



Our Voice

VOLUME 3, ISSUE 1

MARCH 2006

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Central Ohio Chapter President's Article

Last January we held an event titled, "Vision 2005," in hopes that we could entice new volunteers to become part of our organization. We've been thrilled by the vast number of volunteers who have joined our fight. Many of these people do not have Huntington's in their family. Most of the attendees chose to participate because they saw our passion and a worthy cause. They wanted to make a difference.

We are in awe and at the same time humbled. At the end of 2005, Central Ohio was blessed to have 82 new volunteers participate in the incredible growth of our chapter! It is so important to recognize everyone for their dedication—not just the Board members or Event Chairpersons. Volunteers are the lifeblood of our organization. This is probably the perfect place to announce... **last year Central Ohio raised \$240,000!** Our best year to date, a year we could not have achieved without our amazing volunteers and leaders. This is an amount I could not even conceive of 12 years ago when I joined the Board. It is easy to see, **WE ARE MAKING A DIFFERENCE! YOU HAVE MADE A DIFFERENCE!**

I have been lucky enough to work with, speak to and learn from a number of our volunteers. I have even written about some of my more touching stories. Remember? Who can forget Jack who helped with the Dream Date sound system and date packages? Or what about Melody who asked her friends, to ask their friends, to ask their friends... and we raised another \$3,000. We then met Gloria who introduced us to Jeff who donated a tremendous amount to our Silent Auction. Rich wasn't able to be in the Dream Date, but donated \$1500 and introduced us to two more groups who participated in our event. Recently, Drew, a soccer coach, spent a year working within his corporation to assist us with corporate sponsorship... the success stories simply keep coming.

There are many individuals closer to home who constantly endeavor to bring an end to this disease. They do the work, learn new things and make sure that all of my "crazy ideas" occur. These individuals somehow manage to make me look good. I would like to personally thank: Theresa, Marty, Dawn, Maureen, Wendy, Laura, Craig, Hal and Pat. For me, you are the definition of charity—thank you so, so much. Without you, I'd still be saying, "Wouldn't it be nice if..."

We have listed the individuals who volunteered at our event last January. I am sure there are many others that are dedicated volunteers but weren't able to attend our luncheon; their value is no less important and we will do everything we can to recognize them throughout the year. I am immensely grateful for the blessings of our chapter, the growth and, in particular, the friendships that have formed. I look forward to getting to know all of our volunteers. For now, please know, we could not have done it without you!

\$115,000 was raised to support the HDSA Center of Excellence at the OSU Medical Center

See Pg. 5 for details!



21st Annual HOOP-A-THON, April 8th

The 21st Annual Hoop-A-Thon fundraiser for research and fun day will be held on

April 8th, Time: 9:00AM to 3:00PM
at the **Hastings Middle School,**
1850 Hastings Lane in Upper Arlington, Ohio 43221.



A Hoop a Thon is a free throw basketball event to benefit HDSA. Sponsored shooters stand at the free throw line and shoot baskets for 5 minutes. Try to sink as many as you can. Prior to the day of the Hoop, each shooter attempts to get sponsors either to donate a flat rate to HDSA or dollars per basket made. At the end, tally up your baskets and see how much money you just raised for research to cure HD! All shooters with pledges receive a free t-shirt.

Research on HD continues to progress and there is reason to hope for a cure! Check the

most recent and most promising findings at www.hdsa.org; click on "research". The research scientists are getting closer and closer. Progress is being made!

We need more SHOOTERS and VOLUNTEERS! Time is crucial and money continues to be part of the obstacle. Be a shooter, 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! OR better yet, come down and be a volunteer for the day. All students can get community services hours. Please call Norm Baldwin to schedule your time to shoot or be a volunteer at 1-740-468-9081.

