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*Presidents Message*

Our Voice is the official publication of The Central Ohio Chapter, HD SA  
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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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**& Julie Znamenacek, Editors**

Our chapter has been making great strides over the last 5 years. We have grown financially as well as in the number of people volunteering and donating. I've told you before, this is very exciting and more than energizing. Individuals and corporations are joining in the fight against Huntington's Disease. Our chapter has been striving for these developments for a long time. It is exciting to see the growth as well as the honest interest in our charity.

I have been lucky enough to see many of these developments personally. In May and June our chapter held two of our most important events - the Hoop-A-Thon and the Dream Date Auction. Both of these events continue to grow as community wide participation increases. Our organization depends on the assistance of others as we work to increase our network. We speak about expanding our circle of friends; we speak about increasing awareness as well as procuring more publicity.

Recently, I have been lucky enough to see the benefits of expanding our circle of friends and increasing our network. I have been touched, yet again,

by the generosity of others and the value of sharing our story. In helping my sister with the Dream Date Auction, we asked a few of our friends to reach out to their contacts to consider assisting us with this fundraising event. The response was unbelievable! We were invited to the Columbus Ski Club to talk about the event. Here we found an individual with HD in their family and a partnership began. Through this network, we located two more bachelors as well as an individual who helped us find sponsors. These individuals have now decided to join in the fight to end HD.

Yet, the story doesn't end there. One person was unable to attend the event so he donated \$1500 to our cause and also introduced us to two singles services. Now, one of these services wants to help with the entire event next year, someone has offered to assist with marketing ideas and the list goes on... Later that same day, a friend of a friend of a friend contacted me. He introduced himself as Jack. Another friendship and partnership has begun. His group donated a 4-day trip and the sound system for the Dream

Date event. Yet again, I had the opportunity to share the HD story and why it touches my life. I learned, that day, that there are many great people just waiting to help. Jack asked me to write my story down and email it to him. He proceeded to send it to all 160 people in his travel group and asked them to think of a way to help. Within 3 days I had received 4 phone calls, set up 2 more meetings and, I believe, started some wonderful new friendships.

I am re-energized, again. I am ready to build off these budding relationships and continue to spread the word about the fight against Huntington's Disease. I am grateful for the thoughtful kindness of others. I am more confident than ever that we are able to expand our "circle of friends." I'm looking forward to the future and watching each of you "tell your story one more time." As each of us continues to tell our story, we will find success.

Sheri Nash

### 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. Following is the schedule currently set for the year.

- July 14: Convention Reports
- August 11: Medicare Prescription Drug Plan. Chris Reeg from OSHIP, speaker
- September 8: Discussion/Support Group
- October 13: "Savy End of Life Planning" Decisions for yourself and your loved one." Marie Lorz, Speaker
- November 10: Discussion/Support Group
- 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.

## Ohio State Fair Tickets Available! Order Now!

The family service committee has once more requested admission tickets for the Ohio State Fair which runs from August 3-14. Please call or email Dolores Meeker to request tickets. Indicate the

number of admission tickets and the number of Children's ride tickets needed for your family for one day at the fair. We will also pay for parking if there is need. For tickets, or more informa-

tion, please call Dolores Meeker at 614-879-8165. Leave a message with your name, address and phone number. You may also contact Dolores Meeker by email at meekerdp@earthlink.net.



Thanks to **Norm Baldwin and Marty Vaughan** for being Co-Chairs at this years Hoop-A-Thon!

### 20<sup>th</sup> Annual 2005 HDSA National Convention

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



**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](http://www.hdsa.org).

See you in Atlanta!



