

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

Volunteers Needed! If not you than who?

Welcome to the HDSA Central Ohio Newsletter. I would like to introduce myself. My name is Wendy Vaughan. I am the new President of the HDSA Central Ohio Chapter. I have been volunteering in leadership capacities and as a committee member of non-profit organizations most of my adult life. I have been president of several boards over the year such as Buckeye Boys Ranch Sustaining Board 8, Kinder Key of Children's Hospital, Barrington Elementary PTO, The Women's Auxiliary Council of Children's Hospital, and CD101 for the Kids. I have served on the executive committees of Goodwill Columbus, The Memorial Tournament, Festival of Trees and Childhood League. I have been a worker bee for lots of little but important projects in between for my community and my family. Volunteering has become a vocation for me, but it doesn't have to be that way for you.

For the past 15 years I have been volunteering for HDSA.

My first major role with HDSA was to work with Norm Baldwin (past board member and past president) and Marty Vaughan (past treasurer, past president) to help get the grant to start the Center of Excellence at the OSU Medical Center in 2000. I chaired the first "Celebration of Hope" to fund the Center of Excellence in 2001. People often ask me "Why do you keep doing this?" I keep volunteering because it is important to all of our HD families. I want to affect change in the face of this disease.

The reality is that I just can't seem to walk away because I care about all of you. But I cannot do this alone or with just a few members on the executive board. **I need your help too.** I understand that many families cannot volunteer because HD is just too overwhelming or that many people do not want the world to know about HD. However, every act of volunteerism, no seemingly how small, helps in some way. We need more people who are willing to be involved. The answers are within reach. But with your help, they will come faster than without your help.

The role of HDSA is to make money to fund researchers to find a cure to this disease and care for the families who are suffering. We cannot provide services or fund research without money. We need to work to help ourselves. HDSA has strength, commitment and compassion. WE CAN do this. There is strength in numbers and as a community we need to stand together. So if not if it is NOT US who volunteer for HDSA then who will do it?

We are looking for family members and friends of HD patients who are willing to serve on the Central Ohio Board of HDSA. Your volunteer experience need not be extensive. The only thing that really counts is a passion to make a difference. The committees that we need your help with are: Executive, Fundraising, Family Services and Education. We need people who can give a few hours a week, perhaps willing to type, head up a social event,



make a few phone calls, work at a couple of events or you tell us what you can do. Norm Baldwin is currently taking the lead on the nominations committee for this fall. The position of Vice President is currently open. Please come and join our team. The work is rewarding and the pay is priceless. That is what keeps me going. Please call the office or send me an email if you would like to get more involved with the chapter. We will find a spot for you!!!

Wendy Vaughan



Central Ohio Chapter Annual Dinner on October 22nd

The HDSA Central Ohio Chapter Annual Dinner will be held on Wednesday, October 22, 2008 at the Florentine Restaurant, 907 West Broad Street, Columbus, Ohio 43222. It will be a year in review, updates on research, and a recognition of volunteers and sponsors. The cost will be \$18.00 per person. For more information contact Brenda Francis at: Brendafrancis@ymail.com.

HD Awareness Calendar

The Huntington's Disease Society of America is putting together an HD awareness calendar for 2009 and we would like you to become a part of it. We are looking for photographs of HD families to include within the calendar. We will select photographs from among those provided to be included in the calendar. If you would like to participate please send in your electronic image in a high resolution jpeg or pdf format to mperez@hdsa.org no later than September 1, 2008.

Please note that this calendar will be sold through the National Website to raise funds to continue our fight against HD. By sending the image you are authorizing the Huntington's Disease Society of America the use of the image.

We thank you for your cooperation and participation.

Regards,

Barbara Boyle
National Executive Director/CEO

HD Research Study

We (Drs. Kloos/Kegelmeyer/Kostyk) are conducting a study about the effects of an exercise intervention on the ability to balance and walk in people with Huntington's disease. The information gained from the study will be used to help health care professionals to prescribe the most effective exercises to improve balance and walking for people with Huntington's disease. You will be asked to participate in two activities, one a video-based game to move your feet to music and the other a handheld video game like solitaire or crosswords. These activities will be done two times a week for about 30-45 minutes for six weeks. You will also be tested four different times with a variety of tests. One test will require you to step quickly in different directions over a cane. You will also be asked to walk across a 16-foot walkway 4 times under three conditions: forward, backward, and through an obstacle course. You will be asked questions about falls; you will also be asked to complete a questionnaire about your confidence to complete certain daily activities without falling and another questionnaire about your general physical and mental health. It will take approximately one hour to complete the testing. Your participation is strictly voluntary, and your decision to participate or not to participate will not affect your care at the Clinic.

