

Our Voice



Huntington's Disease Society Of America
Central Ohio Chapter

MARCH 2005

VOLUME 2, ISSUE 2

President's Letter, "The Big Thank You"

Vision 2005 was a great success! The Central Ohio Huntington's Disease Society was delighted and proud to host over 70 people at our event on January 29 at Atonement Lutheran Church. Many of you might recall that we had asked each of you to consider what you might be able to offer our chapter and the HD community in terms of your talents, skills and time. I actually termed it, "The Big Ask..."

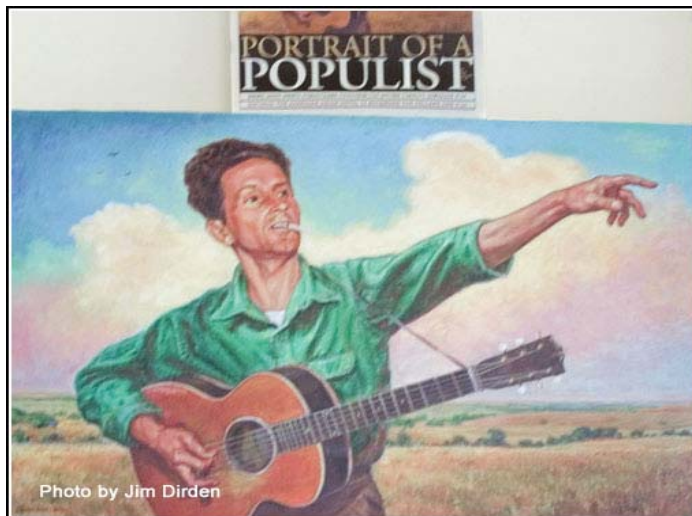
We asked and You answered in big numbers! Vision 2005 highlighted our chapter's greatest needs and implored everyone in attendance to determine how each individual would be willing to assist HD in achieving

significant goals. The community spirit and high interest levels displayed by all in attendance have energized our Board, and volunteers. We outlined committee needs, fund-raising goals and specific tasks necessary to enable our chapter to maintain momentum and succeed into the future. I am so excited to announce that each person in attendance identified an area that they would be able to assist HD. A large number of the attendees signed up for more than one task and also spoke to me later about their own ideas and abilities. Don't worry, though, if you have not had an opportunity to volunteer, we are ready to accept your help. We

really are moving into the future. January 29 was a day that filled me with great anticipation and promise as I look toward the future of our chapter. Thank you doesn't really do justice to my feelings.

I wish I had better words than thank you. Since I don't, I will say that our entire organization appreciates and values your interest in Huntington's Disease. I look forward to seeing you at the next committee meeting or fundraiser. I guess I will call this, "The Big Thank You."

Sheri Nash



Charles Banks Wilson's Portrait of Woody Guthrie

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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Support Group

Meeting Dates & Times for 2005

Any suggestions you may have for speakers or topics of interest please contact Barb Heiman. 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.

- May 12: Dr. Kostyk
- June 9: Discussion
- July 14: Convention Reports
- August 11: Discussion
- September 8: To Be Announced
- October 13: Discussion
- November 10: To Be Announced
- December 8: Christmas Wrapping/ Card Signing

Barb Heiman, LISW

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:

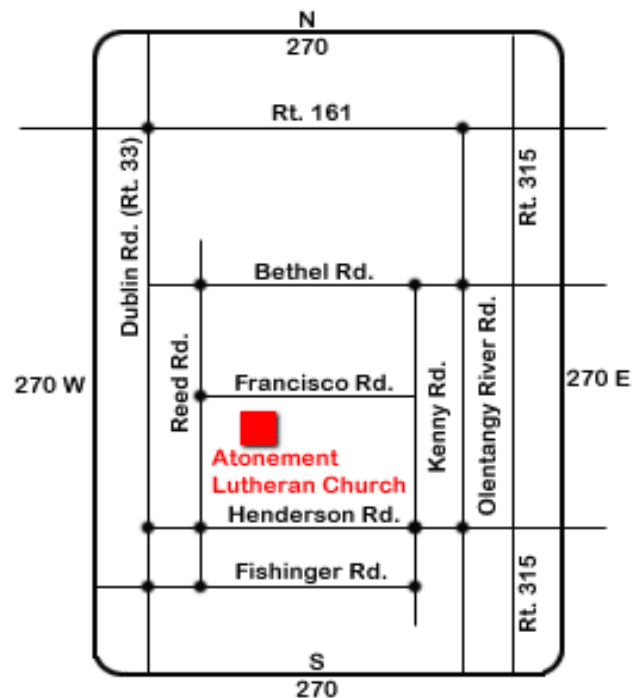
The Atonement Lutheran Church
1621 Francisco Road
Columbus, Ohio 43220

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.



