to hear discussed?

**Fundraising Activities:** Hoop-A-Thon, Walk-A-Thon, Amaryllis Sales, Celebration of Hope

## Chapter Memorials and Honorees

### *In Memory of...*

**Ann Huey**  
Sally H. Hess

**Winfried Bostelman**  
The Bostelman Family

### **Patricia Hindel**

Beckie McInerney  
Judy Morgan  
Dorothy Reeves  
Jeanine Kurtz  
Carol Wheeler  
Erma Hindel  
Susan and Rick Bunner  
Lillette Holdren  
Shirley Vickers

### **Frederick W. Miller**

Karen and Mike Gagel  
The Officers and Employees of  
Citizens Bank  
Ben and Miriam Kensinger  
Rita and Tim Yore  
The Dick Families  
Revs. Richard and Rhonda Holbrook  
Aron and Celia Holbrook  
Barbara Newland  
Mr. and Mrs. Roger Holbrook  
Tom and Linda Cooke  
Viki Deruy  
Lori Zapf  
Richard and Donna Newland  
Jason and Lynn Snyder  
Paul Curren  
Sally Young

Paul and Miriam Schroeder  
Beth Fenner  
Cathy Whittington  
Bea Hall  
Thomas Knoll  
Hal and Annette Gibson  
Barb Heiman

### **Richard J. Lowry**

Barbara Lowry and Family

### **Laura Lynn Odenbach**

Mark A. Preusser  
The Colelli Family  
Ruby Massarelli  
Mark and Shelley Petruccio  
Paul Blubaugh  
Barb Heiman  
Ken & Judi Collica  
Grace and Arvid Erlandson  
Jodi and Nick Caryer  
Becky Massarelli

### **Sherry Kay Hinger**

Bob and Shirley Hull  
Lisa Easterday  
Larry and Joyce Huffman  
Ann and Dennis Luna  
Keith Syler  
First Church of God  
The Laboratory Employees of Knox  
Community Hospital

### **Elsie Znamenacek**

Ken Tumblison  
Melissa Schmidgall  
Melissa Valentine Snider

Elizabeth Reyna  
J Tara Windle  
Lori Allington  
Barb Heiman  
Judy & Clarence Thompson  
Jackson Middle School  
Sheri Nash  
Patricia Meeker  
Melissa Parker

### **Henry Conrad**

Lisa Vaughan

### **Phil Hess**

Erich and Mary Hunker  
Jim and Betsy Burke  
Bob and Martha Henshaw  
Don Wynkoop  
Joseph O'Daniel, Jr.

### **Martha Baldwin**

Norman Baldwin  
Craig and Lori Baldwin  
Fred and Barbara Warncke, Jr.

### *In Honor of...*

**Jason and Amy Lieb**  
Kathleen Lieb

**Gary Nash and Family**  
James and Verdale Metzger

**Dave Hess**  
Bob and Martha Henshaw

"If I had a flower for every time I thought of you  
I would walk in a garden all day." —Blu Jewel, 2006

## We NEED Volunteers!

HDSA is a grassroots organization and the families affected by HD are our number one source of energy. Nobody else can care about this issue as much as the families with HD do, so we need you to join in and help HDSA because the more volunteers we have, the faster we can find a cure. Without volunteers and their support and generosity, HDSA would not exist. We would not be able to make the breakthroughs in science that are happening every day, and we would not have hope.

Becoming a volunteer is easy and fun, and orientation is provided.

### Why become a volunteer?

- To know that you are making a difference
- To have a sense of community involvement
- To meet new people
- To gain valuable work experience

### What makes a great volunteer?

- Your desire to cure HD
- A positive attitude
- A team-player attitude
- Good communication skills
- Willingness to commit three hours a week or more
- Here are a couple of things to think about...