Would you be interested in participating in this study? If so call or email:

Dr. Anne Kloos
614-688-5942
Kloos.4@osu.edu

Dr. Deb Kegelmeyer
Kegelmeyer.1@osu.edu

HD Convention Report

The 23rd Annual HDSA Convention was held in Pittsburgh, Pa June 6th – 8th. Approximately 750 individuals were in attendance.

The HDSA Convention is primarily an educational conference that provides information about both the care and cure of Huntington's Disease to allied healthcare professionals and lay individuals within the HD community. Numerous workshops and plenary sessions were offered in areas including HD research, symptom management, caregiver support, genetic counseling, testing issues, living at risk and more.

More information about this year's convention can be found at HDSA.org or by contacting the National office at 1-800-345-4372. Next year's Convention will be held in Phoenix, AZ June 5 – 7, 2009. Plan now to attend the 24th annual National HDSA Convention.

Ohio Chapter Meeting Times & Places

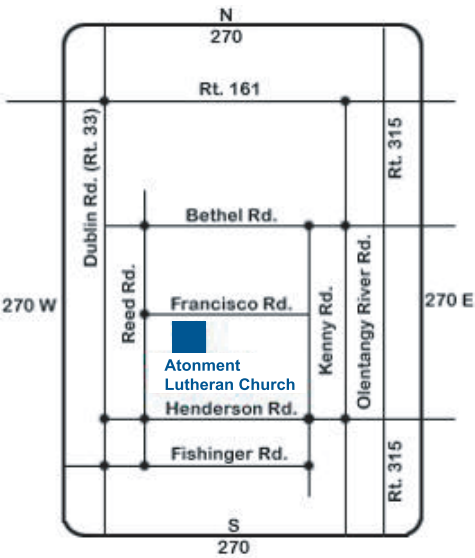
Central Ohio

Our 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

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. 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 for the families to allow for open discussion with the caregivers and provide a fun activity for our HD individuals.

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.



"Through my illness I learned rejection. I was written off. That was the moment I thought, Okay, game on. No prisoners. Everybody's going down."

-- Lance Armstrong

Teen Support Group

We are planning to reestablish the Teen Support group. Any teenager between the ages of 10 – 18 are encouraged to attend. 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 ½ hours.

This is an important group in our HD family. We want to meet the needs of our young people through group support, information, education, and socialization with other teens who understand.

This group is facilitated by Barb Heiman, Social Worker. Please call 614-292-9960 if you have questions or are interested in attending.

HDSA Central Ohio Support Group 2008 Monthly Theme for the HD Persons Support Group

Feb.	Make Valentine Cards
March	Color Easter Eggs and hunt eggs if time allows
April	Water Color painting
May	Plant flowers in small pots/ decorate pots
June	Ann Kloos Physical Therapist (speech and exercises)
July	Picnic and Corn Hole Game
Aug.	Music and Dance
Sept.	Movie Night
Oct.	Painting of small pumpkins
Nov.	"Giving Thanks" craft
Dec.	Wrapping of Christmas gifts

Akron: Meetings are on a Monday or Tuesday, based on the availability of a meeting room. 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

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 at 513-741-4372.

Toledo: Toledo group meets every third Sunday from 2-4 p.m. in the fellowship hall at Our Savior Lutheran Church, 2820 W. Alexis Rd., Toledo, 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 & Catamba). For more information please call Cincinnati Chapter Social Worker, Mary Beth Bialic at 513-741-4372.

Chapter Memorials and Honorees

In Memory of...

