

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



My name is Rob Cleveland. I am the new president of the Central Ohio Chapter of HDSA. In my home life, I am husband to Laura Cleveland and father to 3 wonderful children. In my 9-to-5 life, I am Assistant Director of Trademarks & Licensing at The Ohio State University.

And then, in my worst nightmare, I live at risk for Huntington's Disease.

You would think that this personal Sword of Damocles would be the impetus behind my entrée into board service. But really, that has not been my motivation. Honestly, it is more in my nature to hide from the sword than face it and yet, here I am.

Why?

Simply, I am here because I fell in love with the people in this chapter. Laura and I were introduced to Wendy and Roger Vaughan at the national meeting in Pittsburgh and they in turn introduced us to what was happening locally with HDSA.

We learned that we didn't have to sit idly by while the disease cut its terrible swath. We could fight back against it through this instrument of HDSA. We began to volunteer our time at the events and truly our lives have not been the same since.

Along the way, we have been blessed to meet families with whom we shared a common plight. We marveled at their uncommon stamina and what they had accomplished through the years.

With each event, each meeting, each day, we began to meet more and more of you at local, regional and national levels. Each story, every connection and every

situation was compelling and poignant. Some affected directly and others indirectly but each one so very passionate about the cause.

We also learned about the Center of Excellence and all of the great work going on there on a daily basis. It has given us a tremendous sense of personal security to have such a resource so readily available.

Together you represent literally centuries of experience in HDSA and so I find myself honored and at once intimidated that you have passed the gavel to me.

As president, my goals for the chapter are simple. I want to continue with what Wendy Vaughan and the past boards have been doing to come fully in line with the standards set forth by national leadership.

We aim to march in step not only in mission and operations but in the society brand message as well. We know that a uniform message given in unison is heard more clearly and is more likely to elicit response.

Response, of course, is the payout. It is the ultimate validation. It confirms that we have been heard and makes our efforts worthwhile. Response in the form of donations of time, talent and dollars...response in the form of delivery of caring services. I hope that each of you will continue to respond as you have and that you will invite others to respond time and again.

I have great faith in our ability to get where we need to be because we have such a great blend of exuberant greenhorns and cagey veterans. Those of us in the greenhorn pack will look to you veterans for guidance, encouragement and patience as we build our stamina.

Once upon a time (circa 1676), Sir Isaac Newton said in a letter to Robert Hooke "If I have seen further it is by standing on the shoulders of giants."

And so if we advance as we hope we will under this new administration it will be so because the new administration has had the advantage of standing on the shoulders of the giants who have gone before us.

Thank you!

Help HDSA Save Money—Provide your Email Address!



As we all know, the money in our pockets is in short supply these days. HDSA is severely affected by this. Therefore, we would like to run our operations as efficiently as possible.

We need your help keeping our database up-to-date. Let us know if:

- You have moved or are planning to move.
- You are receiving this newsletter and would like to receive it via email.
- You are receiving this newsletter or other information from HDSA and you no longer want to receive it.

Please contact the Central Ohio office at 1-614-460-8800 or email at wvaughan@hdsa.org.

PREDICT-HD renewed for five more years

NIH renews funding at \$6 million a year; researchers aim to build off findings as study redesign is implemented

By Sean Thompson

PREDICT-HD has already produced encouraging results thanks to the tireless efforts of its participants.

Now, following a review by the United States National Institutes of Health, the study has been renewed and will be funded through 2013.

"I want to thank everyone for the amazing contributions they've made," said Jane Paulsen, Principal Investigator for PREDICT-HD and professor of Psychiatry and Neurology at The University of Iowa. "Because not only have we advanced Huntington disease research by your willingness to participate in this study, but other researchers have come to us and wanted to borrow the model."

With the renewal, researchers are taking what has been learned in the last seven years and applying it to a new protocol: PREDICT-HD 2.0 (read more about the changes in PREDICT-HD 2.0 throughout this newsletter).

With the data gathered from participant visits, Paulsen and her researchers have identified over a dozen markers of very early HD. Subtle changes in the way people perform certain tasks, think or behave, and changes in the brain have been observed.

These early markers are important because they allow researchers to track HD for 30 years, which leads to more knowledge of the disease.

