



Our Voice

VOLUME 2, ISSUE 1

JANUARY, 2005

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Our New President, Sheri Nash



Vision. Focus. Momentum. Drive. Determination. Belief. Hope.

Dream. Faith. Our Mission: Educate, Serve, and Raise Funds.

Each of these words holds special meaning to myself and many others who have served and will continue to serve HDSA into the future. These are the values that I carry in my heart when I am asking for donations, volunteers or service from others. Please remember these positive words as you are called into action. Our chapter needs YOU.

Specifically, our leadership has been concentrating on VISION. Our chapter has grown from an organization that served many, many families through support and family services with a budget of approximately \$10,000 to an almost \$200,000 chapter! I am amazed and so very proud to be part of this organization. I have found friendships that will continue for many years as well as support and a group of people that are more dedicated than I thought possible.

Beyond that, I have learned about commitment and passion. I have found a home - in more ways than one.

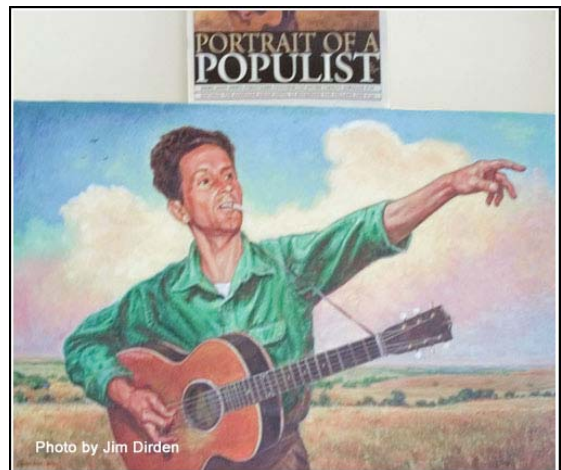
Service to HDSA continues to be a fantastic experience and I would like to share this journey with you. It is with great excitement that I am asking each of you to join us as we move beyond our all ready great successes. I am asking for your help. I am

asking you for some of your very valuable time. I am asking you to share your talents, your drive and your commitment. Believe me, I know that this is a big "ask." Please

respond to our call for new volunteers, new talents and a greater commitment. On January 29, 2005 we will be hosting a luncheon at the Atonement Lutheran Church (see page 4 for details). Our Board and some very key leaders have been working tirelessly to take our chapter into the future. We are taking yet another step as we prepare for more growth. We need committee members, expanded skill sets and fresh perspectives. At our luncheon, we will explain our specific needs and identify potential dates of service for each

volunteer. We are offering clear guidelines and clear explanations; it is as easy as possible to assist our charity achieve our mission. This newsletter, telephone calls, personal requests and invitations are some of the ways we are reaching out to the community for specific assistance. I look forward to seeing you on January 29 and personally invite each of you. Again, we need your time and talents. Please consider our request.

Sincerely,
Your new chapter president,
Sheri Nash



Charles banks Wilson's Portrait of Woody Guthrie



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

Francisco Road is just north of Henderson Road and runs east and west between Reed and Kenny Roads. There is a traffic light at the corner of Reed and Francisco Roads and the church is on the south side of the road, not too far from Reed Road.

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.

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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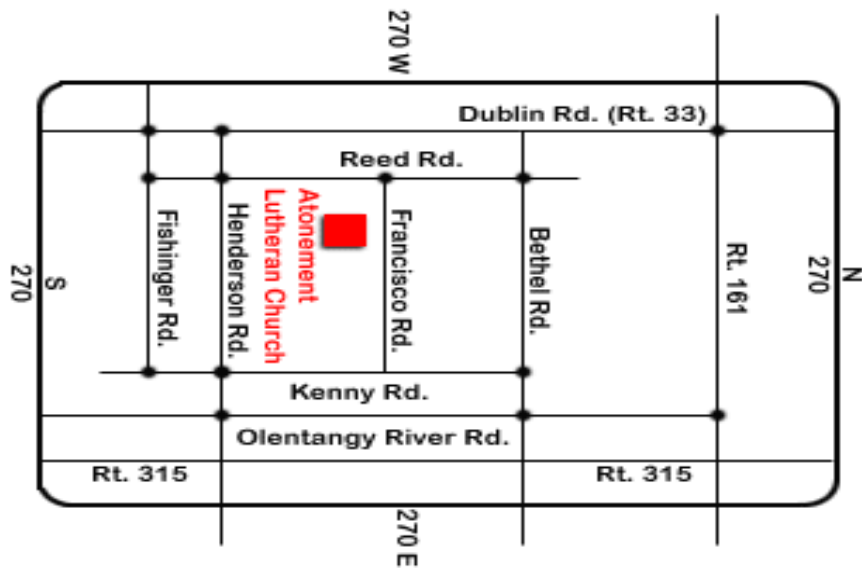
Family Service Coordinator