Cheryl Peterson:

James & Sandra Lee
Todd & Karyn Recher

Dee Rhinehart:

Peter G. Thielen

Eugene Neff:

Richard, Jeanette, & Ronald Lee
Shirley A. Rhymer

Jack Mapes:

Donald & Gretta Hahn

Jane A. Reed:

William & Janice Smith

Janet Haney:

Brad & Mary Haney

John Hindel:

Jane & Delmar Dutro

Mark Wilkins:

William & Ara Lou Waldock
Geraldine Behrendsen

John Schumm

Mr. & Mrs. Noel M. Larson

Kathy J. Capucini

Allen & Jean Puckrin

Sandra & Thomas Lesch

Jim W. Colwell

Richard & Annette Gallagher

Carol & Frank Fosco

Carol L. Greene

Linda K. Poggiali

Mary E. Fletcher

Ann W. Cassidy, P.E.O. Sisterhood

Benoit & Katharine Schneider

BettyAnn Guss

Richard & Patricia Dehn

John & Lori Schlessman

Kathleen & Michael Holmes

Michael & Stacey Znamenacek:

Norm & Bonnie Baldwin

Roger & Wendy Vaughan

Phillip N. Hess:

Rainey & Mary Taylor

John & Nancy Dalton

Roger & Wendy Vaughan

Richard Kidwell:

Roger & Wendy Vaughan

Patricia Meeker

Thomas Iola:

Constance Nightwine

CMAGE/CWA Local 4502

Mark & Nancy Pugh

Gerald & Sharon Chapman

Wayne Erlandson:

Patricia Meeker

Roger & Wendy Vaughan

Norman L. Baldwin

Dale & Karen Erlandson

Adele Erlandson

Barbara Heiman

Roger & Wendy Vaughan

William R. Fultz, Sr.:

David Benning

In Honor of...

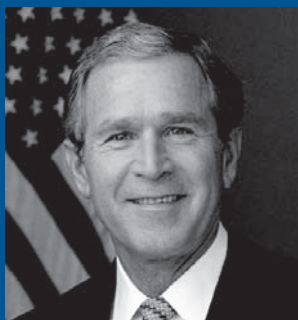
Bonnie Baldwin:

Leo & Gloria Gerhold

In Honor of Gary Nash & Family:

James & Verdale Metzger

President Bush signed the Genetics Nondiscrimination Act (GINA)



On May 21, 2008, President Bush signed the Genetics Nondiscrimination Act (GINA), enacting it into law. GINA prohibits discrimination against individuals based on genetic information in respect to employment and health insurance coverage. Under this new law, which will take full effect in 12 to 18 months, health insurers cannot deny

coverage nor set premiums based on a policy holder's genetic information. The law also prohibits health insurers from requiring, purchasing or releasing genetic information. Similarly, employers are prohibited from firing, refusing to hire, or otherwise discriminating against employees based on genetic information.

The passage of GINA is an important and long awaited development for the Huntington's disease community. By

eliminating the fear of discrimination, GINA will increase accessibility to medical care and cutting edge research for individuals with HD and their family members. Those diagnosed with or at risk for HD can feel more confident seeking medical advice including genetic counseling and genetic testing. GINA is also an assurance that genetic discrimination will not stand in the way of advancements in HD research. In the past, fear of discrimination reduced the number of participants willing to take part in HD clinical trials. Lack of participation in research slows clinical trials and the development process of new therapies. GINA promises that fear of discrimination will no longer be a barrier to personalized medical care nor to the advancement of HD treatments. The law is major step forward in improving medical care for individuals affected by HD for generations to come.

For more information regarding the Genetics Nondiscrimination Act and its effects visit the website of the Coalition for Genetic Fairness at www.geneticfairness.org.

2008 “Shoot for a Cure” Hoop-a-thon Raised \$22,000 for HD Research!

The Hoop-a-Thon was held for second year in a row at the Upper Arlington HS. Celebrity shooters from Ohio State University Men's and Women's basketball team came to shoot hoops. The outstanding PJ Hill and freshman star Evan Turner were fabulous and a delight to watch. We would also like to thank the very talented and generous Star Allen, Jantel Lavender, Amber Stokes, Andrea Walker and Alison Jackson! These women could swish the hoops like no other players around. Star Allen shot 116 baskets in a 5 minute period of time!! Their appearance at the Hoop was a true delight to all of the HD families. Thank you for coming!



"Shoot for a Cure!!!"