To download your Hoop-A-Thon pledge form, do to our COHDSA website: www.hdsacentralohio.org

Upcoming COHDSA support groups

- March 9th speaker Lindsay Meeker, report on MN HD Youth weekend
- April 13 No Meeting due to Holy Week
- May 11 Support Group Discussion
- June 8th Speaker, to be announced (National Convention June 9 - 11th Milwaukee Wis)
- July 13 Report on the Convention
- August 10th support group discussion

HOOP A THON RAFFLE

Cost: 1 Ticket for \$10 Dollars OR 6 Tickets for \$50

Prizes: 20' Toshiba LCD Flat Screen TV with a built in DVD Player Retail Value \$899.00, Donated by Digital Interiors, Dublin, Ohio

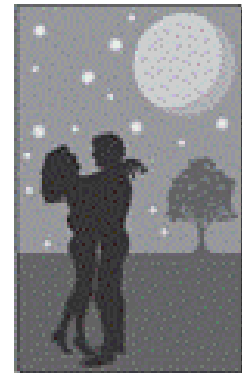
Details: Drawing will be April 8th at the Hoop A Thon. Winner need not be present to win. All proceeds benefit the HDSA "Coalition for the Cure" research..

Call Norm Baldwin to get your raffle tickets 1-740-468-9081!

Dream Date, 2006

The Dream Date event has been a great success in the past and we would like to invite you to be apart of this year's event! The third annual Dream Date will be held on Saturday, June 24, 2006 at Coach's Bar & Grill in the Bethel Center.

The event is currently in the planning stages. If you would like to help with date donations, flyers, raffle items or service items please email Sheri Nash at terryash@sbcglobal.net.





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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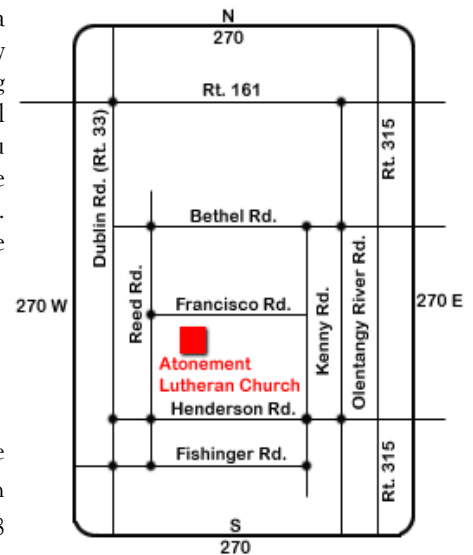
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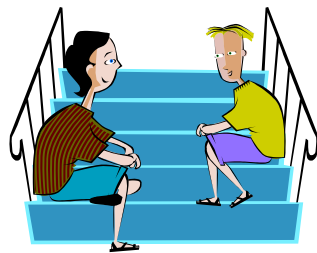
Theresa Z. Hanson
&
Julie Znamenacek, Editors



Teen Support Group

The teen support group has been on "hold" for some months. We would like to know if there is an interest in continuing this group. The age range is from 10 - 18 years old. 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 1/2 hours. This group is facilitated by Barb Heiman, Social Worker. Please call 614-292-9960 if you have questions or are interested in attending.



*Let's give a warm welcome to our new part-time office manager,
Elizabeth Reyna! Welcome Aboard!*

Vice President, Sarah Morrison's 2006 Message



I've often heard that HD is a "family disease" - but what does that mean? It means a lot.

First, it means that the disease runs in families. This is the part that means the most for testing, preparing and finding a cure. If a parent has HD, the child knows he is at risk and he knows that testing is an option. A child of HD knows that he must prepare for the possibility that "at risk" will become "symptomatic". But that child also becomes a good research subject as scientists and researchers look for a cure. An at-risk child, who does not know his gene status, may qualify for the PHAROS study or some other research project.

As a family disease, HD affects the entire family. When an individual becomes symptomatic, every member of the family must make changes. Whether it is driving your mom to a doctor's appointment, helping your brother get out of a chair, or helping your wife get dressed, families rally together

to assist and care for the HD patient. The family can provide a support network for each other and for the patient.