### A volunteer has the right:

- To be treated as a co-worker
- To be given a suitable assignment with a written position description
- To learn about the organization
- To receive an orientation and training for their volunteer position and opportunities for continuing education
- To be given sound direction and guidance
- To have regular evaluations of his or her performance
- To apply their skills and have a variety of experiences
- To be heard
- To be recognized

### A volunteer is responsible for:

- Being sincere in the offer of service and believing in the value of the task to be done
- Being loyal to the organization
- Maintaining the dignity and integrity of the organization with the public
- Carrying out duties promptly and reliably
- Accepting supervisor guidance and decisions
- Being willing to learn and participate in orientation, training programs and meetings
- Understanding the function of the paid staff, maintaining a smooth working relationship with them and staying within the bounds of the volunteer description

### Volunteer jobs that need to be filled:

**Vice President of Executive Board:** Shall serve, in the President's absence, as the top volunteer officer of the chapter; assist in providing leadership to ensure all chapter activities are conducted in accordance with the HDSA By-laws; help the chapter set goals, determine budget, create a strategic annual plan of work and develop awareness of HDSA in the community. Term of Service: one year, elected for two terms.

### Duties and responsibilities:

- Attend board meetings
- Review chapter's budget and plan of work
- Serve on at least one fundraising committee
- Help to fill vacancies in leadership positions
- Participate in fundraising activities
- Make a personal contribution to HDSA
- Represent HDSA's position and policies
- Approach all issues with an open mind and prepare to make the best decisions for the whole chapter
- Work with national HDSA leadership as required
- Provide personal and professional expertise to the chapter
- Be knowledgeable about HD and the mission work of HDSA

### Fundraising Assistants

- ***Amaryllis Sale:*** Sell and coordinate deliveries.
- ***Team Hope Walk:*** Encourage walkers and sponsors, and help coordinate the activities of the Walk.
- ***"Celebration of Hope":*** Silent Auction Committee and Sponsorship Committee.

### Family Services Committee

- ***Support Group Coordinator:*** We need to have one person work with Barb Heiman to come up with a schedule to coordinate topics and speakers for the support group.
- ***The Gift Wrap Party Coordinator:*** We need someone to work with Barb Heiman, Georgia Bruce and Pat Meeker to make sure all of the names on the list receive a Christmas card or gift from the chapter.
- ***Teen Support Party:*** We need someone to plan and implement a party for our teens and younger kids.
- ***Annual Board Meeting:*** We need someone to help plan the Annual Dinner.

Contact Wendy Vaughan at 614-783-6757 or email [wvaughan@hdsa.org](mailto:wvaughan@hdsa.org) on how you can help the chapter.

## Stack the Deck against HD!

Calling all high rollers to join us at The Celebration of Hope – Casino Night! The bankroll of this event will go toward supporting the HDSA Center of Excellence at the Ohio State University Medical Center, and vital research conducted by Coalition for the Cure, sponsored by the National Office of HDSA.

Plan your strategy to enjoy a lively casino with blackjack, roulette, craps, raffle prizes and a silent auction. The Comps will include heavy hors d'oeuvres and open bar, so stack the deck against HD by signing up to be a VIP sponsor. For more information, please contact the Pit Boss, Wendy Vaughan of HDSA Central Ohio Chapter, at [wvaughan@hdsa.org](mailto:wvaughan@hdsa.org) or 614-460-8800.



Date: Friday, Sept. 25, 2009

Silent auction and raffles all night!

7 p.m. — Heavy hors d'oeuvres and cocktails

7:30 p.m. — Game tables open

10 p.m. — Silent Auction closes

10 p.m. — Raffles Drawn

The House: The Makoy Center, 5462 Center St, Hilliard, OH 43026

Dress: Cocktail Attire

Cost: \$125 per person, or buy a table for a full house. Raffle tickets \$10 each or six for \$50.00.

**Make your reservations by Sept. 1 to receive six FREE raffle tickets!**

## Golf, Rock and Bowl 2009!

Golf, Rock and Bowl was a complete success! The June 19 event benefitted the HDSA Central Ohio Chapter and took place starting at Raymond Memorial Golf Course and then at Ten Pin Alley and Spikes of Hilliard, Ohio. This year we dedicated the golf outing in memory of Phillip Hess and to honor Dave Hess and his family.