614.292.9960

Theresa Z. Hanson

&

Julie Znamenacek, Editors



Teenage Support Group

The next Teen support group is scheduled for January 23, 2005 at Atonement Lutheran Church, 1621 Francisco Road, Columbus OH 43220 (Between Bethel and Reed) from 3p.m. to 4:30 p.m. Please encourage any teens living in an H.D. family to attend. Ages are from 10 to 18. Parents meet separately while their children are in the group which is facilitated by Social Worker, Barb Heiman. For more information call Barb at 614-292-9960.



2005 Huntington's Disease Educational Conference

We are planning an educational conference for the Spring of 2005. Details are being worked out and information will be posted on the www.HDSACentralOhio.org website and in the Spring Newsletter. For more information call Barb Heiman LISW at 614.292.9960.



Stanford's "HOPES" [Huntington's Outreach Project for Education at Stanford] Updates

<http://www.stanford.edu/group/hopes/>

Updates on Potential Treatment in HD

- **Trehalose** - the sugar that has great potential to be a good, safe HD treatment. <http://www.stanford.edu/group/hopes/treatmts/pbuildup/h3.html>
- **RNAi** - <http://www.stanford.edu/group/hopes/treatmts/pbuildup/h2.html>
- **TUDCA** - An FDA approved medication that has shown amazing results in the lab and could be highly effective in treating Huntington's Disease. <http://www.stanford.edu/group/hopes/treatmts/ebuffer/j7.html>
- **Cystamine** - Another FDA-approved medication that might be highly effective in Huntington's Disease. <http://www.stanford.edu/group/hopes/treatmts/pbuildup/h4.html>

Previous related information:

- **Remacemide** - An Anti-Glutamate Drug And Energy Buffer http://www.stanford.edu/group/hopes/treatmts/antiglut/1_remacemide.html
- **Coenzyme Q10** - An Antioxidant Drug http://www.stanford.edu/group/hopes/treatmts/antiox/k_coenzymeQ10.html

Resources For Children

HOPES For Kids Games: <http://www.stanford.edu/group/hopes/basics/forkids/ac0.html>

Kids! Use your wits & knowledge of HD to complete these interactive puzzles!

Support Group Meeting Dates & Times for 2005

Any suggestions you may have for speakers or topics of interest please let me know. This is your group and we want it to serve the needs of our HD families. We plan to have a speaker for the support group every other month for 2005. The alternate months will be our regular discussion format. Following is the schedule currently set for the year

- January 13: Social Security Administration; Speaker Elizabeth Sammons
- February 10: Discussion
- March 10: Legal Issues; Steve Brooks, Attorney
- April 14: Discussion
- May 12: Dr. Kostyk
- June 9: Discussion
- July 14: Convention Reports
- August 11: Discussion
- Sept. 8: To Be Announced
- Oct. 13: Discussion
- Nov. 10: To Be Announced
- Dec. 8: Christmas Wrapping/ Card Signing



Buy Groceries and Help Fight Huntington's Disease

Running low on Kroger or Giant Eagle gift certificates? Remember, these certificates are at no cost to you, and these grocers will donate 5% of the sales to our chapter.

If you would like to order more certificates, please send your checks or money orders, along with a self-addressed, stamped envelope to Sheri Nash noting which certificates you prefer.

Your gift certificates will be returned to you, along with an envelope for your next order.

Please send your checks or money orders to:

Sheri Nash
1751 Ramblewood Avenue
Columbus, Ohio 43235
Phone: 614.457.8480



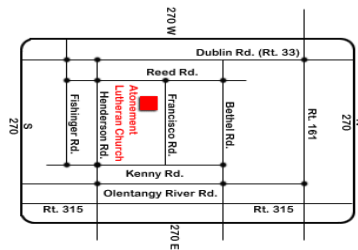
The Central Ohio HDSA Vision 2005



Come join our Central Ohio Chapter and Out of Our Heads (an improv comedy troupe) as we all put our heads together to create a uniquely tailored performance.