Through the Central Ohio Chapter, I've also learned that HD is a family disease in that people who were once strangers have become family. Over the past several years, my support network - my friends - my family has grown tremendously. My adopted brother and sisters are the people I've met at support group, at committee meetings, at the hoop-a-thon. We are all so fortunate to have such a great, caring family.

So HD is a family disease. And as a family, we will continue to fight the disease, search for a cure and help each other through the tough times.

As we begin a new year, I encourage you to tell everyone in your family (both biological and adopted) that you love them. Hug them, call them if they are out of town, let them know that they are cared for.

Best wishes to everyone in 2006!



Amaryllis Campaign

Thank you to all who supported the amaryllis campaign. Once again, Eva Weissman, Marion Good and their stellar committee broke all records for Chapter Amaryllis Sales. They also were able to increase awareness of HD through publicity in Cleveland Magazine and The Plain Dealer. We hope you are enjoying your amaryllis!



Thanks 2005 Vision Volunteers!

We would like to thank the following Vision 2005 volunteers for signing up to help us fight for the cure: Karen Znamenacek Baker, Laura Bamberger, Norm & Bonnie Baldwin, Joe Boxer, Jim, Hannah & Jeremiah Bustin, Bill & Cathy Calder, Raeann Carrier, Drew Domeck, John Douglas, Tina Farley, Dave & Bonnie Fisher, Kathy Gallen, Merrilee Greenbaum, Mickey & Patty Halls, Theresa & Will Hanson, Jean Carpenter-Haycock, Ginny Harris, Stanley Haycock, Julie Hazelbaker, Barb & Gary Heimen, Hal Hixson, Chip Hixson, Marilyn Hixson, Kari Hoyt, Colleen Johnson, Marissa Johnson, Cheryl & John Karnemaat, Dr. Sandra Kostyk, Mary Thomas Leathly, Shelley Lee, Jeanne Lester, Thong Ma, Dawn Martin, Tara Meehan, Tom Meehan,

Krista Morehouse, Dolores Meeker, Pat Meeker, Jane Meese, Marley Moorman, Mike & Sarah Morrison, MaryAnne & Gary Nash, Maureen & Grant Nash, Cindy Newcome, Elizabeth & June Nash Pittman, Gina Nguyen, Laurie Pecuch, Melissa Pennington, Jeff Pittman, Michele Ross, Clayton Shipley, Ross Shipley, Jenny Smith, Carol Usko, Marty & Cindy Vaughan, Wendy & Roger Vaughan, Lou Ann Walter, Tom Widney, Patty Wiseman, Connie (Meeker) Young, Jani Znamenacek, Julie & Kali Znamenacek



Celebration of Hope was a BLAST!



Central Ohio HDSA hosted our 5th Annual Celebration of Hope event, however this year's "Martini Blast" theme stirred things up! On Friday, September 30th, top business leaders, community officials and other notable guests gathered downtown for one of Central Ohio's premiere charitable events. Master of Ceremonies, Megan Pringle, of WSYX Channel 6/ WTTE Fox 28.

The evening was a great success by all measurable means. Nearly 300 people attending the "Martini Blast" presented by 3 Olives Vodka and Made From Scratch Catering, The evening began at 7 p.m. on the 2nd Floor of The Hartman Building, as guests sampled a bevy of specialty martini cocktails and enjoyed heavy hors d'oeuvres located throughout the New York styled loft space. Bidding was heavy on the wide selection of silent auction packages. The highlight of the "Rat Pack"-inspired evening was the live entertainment, a Tribute to Frank Sinatra and friends by Michael Sutherland. He led guests with his classic croon-

ing ballads as they hit the dance floor. The event was truly a celebration and we have hope that some day we will find a cure to HD.