"Being able to measure and follow a disease for that long will give us many advantages in designing clinical trials and treatments for the disease," Paulsen said. "We will be able to track which treatments are working and which ones aren't."

Now that researchers have a better idea what to track, participants in PREDICT-HD 2.0 will be given treatments for the first time in the study's history. Paulsen said at least two compounds will be given to participants, and one may be given later this year or early in 2010.

Researchers will be looking to see if any of the early markers improve with the implementation of drug treatment. That way, symptoms can be treated before they get too severe.

"The longer we can track our disease, the better we can put treatments in earlier to stall the disease and allow for more healthy years," Paulsen said. "You want to detect it before it impacts you."

Going forward, Paulsen says her enthusiasm and passion for HD research has not waned. The discoveries that have been made because of PREDICT-HD have been encouraging, but much work remains to be done. Whether you're new to PREDICT-HD 2.0 or approaching your eighth visit, Paulsen encourages all participants to continue volunteering.

"If we're going to be able to understand the course of this disease, we need people to volunteer for as long as possible," Paulsen said. "And let us know any way we can make it easier for you to stay in the study."

The Cleveland Clinic is currently enrolling patients for Predict HD 2.0. They are currently looking for participants who have tested positive for the HD gene but have not yet been diagnosed with manifest disease. These participants can be enrolled in any other drug or observational studies that they wish while they are enrolled in our project. For more information please contact Christine Reese, Research Coordinator at 216--445-9833.



**Postponed
until
Spring 2011!**

A Recipe For Caregiver Survival

1) Use the team approach: enlist the help of others. The more players on the team, the better. Put an announcement in the church bulletin or the local paper. The local girl or boy scouts can adopt you to help run errands, rake leaves, shovel snow or whatever other help you may need. Take the initiative to assign some tasks to family members and friends—you'll soon realize which individuals are good team players and which ones are not. Allowing others to do easier tasks can leave you more energy for the more difficult tasks.

2) Plan time in your schedule for activities that you enjoy. Maintain this schedule and make it a priority. Some caregivers join a photo club, others have purchased season tickets at the local symphony or theater, whereas others schedule in time to take long walks, go shopping or meet with friends. Make the breaks in your schedule part of the daily routine.

3) Arrange backup caregiving that is regular. Have Aunt Shelley come the first Saturday of every month from 8–10 p.m.; have a volunteer from church take the HD-affected individual for a walk every Monday after work from 5–5:30 p.m.; join the local Alzheimer disease “morning out” program and take the HD-affected individual every Wednesday and Friday morning; have your son stay with Dad while you attend the local support group meeting once each month; and so on.

4) Many activities will change from the way that you've done them in the past but just because something is different doesn't mean that it's not as enjoyable. Find new ways to enjoy old things. Be prepared for holidays to be different for both you and the person with HD because some family traditions will need to be varied to accommodate the changing needs of both of you.

5) Change your expectations for success. Success changes with ability. If you feel a day (or a week, or a visit, etc.) has to go just as it did before onset of HD to be a “good” one, you will spend a lot of time being upset and the person with HD will be the more frustrated for not being able to live up to your expectations. If, however, you redefine

success as the situation changes, you'll both be happier. A successful meal is not one completed in 30 minutes, but one completed without major incident. A successful day is not one without frustration, but one with some resolution, communication, or whatever works in your individual circumstance.

6) Use humor as much and as often as possible. Rent funny movies, read the comics each day, share the best ones with each other, cut them out and put them on the refrigerator. Don't be afraid to laugh at yourself and even at HD. It's probably the best known treatment for HD at this time.

7) Enjoy several methods of relaxation—yoga, meditation, bubble baths or just sleeping in.

If a loved one with HD resides in a care facility, recognize that it is common to “put off” visiting. Sometimes the atmosphere is difficult for visitors to observe. It may be reminiscent of where we all believe we will spend our final days and we may not want to think about it. Some family members share that “I hate to visit because all I hear are gripes and problems that I can't solve.” Avoiding visitation, however, is not helpful.

Feelings of guilt or dread typically strengthen, rather than weaken, with time. This potential for emotional build-up and drain surrounding the visit can heighten the possibility of stressful visits. Structure the visits and limit the time of the visits. It may be helpful to consider the visit as “refilling the gas tank” for the HD person.