# Caregiver Conference



*Huntington's Disease  
One Day Caregiver  
Conference*

*Offered By Jim Pollard &  
Sandra Kostyk, M.D., Ph.D.  
HDSA Central Ohio  
Chapter  
October 8, 2005*

### *About the Speakers*

Jim Pollard, a special education teacher and healthcare administrator has worked with people with Huntington's Disease for the last 18 years. He's toured England and Wales speaking to healthcare professionals for the HD Association of Great Britain. A regular speaker at biennial meetings of both the International and European Huntington's Associations, he is the former administrator of Sunbridge for Lowell (MA) and current Program Director of the Laurel Lake Center's HD programs. He helps run HD-related events at The Guthrie Center in Great Barrington, MA, and for the last several summers he has organized an event at the Woody Guthrie Folk Festival in Okemah with the Oklahoma Chapter of HDSA. He taught special education, behavior analysis and child development at the graduate level for many years.

Jim is the editor and author of "A Caregiver's Handbook for The Advanced Stages of Huntington's Disease" which has been published by HD societies in seven countries in North America and Europe. Jim also authored the brochure "CNA's First Shift" to help aids and

others helping to care for someone with HD better understand the disease.

Dr. Kostyk received her M.D. and Ph.D. from the University of Chicago. Her Ph.D. thesis research was related to understanding motor circuitry related to targeted movements. She completed her neurology residency training at Massachusetts General Hospital and pursued further postdoctoral research at Harvard University. Since June 2000, she has been the medical director of the HDSA Center of Excellence at Ohio State University Medical Center. She is an active member of the Huntington's Study Group, a national association of neurologists dedicated to improving the care and treatment of individuals with Huntington's Disease through their research efforts.

### *Suggested Audience*

This program focuses on topics of special interest to family members caring directly or indirectly for loved ones with HD and those who oversee their care in nursing homes or residential settings. This program is not recommended for children as we address some practical topics.

If you have HD yourself, we ask that you pass up this day. The risk of unintentionally offending you or hurting your feelings in some way tends to inhibit us as we try to figure out ways to become better partners in your struggle with HD.

### *Conference Location:*

Ashland Inc., 5200 Blazer Parkway, Dublin, OH 43017

*Fee: \$30.00 Professionals*

*\$15.00 Caregivers, family members*

*Fee includes breaks, box lunch and continuing education credit for LSW, RN, LPN. Professionals must attend the entire conference and complete the evaluation. Must have license number for registration and continuing education credit.*

*Make checks payable to: Central Ohio Chapter HDSA and send to:*

*Barb Heiman LISW, 1060 Olmstead Rd., West Jefferson, OH 43162*

*Registration—Please RSVP by September 22, 2005.*

### **Conference Topics:**

- ✓ A caregiver's introduction to HD.
- ✓ Less Apparent Aspects of Movement Disorder .
- ✓ Why the Cognitive Disorder is So Difficult .
- ✓ A Basic Review of the Signs of Depression.
- ✓ Huntington's Disguise
- ✓ The Importance of Routine.
- ✓ The Importance of Proper Positioning.
- ✓ How To Give A Shower
- ✓ Keeping Folks Engaged in More Advanced HD
- ✓ Research and Clinical Trials

Briefly we will also discuss:

- Some New Observations About Feeding Tubes
- Some New Observations About Feeding Tubes
- A Few Words About Haldol Problems with Smoking

*Please print legibly. Name tags and certificates will be made using the information below.*

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_

Agency \_\_\_\_\_

\_\_\_\_RN\_\_\_\_LPN\_\_\_\_SW\_\_\_\_Family Member\_\_\_\_Other



## Hoops Raise \$20,000!

The 20<sup>th</sup> annual Central Ohio Chapter Hoop-a-thon was held on May 7<sup>th</sup> at the Jones Middle School, Upper Arlington, Ohio. **Marty Vaughan** and **Norm Baldwin**, Co-chaired another success event with pledges totaling \$20,000! In past years the total raised has exceeded the pledges and we are confident that will happen again this year.

This years Hoops had 31 enthusiastic shooters. **Marty Vaughan** was again the leading fundraiser. Age bracket winners were **Steve Buhrts**, **David Thompson**, **Stephanie Thompson**, **Marty Vaughan** and **Norm Baldwin**. Stephanie led all shooters with 86 baskets in the five-minute period.