Before night's end, a special moment was taken to honor Pat Meeker and Dolores Meeker, as our HD Humanity Award recipients, and our event sponsors who generously support the HDSA's Center of Excellence located at the Ohio State University Medical Center. The Corporate Leadership Awards went to Don Kelley and Bob Weiler for leading this campaign. They demonstrated again, the compassion of friendship and the importance of giving. Their speech was moving as they highlighted the career and courage of Gary Nash and our many HD patients. All proceeds from the event are to be donated to the research and treatment of individuals living with Huntington's Disease.

An official after-party took place at Spice Restaurant & Lounge, 491 N. Park Street in the Short North allowing guests a VIP access. The "after party wristbands" were sold at the event. Spice was a fun,

"happening place" to be. Thank you, Chris Corso.

A very special thanks go out to our Gold, Silver and Bronze sponsors for whom we would not be able to keep the doors of the HDSA Center of Excellence open without their support. Our Gold Sponsors are: 3 Olives Vodka, Spice Lounge, WWCD 101.1FM, Pat Dorrow, Coldwell Banker/King Thompson Realtor, The Cullman Family, Maxine Vaughan and The Marty Vaughan Family. Our Silver Sponsors: Digital Interiors, Wayne and Paula Harer and Debbie Urton. Our Bronze Sponsors: Frank and Linda Kass, Bob Evans Restaurant, Rich Products, Made From Scratch, Pat Meeker, Lynda Jollay, Dolores Meeker, The Martin/Vetere/Burns Families, Jason and Sara Boyer, Tony Farinacci and David Hickey.

We HOPE that EVERYONE will mark your calendars for next year's "Celebration of Hope" Martini Blast #2! September 29, 2006!

2006 National Convention

The 2006 HDSA National Convention will be held at the Hilton Milwaukee City Center in Milwaukee, WI from June 9 -11. Hotel cost is \$109 plus tax and the Group Code is "DSA". This rate applies for three days before and after the convention. Hotel direct number is 414-271-7250 and mention that you are attending the HDSA 21st annual convention.

The registration form and additional information is on the national web site www.hdsa.org. We encourage all of our families to consider attending this year's convention. The workshops will be helpful and informative. The interaction with other caregivers and families will be supportive and encouraging. Hope to see you there! ~ Barb Heiman



Check out this link to the Center of Excellence webpage:

[http://
www.neurology.med.ohio-
state.edu/
movementdisorders/](http://www.neurology.med.ohio-state.edu/movementdisorders/)



See the Central Ohio HDSA website to find out why!
www.hdsacentralohio.org



Immunosuppressor Drug Shows Promise in the Fight Against HD

Huntington's is caused by a flaw in a single gene, IT15, which causes a mutated form of a protein called huntingtin to proliferate, killing cells in the striatum region of the brain, a study published on Wednesday says.

A combined team from three French medical research institutes found that a calcineurin, a protein that is plentiful in the brain, chemically modifies the rogue form of huntingtin, making it more toxic for brain cells.

But they also found

that a drug called tacrolimus inhibits the calcineurin, thus correcting levels of the huntingtin.

So far, the tests have been carried out only on brain cells in lab dishes and on lab animals.

The authors say, there are good hopes that the medication will also work on the same molecular pathways among humans, although only further work will bear this out.

The study is carried in a US publication, The Journal of Neuroscience. Lead

authors are Frederic Saudou and Sandrine Humbert of Inserm.



Tacrolimus, also known under the laboratory designation of FK 506, is used to prevent rejection by liver recipients and, more recently, has begun to be prescribed, as a cream, for chronic cases of the skin disease eczema.

Article taken from www.yahoo.com health section. Printed in the Journal of Neuroscience.