Many families have found it helpful to have two people visit at one time, rather than one, as they can “carry” the conversation together. Bring photos, news clippings and videos of people that are important to the HD-affected person. Inform them about the news on the home front. Avoid topics that are typically argumentative.

Plan ahead of time how long the visit will last. Frequent short visits, if feasible, seem to work better than long visits. Mark on the calendar when the next visit will occur and stick to it!

The Annual Chapter Board Meeting/Dinner

October 20, 2010 at J Liu Restaurant
6880 North High St., Worthington, OH 43085

Brian Viau of the HDSA Minnesota Chapter and Lundbeck Pharmaceuticals will be the guest speaker for the evening. Brian's family conducts one of the most successful Hoop a Thon's in the country. Join us for this fun and informative night.

For more information, please contact Wendy Vaughan at **614-460-8800**. wvaughan@hdsa.org

\$15 per person for dinner. Cash bar available.

Chapter Memorials and Honorees

In Memory of...

Erna Witte

(Aunt of Bonnie Baldwin)

Mark and Kathy Meyer
 Kathleen Lieb
 Teddy Meyer
 Patty Ann Michaelis
 Kenneth and Wylodene Durham
 Russell and Elaine Meyer
 Loren and Jean Plassman
 Jean Damman
 Mildred Flory
 Marie Bockelman
 Lyle and Arlene Wallace
 Norm and Bonnie Baldwin
 Lee and Sarah Rupert
 Betty and David Meyer
 Dorothy Precht
 Kenneth and Arlene Freytag
 Arthur and Connie Roehrig
 John and Laura Precht
 Scott and Jennifer Plassman
 Mildred Bruback
 Betty Marihugh
 Timothy and Becky Buchhop
 Marna Lou Bechtol

Roger O. Davis

(Father of Wendy Vaughan)

Richard Swanson

John Karnemaat

Karla Oard thru the
 Blanchard Foundation
 Herb and Jen Butler
 Jeffrey and Chelli Ward
 Ella and John Dorgan
 The Katula Family
 Wayne Stefanko
 Wendy Vaughan
 Sally and Tom Currie
 Karen and Marcus Ingram

Phil Hess

John Dalton

Karen L. Wrightsman

Evilue Demler
 Brad and Joan Batton
 Brenda O'Neil
 Jane Vogel
 Catherina St. Francis-Brooks
 James and Sally Shull
 William and Sylvia Evans
 Lorraine and Robert Bower
 Ronald and Marilyn Moser
 Ronald and Alicia Bailey
 Mark and Nancy Johnson
 Don Bower
 Susan Crow
 Richard Wrightsman
 Joseph and Diane Wrightsman
 Thomas and Susan Harley
 Nevada Euchre Club
 Thomas and Patricia Gault
 Lee and Mary Bailey
 Karen Castanien
 Chris Boden and Family
 Jeff Wentz and Family
 Cindy Wright and Family
 Mr. and Mrs. Paul Wymer
 Tim, Karen, Nicholas Koehler
 Susan Koehler and Family
 Phyllis Koehler and Family
 Sharon Saam
 Marie Frey
 Mr. and Mrs. Russell Bailey
 Dick and Mary Lou Miller
 and Family
 Chuck and Ladonna Roberts

Deborah Kofod

Patricia Meeker
 Dr. Roy L. Donnerberg
 Her friends at Castleton Gardens
 Frances Gorman
 Barb Heiman
 Wendy Vaughan

John and Patty Hindel

Lillette Holdren

Donna Koger

Barb Heiman

In Honor of...

Richard Eckels and Beth Blanchard

*(on the occasion of
 their wedding)*

Pete and Jean Ullman
 Catherine and Larson Lang
 Diane Grill
 Mr. and Mrs. James Walton
 Carol and Jack Eckels
 Rufus and Sandra Hurst
 Carol Wright
 Earl Shurtz and Cathy Wolpe
 Ruth Altomonte
 Wendy Vaughan

Dave Hess

John Dalton

Grant Nash

*In honor of his graduation
 from eighth grade*

Karen Morrison
 Judge Harland
 and Janet Hale

Thank you!