The Ohio State University Fencing Team provided the

entertainment for the day. Assistance Coach, **Terrance Lasker** (a five time national champion) narrated an exhibition between OSU fencers, **Christian Rivera**, Bloomfield, NJ and **Denis Tolakachev**, St. Petersburg, Russia. Tolkachev finished 4<sup>th</sup> in the NCCA championship and Rivera finished 12<sup>th</sup>. The OSU team narrowly lost out to Notre Dame for the national team championship. These fine young men displayed their skills with the epee weapon to the delight of the hoopsters.

Norm Baldwin then challenged Marty Vaughan to a “Duel to the Death (of HD)” Marty’s quick feet and slashing epee made quick work of the ill-fated challenge by scoring three quick kills to end the aging warrior’s hopes for eternal fame. In some peoples minds, the “Duel to the

Death” will go down in history, second only to the Burr – Hamilton duel. Marty and Norm want to thank the OSU Fencing Team; the OSU participation in the Hoops is very much appreciated.

Thanks also, to **Mike Mavromatis**, Georges All American Grill, Georgesville Road, Columbus, Ohio. Mike donating all of the food included their award winning Coney Dog. Please stop by the grill and thank Mike and his wife, **Dawn**, for their support of the Hoops.

Over 50 people helped in some way to make the Hoop-a-thon a success. Thanks to all who helped in organizing the event, helped the day of the event, helped with the silent auction, and especially to those who donated to support the Central Ohio Chapter and fund the research to find the “cure”.



*Stephanie Thompson putting away the competition at the Hoops! Great job Stephanie! See you next year!*



*Great Coney's from George's American Grill and support from our fans (From left: Elsie Znamenacek, The Singing Clown, Norm & Bonnie Baldwin) made the Hoop-A-Thon a fantastic event!*

## Loan Program Helps Local Homebuyers Support Communities

Columbus, Ohio – October 23, 2003 – Columbus area homebuyers now have a financing option allowing them to realize their dream of homeownership and support their community in the process. Wells Fargo Home Mortgage, a leading national mortgage leader and the leading lender to minority homebuyers, launched an initiative called the Sharing Advantage Program that helps homebuyers help others improve the quality of life.

help organizations that serve the needs of ethnic minorities and/or low-to moderate-income individual,” and Kile Cameron, Home Mortgage Consultant for Wells Fargo



Through the Sharing Advantage Program, homebuyers have access to Wells Fargo Home Mortgage’s vast array of financial resources, including first-time homebuyer seminars, one-on-one family meetings, and unlimited mortgage product and service information. These services are available free of charge from Wells Fargo Home Mortgage.

Home Mortgage. “The charitable contributions made by homebuyers help strengthen communities with designated programs such as tutoring, after school activities, day care, food services and more.”

The Sharing Advantage Program allows participating members to direct Wells Fargo Home Mortgage to make a \$300 contribution on their behalf to the faith-based or non-profit organization of

“The Sharing Advantage Program is uniquely designed to

choice following the loan closing. The organization must be exempt under Federal law. This contribution is paid for by Wells Fargo Home Mortgage and distributed directly to the designated church or charity.

For more information about the Sharing Advantage Program, call Kile Cameron at 614.413.6013.

Based In Des Moines, Iowa, Wells Fargo Home Mortgage, Inc., Is a subsidiary of Wells Fargo & Company (NYSE: WFC). It is a leading originator and servicer of residential mortgages. With a presence in more than 1,200 mortgage and Wells Fargo bank stores serving all 50 states, Wells Fargo Home Mortgage operates the leading mortgage lending network in the country. Combined, its retail and wholesale lending operations provide funding for approximately one of every 15 homes financed annually in the United States.