We raised more than \$6,000 through the generous donations of the golfers, raffle ticket sales, general contributions and sponsors. The day started with 80 golfers signing up to swing their support for the fight against HD, and the event carried on without a hitch despite severe morning thunderstorms and somewhat unbearable heat and humidity during the day. Following golf, attendees moved over to Ten Pin Alley to enjoy complimentary bowling, food, drinks and fellowship with friends, our HD community and the golfers. This year's raffle prizes were two tickets to the Aug. 8 Rascal Flatts concert, a signed Blue Jackets Jersey and hockey stick donated by Joe Ondrejko of the Columbus Blue Jackets, and a 50/50 cash prize.



**Thank you to our sponsors!** Ten Pin Alley and Spikes • CD101 for the Kids • Lundbeck Pharmaceuticals • Jack and Snyder Law Office • Plahuta Appraisal Group • Continental Real Estate • John Dalton • Advance Graphics and Printing • Fore Hope

**Thank you to our volunteers!** Elyse Jones • Allison Seward • Sally Hess • Kitty and George Popovich • Phyllis Craig • Eric Hammond • Ken and Julie Walker • Maureen Nash • Gary Nash



## Amaryllis Sale: Growing a Brighter Future

Help HDSA/Central Ohio raise funds for patient and family support and research by selling amaryllis kits for \$10 each! The chapter earns \$4.80 for each kit sold.

You may buy individual amaryllis kits in small quantities (less than 16) for yourself or to sell. Dave Fisher will deliver the kits, or if you'd prefer, you may pick them up from his home or at an agreed-upon place. Be sure to include your phone number below.

### SMALL OR INDIVIDUAL ORDERS:

Mark how many of each color:

- Ferrari Lion (red)  
 Apple Blossom (soft pink)  
 Mont Blanc (white)  
 Pink Diamond (deep pink and white)  
 Clown (red and white)

### ORDER BY THE CASE (16):

Cases will be delivered by UPS to your address. Cases may be all one color, or assorted. Mark how many of each color:

- Case of 16, assorted colors  
 Case of 16, all one color:  
 Ferrari Lion (red)  
 Apple Blossom (soft pink)  
 Mont Blanc (white)  
 Pink Diamond (deep pink and white)  
 Clown (red and white)

### DELIVERY INSTRUCTIONS:

Your Name: \_\_\_\_\_

Address:

\_\_\_\_\_  
 \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Send payment with order or send to Dave Fisher after you've sold the bulbs. Make checks out to HDSA. Send this form or contact Dave at:

Dave Fisher  
 5498 Avery Road  
 Dublin, OH 43016

davefisher@wideopenwest.com  
 (614) 879-8165

### GIFT IDEA:

The amaryllis kits are nicely packaged and will make great gifts for teachers, clergy and club gift exchanges. They are especially nice for the homebound, as they grow quickly and bloom freely. It would be difficult to find a \$10 gift that would be more appreciated. Please order early and SELL, SELL, SELL!



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

490 City Park Avenue,  
Suite C  
Columbus, Ohio 43215  
P: 614.460.8800  
F: 614.460.8801  
office@hdsacentralohio.org

Board of Trustees:  
Wendy Vaughan, President  
614.487.9711

Jenny Smith, Treasurer

Rob Cleveland, Secretary

Other Board Members:  
Dr. Sandra Kostyk M.D.  
Gary Nash  
Craig Baldwin  
Maureen Nash  
Barb Heiman  
Dave Hess  
Larry Brown

Additional Contacts:  
Barbara Heiman, L.I.S.W.,  
Family Service Coordinator  
614.292.9960

Newsletter Editors:  
Theresa Z. Hanson  
Sarah M. Z. Baker  
Aaron Sheldon

Newsletter Designer:  
Sarah M. Z. Baker

**Non-Profit Organization**

**U.S. POSTAGE PAID**

**Columbus, Ohio**

**Permit #01514**

**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. Please  
send your information to the address listed above.**

Please fill out and return this certificate.

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone number \_\_\_\_\_

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