



# Huntington's Disease Society of America Central Ohio Chapter Spring 2003



## *Our Voice*

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### MEET OUR NEW PRESIDENT!!!

Dear Friends,

As a new year begins, I have been thinking about resolutions, for me personally and for the Chapter. On a personal front, I always pick the obvious resolutions: to eat healthy and to get more exercise. Additionally, I have resolved to attend more HD support group meetings. The support group meetings are a good opportunity to meet other people dealing with the same issues that we are and to work together to address the challenges facing our HD families.

For resolutions on behalf of the HDSA Central Ohio Chapter, I would also pick the "obvious" resolutions: to raise more awareness about Huntington's Disease (what it is, how it effects families, how we are working toward a cure), to raise more money for research, and to keep growing our HD family of volunteers. These resolutions are much harder for me to meet because I cannot follow up with the resolutions alone – I need help from all of you to make these things happen in 2003.

So for this year, I challenge all of you to help me meet my resolutions. You can contribute by bringing a friend or family member to a support group meeting, bring a new friend to one of our fundraising events. As discussed elsewhere in this newsletter, there are many, many opportunities for you to get involved if you are not already (and to get more involved).

And we have an exciting year to look forward to. We will be dedicating a historic marker honoring Dr. George Sumner Huntington in April in Pomeroy, Ohio. We will also have the 18<sup>th</sup> annual hoop-a-thon in April. The Nashes will be organizing another fun event at BW3s restaurant and the FBI has agreed to host another golf outing with proceeds benefiting HD research. The list goes on and on of events for 2003. I look forward to seeing you at these happenings!

Sarah Daggett Morrison

### **"TAXING TOWARD A CURE," WRITTEN BY MARTY VAUGHAN**

Join us in "TAXing Toward a Cure." If you make your "TAXing Toward a Cure" donation to the Generation 2000 Research Matching Gifts Challenge Fund your **donation will be matched.** Please respond

by return email. If you choose to participate make your check payable to HDSA and send to: TAXing Toward a Cure, HDSA Central Ohio Chapter, 490 City Park Ave., Suite C, Cols, OH 43215.

**Our Voice**  
*Our Voice* is the official publication of  
the Central Ohio Chapter, HDSA, 490  
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Huntington's Disease Society of  
America, Central Ohio Chapter, is  
published three times annually, the  
purpose is 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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## 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

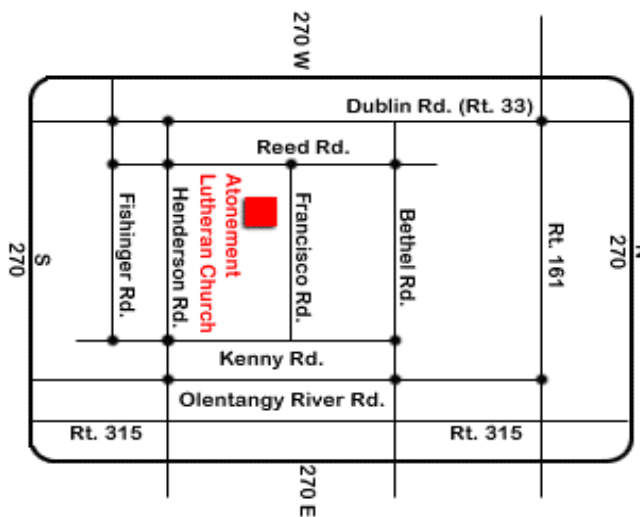
Francisco Road is just north of Henderson Road and runs east and  
west between Reed and Kenny Roads. There is a traffic light at  
the corner of Reed and Francisco Roads and the church is on the  
south side of the road, not too far from Reed Road.

**We are here for you!** Many who attend say that they take  
home with them at least one thought that has been very helpful  
for them. Please join us at our next meeting. We are always  
happy to see new faces!

The meetings begin at **7:00 P.M.** The meeting is on the  
second Thursday of each month at Atonement Lutheran Church.  
Please note your calendars.

### Planned topics for this year include the following:

- Communication technology
- Dr. Sandra Kostyk, Medical Director and Dr. Nonna Stepanov,  
Clinic Coordinator: Speaking on the Center of Excellence
- Financial Planning
- Social Security Disability - Speaker from the Social Security  
Administration
- Genetic Privacy / confidentiality of medical records
- July meeting: Report on the 2003 Convention
- August: NO MEETING (summer break)



**Reminder to all recipients of the newsletter:** The Central Office asks  
those of you who are moving, or have moved, to let us know when  
there is an address change as it costs us 70 cents per newsletter  
when it comes back due to wrong address. Thanks!