Have questions about our chapter?  
Email us:  
[centralohiohdsa@yahoo.com](mailto:centralohiohdsa@yahoo.com)

## Dream Date Auction, An Evening to Remember!

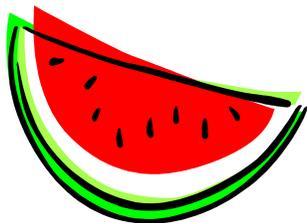
Saturday, June 11<sup>th</sup> was an exciting night for more than 25 bachelors and bachelorettes. The bids were flying, the excitement was intense and we had more interest in this

event than ever! Our chapter, with the help of many people, sponsors and new volunteers, raised over \$11,000. The dates included trips, dinner for four at Abergene by Spagios, a houseboating vacation, a private plane ride to Put-in-Bay and too many others to mention. The event was held at Coaches Bar and Grill and the emcee, Joe

Boxer, kept the audience on their toes. Over 300 people attended the event and it was standing room only inside and outside. This year, the event included a raffle, corporate sponsors, matching gifts and straight donations. Without a doubt, this was the best Date Auction we have held yet! Thank you to all who attended and participated. It was certainly an evening to remember.




**Many Thanks to Maureen Nash for her efforts with the Dream Date Auction!**



**Mark your calendars!**

**Annual meeting: October 22!**

## *Living Wills are Not Just for Seniors: Advanced Care Directives*

### Definition:

Advanced care directives are specific instructions, prepared in advance, that are intended to direct a person’s medical care if he or she becomes unable to do so in the future.

### Alternative Names:

Special medical power of attorney; Power of attorney; Verbal directions for future care; Durable medical power of attorney; DNR – do not resuscitate; Organ donation; Living will.

### Information:

#### PURPOSE

Advanced care directives allow patients to make their own decisions regarding the care they would prefer to receive if they develop a terminal illness

or contract a life-threatening injury. Advanced care directives are also used to designate someone the patient trusts to make decisions about medical care, if the patient becomes unable to make (or communicate) these decisions.

Federal law (1990 Patient Self-Determination Act) requires hospitals, nursing homes, and other institutions that receive Medicare or Medicaid funds to provide written information regarding advanced care directives to all patients and residents upon admission.

Potential advantages for individuals who develop advanced care directives include the following:

- Decreased personal worry
- Enhanced health care

provider knowledge regarding patient’s wishes

- Decreased application of “defensive medicine” by provider
- Decreased implementation of futile, costly, specialized interventions
- Decreased overall health care costs
- Decreased feelings of helplessness and guilt for family
- Decreased legal concerns for everyone involved

The primary limitation of advanced care directives is the inability to predict what situations may arise in the future or what new modes of care may be available for situations considered nearly hopeless today.

## *Celebration of Hope - Friday, September 30th!*



This year our Celebration of Hope will have a twist!! It will be a shakin’ (not stirred) celebration!! An entirely new and different event!! A “ Martini Blast” benefiting those who suffer from HD, is honoring those who give of themselves and supporting the HDSA Center of Excellence at the Ohio State University Medical Center.

Each year the Central Ohio Chapter of HDSA has the responsibility to raise \$50,000



dollars to fund the HDSA Center of Excellence for Patient Care and Family Services. We need your help through sponsorship, ticket sales, silent auction donations and volunteers!! For more information about how you can contribute to make this the best event ever, contact Wendy Vaughan, Celebration of Hope Chair. Call or email 614-487-9711 or [wvaughan@columbus.rr.com](mailto:wvaughan@columbus.rr.com). This will be a fun night you won’t want to miss!!

## Memorials

Robert Swank Lewis Hullinger, Mr. & Stanton Shaw, Mr. & Mrs. Robert Teuscher, Barbara Ransopher, Donald Gunningson, William & Phyllis Fisher, First United Methodist Church, Janice Durre & John Hensler, Chapter DL, P.E.O. Sisterhood

Bryan Hindel Janet Hostetler, Lillette Holdren, Jan & Delmar Dutro, John & Peggy Kelbly, Gloria Kieffer, Roger & Carol Myers, Kim Bice, Raymond & Lois Orr, David & Carol Derwacter, Glenn & Kitty Winters, Dorothy Reeves, Paul & Carol Howard, Suzanne & John Ray, Jeffrey & Beth Cope, Linda & James Cope, Tri-Valley Education Assoc., Doug Hendershot Family, Jake, Shannon & Krystra Smathers, Earl & Margaret Caw, Denise Dougherty, Duane & Kay Huff, Mark & Becky Rawlins, Dan & Gloria Kieffer, Greg & Penny Marshall, Genesis Healthy Generations Clinics, Steve, Theresa, Brandon, Ashley, Julie & John