**Thank you Maureen Nash
 and Larry Brown**
 for organizing the Dream Date Auction
 held at the Patio Bar and Grill in the
 Short North on May 30. \$2000 was
 raised to go to research!

Thank you Robert Hampp
 for selling giant pumpkin seeds to

raise money for research! For more
 information on how you can buy giant
 pumpkin seeds please go to: www.giantpumpkinonline.com

Thank you Carlton Manor
 of Washington Court House, Ohio who
 held their own "Hoop a Thon"! They
 had 14 shooters and raised almost

\$500! This is AWESOME! Thank you
 Ginny Harris and Jane Massie!

Thank you Randy Gilmore
 for the wonderful framed art that you
 donated to the Hoop a Thon for the
 past 2 years.

Thank you to Nanette Purdy
 for helping the Chapter secure Ohio

Volunteers Needed on the Chapter Board of Trustees!

Current open positions: Chapter Secretary and Voting Board Member

Duties and responsibilities:

- Attend board meetings
- Review chapter's budget and plan of work
- Serve on at least one fundraising committee
- Help to fill vacancies in leadership positions
- Participate in fundraising activities
- Make a personal contribution to HDSA
- Represent HDSA's position and policies
- Approach all issues with an open mind and prepare to make the best decisions for the whole chapter
- Work with national HDSA leadership as required
- Provide personal and professional expertise to the chapter
- Be knowledgeable about HD and the mission work of HDSA

Other Volunteers Needed:

Team Hope Walk
Special Event Coordinator
Family Services Committee

Please call the office at **614-460-8800** or send an email to office@hdsacentralohio.org to volunteer your time.

HDSA ADVOCACY:

Help Make HD a National Priority!

Nearly everyone affected by HD has trouble obtaining disability benefits. HDSA is leading a national campaign to address this problem, and we need your help!

A bill in Congress, HR 678, The Huntington's Disease Parity Act of 2009 would revise the current Social Security Administration (SSA) guidelines for determining disability caused by HD. It would also eliminate the two-year waiting period to receive Medicare benefits after a disability determination is made by SSA. If enacted into law, HR 678 would significantly improve the lives of everyone affected by HD.

Support our grassroots HD Movement!

Take 2 minutes right now to contact your Representative about HR 678.

Does your Congressman support HR 678? So far, over 60 Representatives have agreed to co-sponsor HR 678, largely because their constituents have asked them to support it. By contacting your Representative, sharing your personal story, and asking him/her to cosponsor HR 678, you can join our cause! Click on HDSA.ORG and go to the button that says "Living with HD, resources and advocacy. From there you should be able to write a letter with space for your personal story. Send your letter to your Congressional representative! Do it today! Get it done!

If your Representative is already a co-sponsor, congratulations! Now invite your family and friends to join our effort by forwarding this message to them. Since we need support from both houses of Congress, you can also send an email asking your two Senators to introduce the Huntington's Disease Parity Act in the Senate.

Change cannot occur without your help. Persistence is key if we want change. Please join the HDSA advocacy movement today.

If you would like more information about HDSA Advocacy, HR 678, or help in scheduling a home office visit with either your Rep or Senators, please contact Jane Kogan at the HDSA national office at jkogan@hdsa.org or visit the [HDSA Advocacy Page](#).

THE CENTER OF EXCELLENCE AT OSU HAS NEW PHONE NUMBERS!

To Schedule an appointment at the **Center of Excellence HD Clinic** to see **Dr. Sandra Kostyk** CALL: **614-293-4969**

To Speak with our social worker, **Barb Heiman** CALL: **614-292-9960**

To schedule an appointment to be part of the **Clinical Trials** conducted at OSU: CALL **Allison** at **614-688-8672**

This space is dedicated to say thank you to some but not all of the volunteers who have given of their time, resources and effort. Though not everyone is listed here today, we wanted to say thanks to a few highlighted people.

State Fair tickets for our HD Families. If your HD family is interested in going to the fair next year, send us an email to office@hdsacentralohio.org.

Thank you Wendy Rafferty.

Wendy comes every month to support group prepared with an activity for our HD patients. She is a bright spot in

our family services committee.

Thank you Barb Heiman, Pat Meeker and Brenda Francis

who run the support group month after month, year after year!

Thank you to Arnie Jack

for recruiting Hoop Shooters and Golf Teams.