When: Saturday, January 29, 2005
Social begins at 11:00 a.m.
Program/Buffer lunch begins at 11:30 a.m.

Where: Atonement Lutheran Church at 1621 Francisco Rd.



Please join us for this important event to raise awareness of volunteer opportunities in the search for a cure for Huntington's Disease!

Out of Our Heads provides performances, corporate workshops, and classes for actors in the art of improvisation. <http://www.outofourheads.com>

We would love for you to attend! Please RSVP by phone or email today so we can plan for you to receive a free lunch:

Phone: 614.460.8800
Email: pmeecker@qn.net

Huntington's Disease
Society of America
Central Ohio Chapter

Advocacy Issues

The following are important issues for the HD community to support for 2005:

Need to Increase Budget to NIH and NINDS

The National Institute of Neurological Disorders and Stroke (NINDS) funds almost all federally funded HD research. NINDS has received the smallest portion of funding increases of all the National Institutes of Health (NIH) labs.

Do not ask your elected officials for a specific

percentage increase. They will be better able to support legislation to increase the budget overall if they are not locked into seeking a specific number.

Write/fax a letter or send an email to your Senator and House Representatives, or call (www.senate.gov), (www.house.gov), asking that they increase funding for NIH/NINDS.

Genetic Information Non-discrimination Act of 2003

The purpose of this legislation is to protect individuals from discrimination in health insurance and employment on the basis of genetic information.

Status of this Bill:

The Senate approved legislation barring genetic discrimination by employers and insurers, 95-0, in October 2003, but the legislation S.1053 is stalled in the House.

This information was obtained through the Advocacy Online Newsletter, Issue 2; December 2004.

Memorials

Velma Douglas, Jennings & Madis Mollohan

Carol Adams

Louise Carmichael

Elmer & Colleen Myers

Lucy Armstrong Davis

George P. Wick, Mary Jane Gossman, James & Joan Flower, Monica Schneider, Henry & Marilyn Hixson, T.J. & Jeanie-Lou Eberhardt

Marcia Standley

Susan McElheny

Jayne Knox

Henry & Marilyn Hixson, The Nature Conservancy of Tennessee, Mildred Fox, Ken & Margaret Wilson, Roger &

Carolyn Edens, Dorothy Vaughan, Dave & Bonnie Fisher, Amy R. Edwards, Jean & Joe Ohlinger, Jack & Snyder, Greg & Elizabeth, Gerhard, Norma M. Steigerwalt, Steven Vaughan, Don & Ginny Harris, Ron W. Benedict, Patricia Meeker, T.J. & Jeanie-Lou Eberhardt, Sara Gieseler, Norm & Bonnie Baldwin, Stephen & Carol Degnen

James Floyd Farley

Patricia Meeker, Milligan Communications (Ruth Milligan, Dave Daiber, Maggie Daiber), David B. Meleca, Sarah & Mike Morrison, Michael Kenney, Roger & Wendy Vaughan, William & Theresa Hanson, Connie & Gary Robins, Sharon Clay,

Norm & Bonnie Baldwin, David Shaffer, Don & Ginny Harris, Kim Starr, Laura West Jennifer Bordas, Laura Ubert, Lisa Riemenschneider, Wendy Mikola, Kristin Reed, Henry & Marilyn Hixson, Sheri Nash, Larry Ritter, Mark Smith, Jeffrey Wolfe, Heather Mason, Wayne Harer, Brent Stamm, Margaret McC&less Steve Siegel, David Kass, Mark Catalano, Melissa Johnson, Jack Tzagournis, Joy Emmer, Jonathan Kass, Jack Lucks, Rick Lindenmuth, Ashley Greiner, Rick Davis, David Sheidlower, Tom Caldwell, Jeff Zeigler, Sean Cullen, Michael Douglass, Carl Rechner, Larry Lehring, David Royer, Jim Hendrix, Doreen Lawyer, Ken Isenbarger, Antoine Matthews

Honorees

Rick Seymouris

BPOE #77, Circleville, Oh

Henry (Chip) Hixson

Harriet S. Schenk



If you have friends or family who would like to be an HDSA Advocate, please have them visit the HDSA national website at www.hdsa.org and click on "Advocacy" and then "Become an HDSA Advocate".

Would you like to be taken off of our mailing list, or perhaps receive this newsletter only via the web? If so, contact Pat Meeker on Wednesday's at 614.460.8800 or pmeeker@qn.net



HUNTINGTON'S DISEASE
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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 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 _____%