Free Ohio State Fair Tickets

Please send your requests for admission tickets and ride bracelets as soon as possible. Contact Dolores by:

meekerdp@earthlink.net
or phone 614-879-8165.

Cleveland and Akron Support Group Information

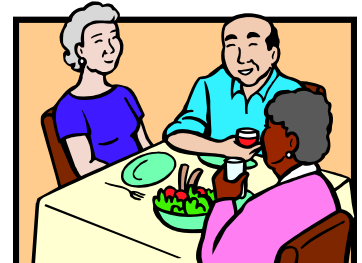
Cleveland Area Support Group Meetings are held on the third Monday of each month from 7:00 to 8:45 p.m. at the Chagrin Highlands Medical Center, 3909 Orange Place, Orange Village, OH 44122.

Akron Area Support Group Meetings are held at 6:45 p.m. at the Ellet Community Center,

2449 Wedgewood Drive, Akron, OH. For questions, contact Wes Johnston (Family Services Chairman) at 330-283-0109.

Following is the schedule for the rest of 2005: **April 4, May 3, June 6, July 11 (no August meeting) October 3, November 8, and December 5.**

Visit the Chapter's website at www.lkwdpl.org/hdsa for maps and driving directions to both meetings.



2005 Hoop-A-Thon, May 7th



The 20th Annual Hoop-a-thon fundraiser and fun day will be held on May 7th from 9:00 to 3:00 at the Jones Middle High School, 2100 Arlington Avenue, Upper Arlington, Ohio.

In the early years of the event the shooters shot free throws for 15 minutes! Wisdom prevailed and the time was reduced to 10 minutes.

Age became a factor for some of the veterans and the time was reduced to 5 minutes. Logic says we will shoot 3 minutes this year..... NOT SO! We will again shoot for 5 minutes, so have the donors pledge accordingly.

Research on HD continues to progress and there is reason to hope for a cure! Check the most recent and most promising findings at hdsa.org; click on "research". The research scientists are getting closer and closer. Progress is being made!

Time is crucial and money continues to be part of the obstacle. Be a shooter in this

years hoops, get those pledges, swish the nets, and feel good about raising money for HD. If you are not a shooter, make a generous pledge(s) to the shooter(s) of your choice; and feel good about giving money to help find the cure!

Please do come and enjoy the day, have a Coney dog, an ice cream cone, and help make this the biggest and best hoops yet. The cure is closer than ever, now is not the time to give up.....please support the Hoops and help cure HD!

Norm Baldwin & Marty Vaughan

Co-Chairs

Highlighting HD Help: Water Exercise Therapy

Exercise is recommended for Huntington patients to help retain muscle mass and body weight, as well as improve quality of life. However, balance problems and in-coordination make exercising difficult. Depending on the style chosen, exercise may even place an individual at greater risk for falls. A new exercise alternative for HD patients experiencing balance and in-coordination symptoms is water exercise therapy.

Why exercise in the water? Water exercise therapy offers a chief benefit not available in any land based exercise style: security against falling and injury. If an individual does lose their balance in water, the water buoys the body and prevents a hard-surface fall. By being able to exercise in a safe environment, partici-

pants feel less hindered and will challenge themselves more because they do not fear falling and hurting themselves.

Water exercise is just as effective as many land-based exercises in improving muscle strength and coordination. Whether you are old or young, fit or not so fit, exercising in the water may help you to manage and maintain a healthy fitness regimen.

Contact your local YMCA or community health center for more information on available water exercise classes. Remember to contact your healthcare provider before beginning any new exercise regiment to determine if water exercise therapy is right for you. To find the YMCA nearest you visit www.ymca.net. Enter your zip code and click on the "Find

Locations" button. The website will provide information about your nearest YMCA branch, including their address, phone numbers, programs offered, and hours of operation.

Printed with permission - Patti Wolf, RN BSN

National Convention

"The 2004 Annual Convention will be held June 24-26 in Atlanta, Georgia. The mission of the Annual Convention is to provide an in depth program of education and information, supported by sharing and camaraderie, for HD patients, family members, healthcare providers and chapter volunteers.