New Rechargeable Kroger Gift Cards

Running low on Kroger or Giant Eagle gift certificates? Kroger is now using rechargeable cards that can be recharged at the register before or after your purchase. Contact Sheri Nash if you would like to order a

rechargeable card that gives 5% of your purchases to our chapter. Please send your check or money orders, along with a self-addressed, stamped envelope noting which store and the starting amount you prefer. Your gift

cards will be mailed to your door. Please send your checks or money orders to: Sheri Nash, 1751 Ramblewood Avenue, Columbus, Ohio 43235. Phone: 614.457.8480

Memorials

Paul Melvin Bernsdorf

Mr. and Mrs. Orville Fuller, Decker Construction Company, Stanley and Sheila Burke, Nancy Bernsdorf, Betty Bernsdorf, Don and Emily Schneider, Randall Bernsdorf, Robert and Sue Miller

Janet Haney

W. Edward, Valerie & Gerry Echard, Bernard Karnematt

Mildred Fox

Marguerite McGregor, Mary Jo Adams

Mary Ann Lambert

Shirley Daley, Bob, Sandra & Emily Lambert

Janet Baldwin

Norm & Bonnie Baldwin

Lisa Williams

Paul and Lorena Kemp

Dale Meyers

Ralph and Dolores Verhoff

Zulus Prince

Steven and Jill Cooper, April Manns, Eva Larribee, Ronda Muler, Paula and Phil Wight, Gary and Maxine Van Buskirk, Adam Miller, Mills Metal, Tom and Jenny Tucker, Cheryl and Mike Ridner

Mike Erlandson

Bob Harris and Family

Blue HDSA Bracelets are on sale for \$1 at the monthly support group meetings. Get them while they are still available!

Area Support Groups

CLEVELAND AREA

Cece Cornell has resigned her position as the Chapter Social Worker. We will certainly miss Cece, and are grateful to her for her years of service to the Northeast Ohio Chapter.

The Cleveland Area support group will continue to meet on the third Monday of each month. The next meeting will be on February 21, 2006 at 7:00 pm. at University Hospital's Chagrin Highlands Medical Center, 3909 Orange Place, Orange Village, OH. The following are the meeting dates for the rest of 2006:

March 21, April 18, May 16, June 20, July 18, August 15, September 19, October 17, and November 21 (no meeting in December).

AKRON AREA SUPPORT GROUP:

The Akron Area Support Group will meet on Monday, October 3, at 6:30 p.m. at the Ellet Community Center, 2449 Wedgewood Drive, Akron, OH. Candace Jones, Medicaid Program Manager for Summit County Jobs and Family Services will present a program entitled *What is the*

Medicaid Problem? Topics for discussion include the scope of medical coverage, asset protection, estate recovery, income limits and information on how to apply for Medicaid. For questions, contact Wes Johnston (Family Services Chairman) at 330-283-0109.

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



Honorees

Elsie Znamenacek

Meryln & Antoinette
Znamenacek,
Robert & JoAnn Renner

Norman &

Bonnie Baldwin

Leo & Gloria Gerhold

Thanks Pat!

All of us at the Central Ohio Chapter wish a very warm thank you to Pat Meeker for all of her hard work and dedication to our Chapter. While words are not nearly enough for all that Pat has done for HDSA, we must express our profound gratitude for all of her efforts. In

addition to the extensive hours that she has volunteered, Pat has worked diligently for the past several years as our office support person. Pat has acted as chapter historian, board secretary, office assistant, assistant treasurer, t-shirt designer, and she has gener-

ally kept all of us on track! We all enjoy seeing Pat at the different HD events, both fundraisers and support group, because she is always wearing a smile and always has a kind word for everyone. In a word, Pat is "brilliant"!!

Wheel Chair Loan

The Central Ohio Chapter HDSA has acquired several wheel chairs which can be helpful for our patients with movement disorder. Currently, all of our chairs are on loan. If you are interested in using one of these chairs and would like to be added to

the list, please contact Social Worker Barb Heiman at 614-292-9960 or the Downtown office at 614-460-8800. This is intended to be a "short term loan" while plans are in progress to secure an appropriate chair for the patient in need.



BMW Sweepstakes

Each year our chapter participates in the BMW Sweepstakes. We are proud to announce that one of our Chapter members won the second prize of \$5,000 at the HDSA National Convention in Atlanta.



HUNTINGTON'S DISEASE
SOCIETY OF AMERICA
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 _____ %