## **The Celebration of Hope Dinner Benefiting the HDSA Center of Excellence at OSU**

On September 25, the Central Ohio Chapter of HDSA hosted its second "Celebration of Hope" Dinner of which 100% of the proceeds go directly to support the HDSA Center of Excellence at the Ohio State University. Over \$70,000 was raised through sponsorship, ticket sales to the dinner, the silent auction and raffle.

This signature fundraising event honors outstanding individuals who have made Columbus a better place to live because of their leadership and contributions to the community in the areas of art, business, and medicine. The 2002 honorees were Cheryl Krueger, Founder/ CEO of Cheryl & Co.; Geoffrey Nelson, Artistic Director for The Contemporary American Theater Co. (CATCO); and Don Higgins, Former Medical Advisor HDSA Center of Excellence OSU, Associate Professor Dept. of Neurology at Albany Medical College. The HD Humanity Award went to Gary Nash and his family for their responses to the challenges caused by HD with fortitude and commitment. The Master of Ceremonies was Cabot Rea of WCMH NBC 4 TV. Congresswomen Deborah Pryce, our Honorary Chairman.

This was truly a celebration. Over 330 people came together to celebrate the achievements of our wonderful honorees and learn about Huntington's Disease. The evening had several dynamic speakers. Dr. Sandra Kostyk, Executive Director of the Center of Excellence at OSU explained the most recent HD medical breakthroughs. Barbara Boyle, the National Executive Director of HDSA was in from New York. She described the future of HDSA as an organization, and it looks very promising. The most important message of the evening was delivered from the Nash Family. They reminded us what is truly important in life

(family) and how they have chosen to deal with this dreaded disease (determination). It was an elegant night that gave purpose to our pursuits and reminded those who attended just how valuable every dollar is to finding a cure.

The silent auction was coordinated by Brook Stein and her fantastic group of volunteers. It was by far one of the best silent auctions in town, bar none!! We raised over \$14,000 on the auction alone and another \$4,000 on the most beautiful diamond necklace raffle graciously donated by Dunkins Diamonds.

The Hyatt did a wonderful job in service and the food was outstanding. Cabot Rea and Gail Hogan of WCMH NBC 4 were warm and delightful to see in person. If you have not had an opportunity to see a CATCO (Contemporary American Theatre Company) show, you must get tickets today. Under the creative and talented direction of Geoff Nelson and extreme acting talent of Jon Putman and Marianne Timmons, CATCO is truly a gem in Columbus that must not be overlooked. Their award presentation to Geoff Nelson was quite entertaining. Don Higgins, M.D. and Larry Elmer, M.D. are committed and passionate doctors that the HD community is lucky to have as illustrated by Dr. Elmer's award presentation to Dr. Higgins. Cheryl Krueger spoke of commitment and the power of giving.

The event was a great success thanks to the many dedicated volunteers, kind and generous donors and friends and family who are so supportive of HDSA in finding a cure. Our sincere thanks goes out to all who participated in any way. We hope that you will come back and attend the 2003 "Celebration of Hope" Dinner.

*Disclaimer: Our Voice is an official publication of the Central Ohio of the Huntington's Disease Society of America, Inc., Suite 37 McCampbell Hall. The Ohio State University Hospitals, 1581 Dodd Drive, Columbus, Ohio 43210-1296. Our Voice attempts to report all items of interest relating to individuals with Huntington's Disease, their families, health care professionals, and interested friends and supporters. HDSA and the Central Ohio Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy, or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Central Ohio Chapter.*

**18th ANNUAL  
HUNTINGTON'S DISEASE SOCIETY OF AMERICA  
HOOP-A-THON  
SHOOT FOR THE CURE  
April 12, 2003  
Resurrection Lutheran Church  
3500 Main Street, Hilliard, Ohio**

Time to lace up your basketball shoes and practice your free throws!!! The 18th Annual Hoop-a-Thon has been scheduled for **Saturday, April 12, 2003**. It will be an all day event again, running from **8:00 a.m. until 5:00 p.m.**

It will be a star-studded event again this year! Many of your favorite **local media celebrities** will be on hand, plus the mascots, and some representatives of a certain national championship program!

The big twist this year is that shooters will only **shoot free throws for 5 minutes!** Yes, just 5 minutes. Why? It allows time for more people to shoot. It also allows more time for a couple of showcase events during the day. Remember the 5 minute time period for shooting this year. Make sure folks don't cut their donations in half!

Volunteers for the day and items for the **SILENT AUCTION** are needed! So far, the great items for sale include: tickets from the Indians, Reds, and Crew; and autographed items. Bids are final around 4:00 P.M.