HDSA Central Ohio Chapter has some funds budgeted to help people go to the National Convention. We'll pay for registration for anyone who completes the application form. We'll help with hotel and/or transportation (part or all). Applicants are selected by need and preference will be given to first time attendees. For information please contact our Social Worker Barb Heiman at: 614-292-9960 or e-mail: gheiman@juno.com.

20th Annual 2005 HDSA National Convention

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

The Convention
is fast
approaching!

When: Friday, June 24- Sunday, June 26, 2005

Where: The Atlanta Hilton, Atlanta, Georgia

For more information or to register, visit our website at www.hdsa.org.

See you in Atlanta!



Reasons for Talking to Kids About HD

Families affected by HD have additional stressors when children are involved. Parents and caregivers may feel the best way of protecting children is to shield them from the knowledge that HD is in the family. While this coping style may appear to benefit the family in the beginning, it is unfortunately detrimental to the child in the long run.

Many adults state that HD was hidden from them and not discussed in their homes. Their reaction to this is anger. This anger makes coping with HD that much more difficult. These adults feel they cannot trust their family members. They also feel robbed. They feel that the choices they have made about their own lives (even if these choices would have been exactly the same), were made without having all the information available right there in from of them.

So lets talk about the reasons for talking to kids about HD. First, a child has the right to know about anything that affects the family. By not telling, children learn that there is not trust within the family. Even if the topic of HD is not discussed, children will pick up that there is something wrong. They may even have fears worse than the real situation. For example, they may imagine that they did something to cause a family member to become ill. In turn, the child might develop anxiety and guilt. By not talking about HD also gives the message that it is a subject too terrible to discuss.

If HD is not discussed within the immediate

family it is almost certain to come up somewhere else. Sooner or later children will find out the truth. HD and other genetic illnesses are continually highlighted in the media and there are many sites on the Internet that go into detail about HD. Genetics is also a topic that comes up more and more on school curriculums. One example was a family where the father was diagnosed with HD. He had symptoms of HD including chorea (involuntary dance-like movements) but was still employed. I had worked with the wife on discussing HD with her daughter. At first the wife was resistant, feeling that she did not want to burden her daughter with this news. When we discussed this further she agreed that this was the best thing to do. She set aside a date to talk to her daughter and two days before this date, her daughter came to her. The daughter said that she was studying genetics in her science class and that the teacher listed some genetic illnesses on the chalkboard. The teacher then spoke in some detail about the symptoms of these illnesses and their prognosis. The daughter said that one of these illnesses was a disease called Huntington's Disease. The daughter wanted to know if this was what her father had. This was not the way the wife wanted her daughter to find out about HD but she sat down with her daughter and explained that, yes, her father had HD. Again, a lot of work had to be done to first build up the trust again in this family as well as help the child cope with what this news meant. This example illustrates that it is never too late to talk

about HD but there are ways to make it easier on yourself to do this.

In addition to the above reasons, it is important to know that children who are informed about HD can be a great comfort to you. It takes a lot of energy to "hide the truth". You may not remember what exactly you told the child about the doctor appointments the patient has or the messages on the voice mail from family and friends who sound concerned. There may be information coming in the mail from organizations about HD or even a new medication lying around the house. By talking to the child about HD, you will not feel that you have to spend more energy into remembering what you actually told the child about all these changes.



Remember, children have an amazing ability to deal with difficult situations. Fears are learned. If something is hidden from a child, the message they get is that this is scary. If a child is told what is happening, it becomes part of their normal routine and there is not need to be afraid of it. Children who know about HD have an explanation as to why Mom or Dad sometimes acts "strangely". Instead of pulling away from the person with HD because they are afraid of them, children will continue to show affection and respect towards that person.

The Indianapolis Support Group Has A New Home !

Calvary Lutheran Church, 6111 South Shelby Street (use entrance off North Lot).

It is between Edgewood and Southport on Shelby.

Time: 7:00 PM The Second Monday of the Month.

For a map go to www.hdsaindiana.org and click on Support Groups. Feel free to call (317) 271-0624 or e-mail info@hdsaindiana.org for additional information.

Everyone is welcome and we look forward to seeing you there!

Progress on HD Treatments Through Its Coalition for the Cure.

Progress on the HDSA's Road to Cure. HDSA is proud to announce that several of our HDSA Coalition for the Cure Investigators have released news regarding their research, partially funded by HDSA, and made possible through the dedication and generosity of HDSA's donors.