German, Howard & Cathy Boykin, Janice Billker, Keith & Susan Scott, Jerilee Moore, Timothy & Nancy Raymond, Charles Jones, Thomas & Melissa Bixler, Michael & Carolyn Chamblin, Dick & Mary Jones, Paul Swingle, Beckie McInerney, Charles & Debra Steil, Randall & Cynthia McInturf, Charles & Erin Allbritain, Chad & Mindy Hendershot, Tami George, Sandy Lowery, Julie Link, Sue Moore, Charmaine Ryan, Renee Ryan, Renee Spiker, Lissa Wolfe, Carol & Carmen Wheeler, Harry & Connie Kaloydis, Theresa Zayac, James & Sharon Clegg, Muskingum Cty. Juvenile Detention, Mary Elise & Marsha Zayac, Sharron & Bob Hayes, Fred & Kay Graham, B. Lynn Schaegele, Evelyn Rittberger, Production & ODOT District 5, P. J. Longstreet, Ernest & Patty Brock, Guy Naples, J. Kinsey & Martha Tanner, Shirley Luburge, Barbara Horlocker, Roger

& Sharon Vickers, Judith King

Michael Erlandson (Ginny Harris's brother) Norm Baldwin

Francis Savely Friends & Neighbors at Lakeland Hills Assoc., Carlene, Nick, Shelley, Andrew, Alex, Annie Lieb, Ralph & Nancy Bush, Virginia Clarke, Dave & Diana Niles, Buckeye Ranch

Jennings Mollohan Nancy Friend

Hazel Laury Janie Thompson  
Thomas William Sloan Office & Professiol EMP. AFLCIO- & CLC

Janet Hancy David & Laurie Moniz, James & Linda Petkosek, Amy & John Wiesterman, Paul & Memory Makad

Thomas Bustin (Mary Anne Nash's Brother) Norm Baldwin, Mary Anne & Gary Nash, Gene & Margaret Pittman

Thomas Sloan Wayne & Barbara Strayer, John & Tammy Boellner,



*Would you like to send a memorial donation to someone close to your heart? See Page 8 for information.*



### Honorees

Bonnie & Norm Baldwin

Alice Katterhenrich

Dennis M. Nash

Mary Anne & Gary Nash

## Resource Corner:

<http://www.stanford.edu/group/hopes/sttools/print.html>

See the website above for HD information that you can print out and share!

### Topics include:

- The Basics of Huntington's Disease
- An Introduction to DNA and Chromosomes
- Juvenile Huntington's Disease
- A Historical Timeline of Huntington's Disease
- The HOPES Brain Tutorial
- HOPES For Kids (Story only)
- Entire Causes of HD Section (All chapters)
- Welcome / A Note on the Term "Cause"
- The Inheritance of Huntington's Disease
- The Neurobiology of HD
- Huntingtin Protein and Protein Aggregation
- All About Mutations
- Population Genetics
- Entire Diagnosis of HD
- Section (All chapters)
- Genetic Testing
- Behavioral Symptoms
- Cognitive Symptoms

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**We're on the web!**

**National Website:**

[www.HDSA.org](http://www.HDSA.org)

**Chapter Website:**

[www.hdsacentralohio.org](http://www.hdsacentralohio.org)

**Our Voice Editors:**

Theresa Znamenacek Hanson

Julie Znamenacek



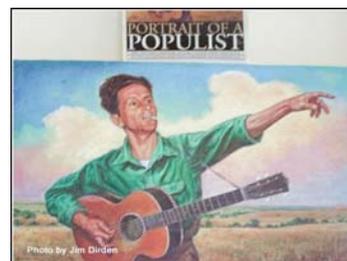
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**Columbus, Ohio**

Would you like to be taken off of our mailing list or receive this newsletter via the web? If so, contact us 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 \_\_\_\_\_

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