We are hoping to have an even bigger year than last year, this event is a great opportunity to increase awareness and teach new people about the disease that we are all fighting together. But we cannot do it without your help. If you are interested in volunteering or have an item for the auction, please contact Randy Rhinehart at 481-7800 ext 141 or by e-mail at [randyr920@yahoo.com](mailto:randyr920@yahoo.com) or call Randy Rhinehart or Norm Baldwin at (614) 351-2686.

**What can YOU do to make this event successful? 1. Be a shooter. 2. Get pledges by asking friends and relatives to support HD research. 3. Make your own generous pledge to HD!**

We really do need **YOU**, plan to attend and support all of the wonderful people who are offering their time and support to HDSA. **Bring your camera and items for autographs!**

## **Remember A Loved One At The Hoops**

Shoot in memory or in honor of a loved one at the Hoop-a-Thon. Your loved one will be mentioned when you are introduced as a shooter. Send a photo(s) of your loved one to Norm Baldwin, 5826 Ravine Creek Drive, Grove City, Ohio

43123 and his/her picture will be shown on the large screen while you are shooting. Pictures must be submitted at least 3 days before the event, please include information on the back of the picture.

## Schedule of Special Guests

**8:00 NewsChannel 4 Live Shots featuring Joe Weasel and more from Channel 4**

**9:30 Brent Bower Girls Coach Hilliard Darby**

**Stan Zody Boys Coach Hilliard Darby**

**Dan Fronczak ONN**

**10:00 Damon Goodwin Men's Coach Capital University**

**11:00 Greg Frey OSU Football**

**1:00 Brutus Ohio State University**

**Stinger Blue Jackets Mascot**

**Crew Cat Columbus Crew Mascot**

**LouSeal Columbus Clippers Mascot**

**Louie the LandShark Mascot**

**The Bone Lady Cleveland Browns fame**

**2:00 Tim Feran Columbus Dispatch**

**Clay Hall WSYX 6/FOX 28**

**Anthony Rothman WSYX 6/FOX 28**

**Ray Crawford WSYX 6/FOX 28**

**2:15 Toni Roesch OSU & Big 10 Basketball Analyst**

**Larry Larson 610 WTVN Radio**

**Clark Donley Sunny 95**

**2:30 Lee Cochran This Week Newspapers**

**3:15 Ronni Hunter New Rock 99 7 The Blitz Ohio State Basketball**

Auctioned items: Indians Tickets, Cincinnati Reds Game, A Fox Sports Net Bag with FSN Premiums Inside, 13" Flat Screen TV/VCR, Autographed Reggie Jackson or Don Mattingly Baseball, A roof Box at Cooper Stadium complete with food and beverages for one Clipper Game, A hockey stick autographed by the entire Columbus Blue Jackets Team, Items from baseball agent Casey Close, 2 badges to the Memorial Tournament, A Weekend Getaway to Indian Bear Lodge Bed & Breakfasts, Gift Certificates and more!

For updated information check our WEB Site: [www.hdsacentralohio.org](http://www.hdsacentralohio.org)

**BRING YOUR CAMERA AND ITEMS FOR AUTOGRAPHS!**

**EXPRESS YOUR APPRECIATION TO THESE STARS FOR SUPPORTING HDSA!!!!**

***SHOOT WITH THE STARS!!!***

**OPEN TO THE PUBLIC – SUPPORT HDSA CELEBRITY SHOOTERS**

**HELP FIND THE CURE FOR HUNTINGTON'S DISEASE!**

**Autographs – Photographs - Silent Auction**

*Free T-shirts to Shooters! Prizes! Awards!*

**Face Painting – Horse Drawn Wagon Rides – Hula Hoop Contest**

Food - Coney Dogs – George's Coney Island

Shooters obtain pledges for free throws made in a 5-minute period

Bonus points for a 3-point shot or slam-dunk!

# HUNTINGTON'S DISEASE HOOP-A-THON PLEDGE FORM

IF SHOOTING INDIVIDUALLY CHECK HERE \_\_\_\_\_

IF A TEAM MEMBER CHECK HERE \_\_\_\_\_

NAME OF TEAM \_\_\_\_\_

Pledger's Name	Phone	Pledge Per Basket	Amount Due	Amount Paid
		<b>TOTALS</b>	<b>\$</b>	<b>\$</b>

Here is what to do:

1. Sign up supporters, the amount they pledge per basket made or a flat donation.
2. On the day of the event, bring this form to the Hoop-a-thon.
3. Shoot and have the scorer record your baskets made on this form.
4. Collect pledges after the event.