Both sets of findings were published in the **Proceedings of the National Academy of Sciences**. The article by Dr. Bezprozvanny, Associate Professor, UT Southwestern Medical Center at Dallas and HDSA Research Grant Recipient was published on 1/31/05 and was co-authored by Dr. Michael Hayden, Director, Centre for Molecular Medicine and Therapeutics, University of British Columbia, another of our HDSA Coalition for a Cure Investigators. The article authored by Dr. Thompson ran 2/15/05.

February 15, 2005, News on Therapeutic Compounds (Irvine, CA)

According to the University of California at Irvine's Dr. Leslie Thompson, Associate Professor, Dept of Psychology and Behavioral Sciences and Dr. J. Lawrence Marsh, Professor, Dept of Developmental and Cell Biology, there is good news to report.

Leslie Thompson described the latest results where she and her collaborator, Larry Marsh, have tested compounds shown "in fruit flies and mouse models to suppress HD neurodegeneration." Scientists use "low doses of each single drug that together provide an even greater benefit while minimizing toxic side effects. The use of a *Drosophila* [fruit fly] model of HD to test possible therapeutic compounds allows us to rapidly assess potential treatment regimens prior to testing in mam-

malian models with great savings in cost and time. These results also raise the possibility that these particular combinations or other similar types of compounds could prove effective in future human trials."

Leslie Thompson goes on to say, "These types of studies would not be possible without the generous and critical support from the HDSA."

January 31, 2005: News on Drugs that may delay the onset or slow down HD (Dallas, TX and Vancouver, BC)

Dr. Michael Hayden, Dr. Ilya Bezprozvanny in collaboration with Dr. Rodolfo Llinas and Dr. Bruce Kristal have discovered that drugs commonly used to treat psychiatric illnesses and blood disorders in humans may protect the brain cells that die in people with HD, thus delaying the onset and slowing the progression of the disease.

Dr. Ilya Bezprozvanny reported, "We have developed a model that links the mutation in huntingtin with degeneration of striatal neurons. The model connects all the dots between the Huntington's disease mutation, defective calcium signaling in the cell, and subsequent degeneration of medium spiny-striatal neurons."

Drs. Bezprozvanny and Hayden found that while using the medium spiny neurons of mice that carry a copy of the mutated human huntingtin gene, treatment of the cells in culture with the drug Enoxaparin prevented inappropriate calcium release and prevented cell death. Enoxaparin (also sold as Lovenox) is an anti-coagulant that is FDA-approved in humans for use in treating blood

clots. Dr. Llinas made the initial discovery that Enoxaparin acts as a calcium blocker and provided the team with Enoxaparin samples for the studies.

Because the signals that lead cells to die can come from multiple pathways, Dr. Bezprozvanny and Dr. Hayden then determined which cell death pathway affected the nerve cells carrying mutant huntingtin. They learned that the nerve cells' mitochondria, the parts of the cell that create energy, released a protein called cytochrome c through a pore just before dying. From previous studies by Bruce Kristal, it was known the drugs nortriptyline, maprotiline and desipramine, which are antidepressants, and trifluoperazine, an antipsychotic, block the mitochondrial pore through which cytochrome c and other death signals are released. By treating the mouse nerve cells containing the mutant huntingtin protein with these drugs, these HDSA scientists found they were able to block the nerve cells from dying.

The next step for Drs. Hayden and Bezprozvanny is to test these drugs and similar drugs in whole animal models of Huntington's disease that have striatal neuronal loss to see if the cell death and neurological dysfunction observed in these models can be prevented.

Ilya Bezprozvanny, Michael Hayden and Leslie Thompson all acknowledge that support from HDSA was absolutely critical for the success of these studies. Here's the concrete proof that donations to HDSA go "Toward a Cure."

For more information, visit the website of *National Academy of Sciences* at www.nas.edu or consult the *Proceedings of the National Academy of Sciences* at www.pnas.org.

Helpful Websites:

The Basics of Huntington's Disease in Spanish:

http://www.stanford.edu/group/hopes/basics/basichd/a1_es.html

The Basics of Huntington's Disease - Polish Translation (Wersja polska):

http://www.stanford.edu/group/hopes/basics/basichd/a1_po.html

The Basics of Huntington's Disease - French Translation (traduction en Français):

http://www.stanford.edu/group/hopes/basics/basichd/a1_fr.html

CAREGIVER RIGHTS

- A Caregiver has the right to care for him or herself.
- A Caregiver has the right to seek support from someone who will listen.
- A Caregiver has the right to seek help and to recognize his or her limits.
- A Caregiver has the right to take pride and to applaud the courage it takes to meet the changing needs of the person with HD.