I would personally like to thank all of the volunteers who helped to make the 2008 Hoop-a-Thon “Shoot for Cure” a great success. Not only did many of these people donate their time, many of them were shooters as well. We need all kinds of people to participate in the Hoop-a-Thon to make it a well-run event. It takes some planning in the beginning, execution of the plans and then the day of the event. Each of these volunteers we key to making the day happen. We hope that they will all come back next year and bring in more shooters as well. We need new faces each year to keep this event energized! You were all amazing!! Thank you for giving us your time and efforts. If you are interested in being the 2009 Hoops Chair, please contact me at 614.487.9711. — Wendy Vaughan, 2008 Hoops Chair

2008 Hoops Volunteers

Randy Gilmore
Susan Malloy
Miles Payne
Don Baldwin
Brenda Francis
Dr. Kostyk
Jamie Vaughan
Evan Kostyk
Michele Ross
Wendy Vaughan
Laura Herbst
Larry Brown & Family
Anne Kiish
Laura Kiish

Grant Nash
Grant Nash's Friends
Maureen Nash,
Marianne Nash
Guy Ford
Richard Meeker and his wife
Brenda Francis and her friend
Bill Bates
Laurie P.
Diana Imbruck
Martha G.
Sean Meyer
Kris Meyer
Pat Meeker

Marty Vaughan
Norm Baldwin
Jeri Reyna
Beth Reyna
Craig Baldwin
James Greenebaum & Pi Kappa Phi
The Police Academy Explorers

We would also like to thank the many SHOOTERS as well! Without them we would not have a “Hoop a Thon”! Thank you getting sponsors and coming to shoot!



Did you miss the Dream Date Auction at Spice Bar?

19 bachelors and bachelorettes were auctioned off to help in the quest for a cure for Huntington's Disease on July 25th. Gary Nash and Marley Moorman kicked off the event in grand fashion, complete with an impromptu ballroom dancing demonstration. Mo, morning DJ from the radio station WRKZ 99.7FM, kept the audience excited and bidding, and more than a few bachelorettes blushing. The event was a blast and, best of all, raised \$4200 for HDSA.

If you are interested in buying or selling amaryllis this year, contact Dave Fisher at 614-932-9358 or davefisher@wideopenwest.com.



Touchdowns for Huntingtons Disease!

The Celebration of Hope – Touchdowns for HD, September 13, 2008! This is a new twist for our Celebration of Hope. The proceeds of this event will go to support not only the HDSA Center of Excellence at the Ohio State University Medical Center but vital “Coalition for a Cure” research sponsored by the National Office of HDSA.

“Touchdowns for HD” will be on outdoor tailgate event to watch the Ohio State Football Buckeyes take on the University of Southern California Trojans in the game of the season!



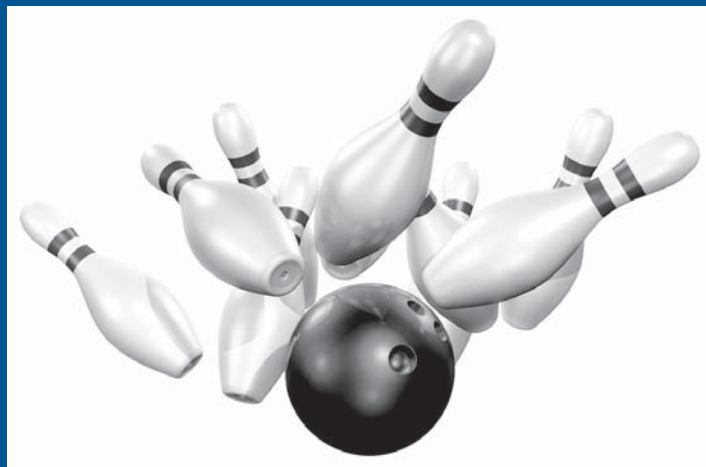
This fun event will start at 6PM with music, buffet dinner, open bar, live and silent auctions. The game starts at 8PM and will be shown on an outdoor screen that is 12' by 7'. There will raffles drawn for every touchdown OSU scores, corn hole games to play and a lounge area complete with fire pits to warm up with. Tickets will be \$125.00 per person. Tables of 10 will be available.

For more information please contact Wendy Vaughan, HDSA Central Ohio Chapter President at: wvaughan@columbus.rr.com or 614-487-9711.