If you know of someone who needs to be highlighted for their efforts in helping our mission, please send an email to office@hdsacentralohio.org or drop us a note to: HDSA 490 City Park Ave. Suite C, Columbus, Ohio 43215.

“3rd Annual Golf Bowl Classic” Fore a Cure of Huntington’s Disease June 7, 2010 raises nearly \$10,000!

We split a day between golfing and bowling for the 3rd Annual “Golf Bowl Classic”. The golf was played at the prestigious Heritage Golf Club in Hilliard, Ohio followed by bowling, awards and dinner at Ten Pin Alley and Spike’s. 100 golfers together with the generous support of our major sponsors: John Dalton in honor of the Dave Hess Family, The Ohio State University Medical Center, CD101@102.5 FM, Miller Lite, Lundbeck Pharmaceuticals and Ten Pin Bowling Alley raised almost \$10,000 for the Central Ohio Chapter.

A special thanks goes to our hole sponsors: Rob Cleveland, Norm Baldwin, All Foreign & Domestic Auto Parts, Inc., Brenda Francis- Able Family Services, Jack & Snyder, LLC, Jill Mountain-NextGen, Plahuta Appraisal Group, Stepping Stones Spiritual Shop, Strategic Business Systems, The Energy Lab, and The Blue Jackets.

The golf outing is in the memory of Phillip Hess, a retired coach and science teacher from Columbus Academy who passed away from complications of Huntington’s Disease (HD) in June, 2008 and in honor of Dave Hess, Phillip’s son who is also affected by HD. Next year we will be returning to Heritage Golf Club on Monday June 13, 2011. Sign up early!

The 25th Annual HDSA Convention

The 25th Annual HDSA Convention was held in Raleigh, North Carolina June 24-26.

Numerous workshops and plenary sessions were offered in areas including HD research, symptom management, care-giver support, genetic counseling, testing issues, living at risk and more.

Professional training was offered on the following: in-service programs for long-term care facilities; caregiver burden; issues surrounding advanced planning for HD families and social security disability issues for HD. Thirty social workers and other professionals from around the country benefited from this training.

Next Year’s Convention will be held in St. Paul/Minneapolis, Minnesota from June 23-26. Plan now to attend the 26th annual National HDSA Convention.

Go to the website HDSA.ORG to see all of the keynote speakers from the convention and power point presentations from the workshops.

Hoops give Hope!

The Shoot for a Cure “Hoop-a-Thon” was April 10th 2010 at the Upper Arlington High School

A swish of the net is a slam dunk way to bring hope to Huntington’s Disease (HD) patients this spring! The 25th Annual Shoot for Cure “Hoop-a-Thon” raised just over \$16,000! This fun family day has been a tradition for the local Huntington’s Disease Society of America (HDSA) Central Ohio Chapter since 1985. The chapter has raised over \$250,000 to support research for a cure to HD.

The HDSA Shoot for a Cure “Hoop-a-Thon” is a basketball free throw event to benefit the Huntington’s Disease Society of America (HDSA) Central Ohio Chapter. Shooters stand at the foul line and try to make as many baskets as they can in 5 minutes. All ages and any skill level can participate! The individual with the most pledges donated the day of the Hoop a Thon won tickets to the Cleveland Cavaliers vs. the Orlando Magic. Special thanks to Zack Byrd for shooting hoops. Thank you to the all time record high of 80 shooters.

Top Shooters in Each Age Group

AGES: 1-12 - Todd Bainbridge

13-18 – Kristi Cheatham

19-35 – Jeff Meyer

36-50 – Troy Meyer

Over 50 – Taylor Staoh

Most baskets Any Age goes to Jeff Meyer with 80 baskets!

We would also like to give a special thanks to John Deibler from the Ohio State University Men’s Basketball team for his special appearance. In addition to a warm and wonderful meet and greet session John, he shot over 95+ shots in 5 minutes!

A very special thanks goes out to all of our volunteers who helped us out but especially to Marie Miller, Marty Vaughan, Lori Zapf and Norm Baldwin for taking charge of the day! Special Sponsors include Lundbeck Pharmaceutical, CD101@102.5FM and Marty Vaughan.

Silent Auction Items Needed for All Events!