In Honor of:

John Karnemaat
Susan Pfeiffer

HD Regional Research Update, Toledo Chapter

Our support group, here in Toledo, in cooperation with Dr. Lawrence Elmer, MD, PhD and the Neurology Department at The Medical College of Ohio are planning another research forum and dinner. The event we held in May of 2003 was such a great success, we decided to plan one again. This year's event, "Huntington's Disease Regional Research Update" is planned for Friday, April 22, 2005 and will be held in the Dana Conference, which is adjacent to the Toledo Hilton,

on the campus of The Medical College. We have invited two widely respected researchers who are involved in HD research - practically in our own backyard: Dr. Alan Tartakoff, PhD, from Case Western Reserve University and from Central Michigan University, Dr. Gary Dunbar, PhD.

We would love to make this a bigger event than last time - so please consider attending to support our efforts in Toledo! You can call, email or write to me for reservations!

Thanks so much!
See You In April!
Robin VanGorder
HDSA Toledo Support Group
Coordinator



Memorials

Coral Toland (Maxine Kidwell's mother & the person responsible for Maxine starting our chapter) Maxine & Dick Kidwell

Jean Mathews Dr. & Mrs. Paul Morton

Hazel Loury Esther Jo Spechalske, Mr. & Mrs. Ed Mullins, Mr. & Mrs. Calvin Cross, Margaret & Janine Price, Wilma Loury family

Marcia Standley (Brooke Stein's mother) Darlene Vida, Carolyn Lamb, Scott & Laura Lamb, Dolores Meeker, Cheryl & Tim Johnston

Lucy Davis (Wendy Vaughan's mother), Paul & Margaret Sloan III

Janet Haney (Dawn Martin's Grandmother) Ruth Milne, Sheila Strekal, Janeine & Connie Van Der Molen, Patrick & Belva Reilly, Brad & Mary Haney, Sheri Nash Pittman, James & Dawn Martin, Sharon Crebs

James Farley Dolores Meeker

Michael Erlandson (Ginny Harris's brother), Don & Ginny Harris, John & Georgia Yacenic, Mike & Nanako Carroll, Dolores Meeker, Gary

& Barbara Heiman

Chester Locher, Jr. Stephen & Deborah Arnett, Nita Spriggs, William & Linda Justice

Frances Frank Savely Dick Masheter Ford, Edward & Linda Gassman, John Sells, George & Anna Flora, Paul & Louise Talbert, John & Carol Torrie, Rosemary Savely, Patheon Pharmaceuticals Quality Assurance Dept., Patheon Pharmaceuticals, Inc, Mid-Ohio Products, Inc

Jane Knox Dolores Meeker

Family Services Committee

If you have hotel samples of shampoo, conditioner, lotion, toothpaste, soap, toothbrushes, etc. please give them to a family service committee member (Ginny Harris, Barb Heiman, Pat Meeker, Sheri Nash, Georgia Bruce and Dolores

Meeker.) Ginny makes an attractive parcel with a washcloth and various items, ties it with a red ribbon with a tag which says Central Ohio HDSA and includes Barb's contact number. We give them to the women pa-

tients who come to the clinic. Everyone appreciates a little present; and a nice gift helps to brighten their day! Please help us continue this project.

PLEDGE FORM
20th ANNUAL
HUNTINGTON'S DISEASE
HOOP-A-THON



Pledge's Name	Phone	Flat Amount or Pledge per Basket	Amount Due	Amount Paid
		TOTALS	\$	\$

Here is what to do:

1. Sign up supporters and the amount they pledge per basket made or flat donation.
2. On the day of the event, bring this form to the Hoop-a-thon.
3. Shoot and have the scorer record your baskets made on this form.
4. After the event, collect pledges. Make checks payable to HDSA, Central Ohio Chapter. Mail this form and checks to Huntington's Disease Society, 490 City Park Ave., Suite C, Columbus, Ohio 43215

Shooter's Name _____

Address: _____ Phone # _____

Shooter's Age Bracket 1-12 _____ 13-18 _____ 19-35 _____ 36-50 _____ Over 50 _____

Shooting in (Memory) or (Honor) of _____

Donations to: Central Ohio Chapter _____% to Research _____%

Number of Baskets Made _____ Attested Scorer: _____



Our Voice

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Would you like to be taken off of our mailing list or receive this newsletter via the web? If so, contact our Columbus chapter at 614.460.8800.

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 _____