Golf & Bowl Event

A special thanks to Sarah Garland and Ten Pin Alley and Spikes for hosting a Golf and Bowl event on June 27, 2008 with proceeds going to HDSA. We were able to raise HD awareness and \$5000 for vital research.

The day and night were a blast!! Thank you to all who attended.



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Email Theresa Hanson at tzhanon@gmail.com to be added to the distribution list.



Researchers Develop First Transgenic Monkey Model Of HD

Experts See Model as Tool to Better Understand the Disease, Develop More Effective Therapies, and Lead the Way to Similar Models for Other Genetic Diseases.

Scientists have developed the first genetically altered monkey model that replicates some symptoms observed in patients with Huntington's disease, according to a new study funded by the National Institutes of Health. Researchers are now able to better understand this complex, devastating and incurable genetic disorder affecting the brain. This advance, reported in the May 18 advance of online publication edition of *Nature*, could lead to major breakthroughs in the effort to develop new treatments for a range of neurological diseases.

Huntington's is an inherited disease caused by a defective gene that triggers certain nerve cells in the brain to die. Symptoms may include uncontrolled movements, mood swings, cognitive decline, balance problems, and eventually losing the ability to walk, talk or swallow. It affects five to 10 people in every 100,000. There is no known treatment to halt progression of the disease, only medications to relieve symptoms. Death typically occurs 15 to 20 years after onset.

This study marks the first time that researchers have developed a rhesus macaque model of a specific human disease using transgenic technologies, a marked improvement over mouse models. Transgenic animals are created using a recombinant DNA method to modify a genome.

"This research allows scientists to advance beyond mouse models which do not replicate all of the changes in the brain and behavior that humans with Huntington's disease experience," said John D. Harding, Ph.D., director of primate resources at the NIH's National Center for Research Resources (NCRR), which funded the study. "Primate models better mirror human diseases and are a critical link between research with small laboratory animals and studies involving humans."

To unravel the genetic components of this disease, NIH-supported researchers Anthony W.S. Chan, D.V.M., Ph.D.; Xiao-Jiang Li, M.D., Ph.D.; and Shi-Hua Li, M.D., Ph.D., collaborated with their colleagues at the Yerkes National Primate Research Center and other components of Emory University in Atlanta. The research was supported by the NCRR and the National Institute of Neurological Disorders and Stroke (NINDS) at NIH.

The Emory research team developed this transgenic monkey model by introducing altered forms of the Huntington gene into monkey eggs using a viral vector. The eggs were fertilized and the resulting embryos were introduced into surrogate mothers, resulting in five live births. The investigators are now studying the onset of the disease and its behavioral and cognitive effects, with the goal of using the monkey model to better understand disease mechanisms and to design therapies.

"Genetic advances make it easy to identify who has inherited

the disease gene," said Walter Koroshetz, M.D., deputy director of the NINDS. "Now, with a primate model of Huntington's disease, we are one large step closer to finding better treatments for people with the disease as well as those destined to develop it."

The Yerkes primate center where this advance was made is one of eight supported by NCRR. The centers provide leadership, training and resources to foster scientific discovery and compassionate, quality animal care. Last year, the eight centers located around the country supported more than 2,000 researchers studying a wide range of diseases using non human primate models.

"Yerkes primate center is an ideal place to carry out this work because of its expertise in nonhuman primate transgenesis, non-invasive neural imaging, and experience with behavior assessment," said Dr. Harding.

For more information about Huntington's disease, visit: www.ninds.nih.gov/disorders/huntington/huntington.htm.

NCRR, a part of NIH, provides laboratory scientists and clinical researchers with the resources and training they need to understand, detect, treat and prevent a wide range of diseases. NCRR supports all aspects of translational and clinical research, connecting researchers, patients, and communities across the nation. For more information, visit www.ncrr.nih.gov.

The NINDS <www.ninds.nih.gov> is the nation's primary supporter of biomedical research on the brain and nervous system.

The National Institutes of Health (NIH) -- The Nation's Medical Research Agency -- is comprised of 27 Institutes and Centers and is a component of the U. S. Department of Health and Human Services. It is the primary Federal agency for conducting and supporting basic, clinical, and translational medical research, and investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.





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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.**

Please fill out and return this certificate.

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Address _____

Phone number _____

Please direct this donation of \$_____ to: Care_____ % Research_____ %