Do you have any items to donate?

Ideas:

- Sports Memorabilia
- Gift Certificates
- Homemade Items
- Tickets to Sporting and Cultural Events
- Restaurant Gift Certificates

A GIFT OF HOPE

by Laurie Pecuch

My grandma had HD. My grandpa had hope. For years, at Christmas time, my grandpa would give each of his five children, 14 grandchildren, and numerous great grandchildren an amaryllis plant. The box displayed the photo of a lovely flower in bloom and an acknowledgement that this flower helped to support awareness and fund-raising for a cure for Huntington's Disease. I couldn't wait to plant my bulb in its given container and then watch it grow. And grow it did! Amaryllis plants have an uncanny sense of sprouting green leaves and shoots of bloom in the middle of winter. The year my grandpa died, my dad took on the tradition of giving amaryllis plants to the family. And so the hope lives on. The past few years, I've given the plants as Christmas gifts to my cohorts at work, to my friends, and to people who have supported my family in our HD journey. They often report back to me on the progress of their amaryllis plant. "Laurie, you should see my plant. It is beautiful." or "I can't believe how fast it grows. It's so much fun to watch." But perhaps my favorite sighting was two winters ago when one of the amaryllis plants bloomed on two separate occasions. Obviously, no one had told that little plant that it was only suppose to show its beauty in one glorious blooming. In the midst of a bleak winter, it clearly was a message of hope. Please consider buying your own amaryllis plant or a box of plants to give as gifts at Christmas. Together, let us share the gift of hope.



Amaryllis Sale: Growing a Brighter Future

Help HDSA/Central Ohio raise funds for patient and family support and research. Sell for \$10 each!! The chapter earns \$4.80 on each one sold.

Buy individual amaryllis kits in small quantities (less than 16) for yourself or to sell. Laurie Pecuch will deliver or you can pick them up from her home or at an agreed upon place. Be sure to include your phone number below.

SMALL OR INDIVIDUAL ORDERS:

Mark how many of each color:

- Ferrari Lion -Red
 Apple Blossom -soft pink
 Mont Blanc -white
 Pink Diamond -Deep pink and white
 Clown - Red and White

ORDER BY THE CASE (16):

Cases will be delivered by UPS to your address.

Cases may be all one color, or assorted. Mark how many of each color:

- Case of 16, assorted colors
 Case of 16, all one color:
 Ferrari Lion
 Apple Blossom (soft pink)
 Mont Blanc -white
 Pink Diamond -Deep pink and white
 Clown - Red and White

DELIVERY INSTRUCTIONS:

Your Name: _____

Address:

Phone: _____

E-mail: _____

Payment with order or send to Laurie Pecuch after you've sold the bulbs. Make checks out to HDSA.

Send this form to:

Amaryllis: Laurie Pecuch
P.O. Box 564
Grove City, Ohio 43123

or contact Laurie at lpecuch@stjohnsgc.org
 or call 614-620-2669

GIFT IDEA: The amaryllis kits are nicely packaged and will make a great gift for teachers, clergy and club gift exchanges. They are especially nice for the homebound, as they grow quickly and bloom freely. It would be difficult to find a \$10.00 gift that would be more appreciated! Please order early and SELL! SELL! SELL!



**HUNTINGTON'S
DISEASE SOCIETY
OF AMERICA
CENTRAL OHIO
CHAPTER**

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614-292-9960

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CASINO NIGHT

2010 Distinguished Leadership and Service Award

Sandra Kostyk, Ph.d, M.D. of the HDSA Center of Excellence at the Ohio State University Medical Center
Barb Heiman, MSW,LSW, the Central Ohio Chapter Social Worker

2010 HD Humanity Award

James Martin (Marty) Vaughan

Donate to the "Celebration of Hope". Your donation will be fully tax-deductible. Please donate what you can. For every \$20, \$50 or \$500 you donate, we will be able to increase the services and support we give to HD families. This is an outstanding partnership between you, our chapter, our Center of Excellence - - but more importantly, it is a further commitment to more help, more support, more care. Help for Today. Hope for Tomorrow.

Yes, you can make a difference! Make it today.

Sponsored by:

Moving Together



**Buy your tickets or donate online
at www.hdsacentralohio.org**