Shooter's Name \_\_\_\_\_

Address: \_\_\_\_\_ Phone # \_\_\_\_\_

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

Shooting in (Memory) or (Honor) of \_\_\_\_\_

Donations to: Central Ohio Chapter \_\_\_\_\_ % to Research \_\_\_\_\_ %

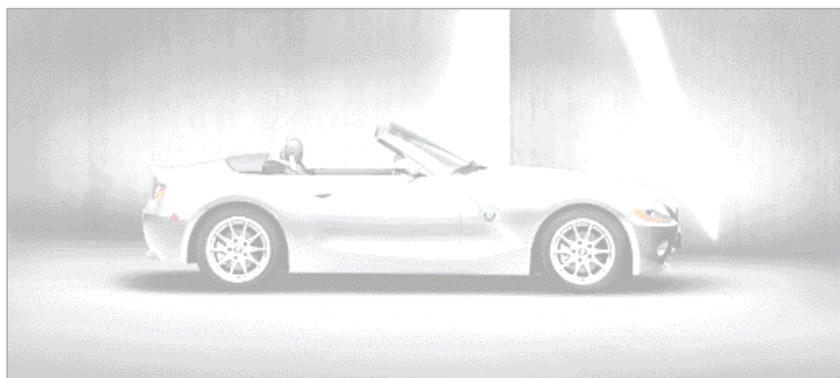
Number of Baskets Made \_\_\_\_\_ Attested Scorer: \_\_\_\_\_

Make checks payable to HDSA, Central Ohio Chapter. You may bring your checks, along with this form to the event and/or mail this form and checks to: Huntington's Disease Society, 490 City Park Ave., Suite C, Columbus, Ohio 43215.

Proceeds benefit the Central Ohio Chapter and research to help find a  
cure for Huntington's Disease

**SHOOTING TIMES MAY BE SCHEDULED**  
Contact: Norm Baldwin 614-871-4301

**JOIN US IN THE 2003  
DRIVING TOWARD A  
CURE HD  
SWEEPSTAKES**



**GRAND PRIZE** 2003 HMWZ4 2.4i CONVERTIBLE OR \$25,000 CASH  
**SECOND PRIZE** \$5,000 CASH  
**THIRD PRIZE** \$2,500 CASH  
**FOURTH PRIZE** \$1,000 CASH (2 WINNERS DRAWN)  
**LIMITED TO 2,500 TICKETS SOLD**  
**\$100 PER TICKET**

**FOR EVERY TWO TICKETS YOU BUY (OR SELL), RECEIVE THE THIRD FREE!**

Winners will be drawn at HDSA's National Convention on June 7<sup>th</sup> in Houston, TX.

For additional tickets or more information call 1-800-3445-HDSA, or e-mail

[hdsainfo@hdsa.org](mailto:hdsainfo@hdsa.org)

You can also log on to [www.hdsa.org](http://www.hdsa.org) to learn more about this year's BMW Sweepstakes.

Good Luck!!!

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**Donor Information**

Name \_\_\_\_\_ Phone Number/Email \_\_\_\_\_

Address \_\_\_\_\_

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

**Payment Information (please circle)**      **Cash**      **Check**      **Credit**

Amount \$ \_\_\_\_\_

**For Credit Card Payments: Type of Card**      **Visa**      **MC**      **AMEX**

Card # \_\_\_\_\_

Name as it appears on card \_\_\_\_\_

Signature \_\_\_\_\_

## Charity Dream Date Auction

On April 9, 2003, the second annual "Charity Dream Date Auction" will be held at the Hilliard Buffalo Wild Wings on Bethel Road, starting at 7 p.m. In 2002, we held the first Dream Date auction at the same facility, and it was such a success that the owners of the Buffalo Wild Wings asked if we would return this year. Last year Stacy McKay of Sunny 95 and Tram Mai of Channel 6 were auctioned and raised almost \$3,000 between the two of them. Ian Fitzsimmons of 1460 was Master of Ceremonies. Several will return this year along with DINO from Sunny 95, JOE BOXER from 92.3 WCOL, and many of the COORS LIGHT GIRLS, including the BLOND DREAM TEAM. We hope to raise more than \$9,000, which was the amount of research funds raised last year. However, we CAN NOT do this without your help.

The Dream Date and Silent auction is for the benefit of the Huntington's Disease Society Association. HD is a dreaded genetic disease, with a 50% chance of passing it to the prodigy of any patient. This disorder afflicts many in our area, as well as around the world. You would be helping us to eradicate this horrible disease, which affects both the physical and mental abilities of the patient. 100 % of the money goes to OSU Neurological HDSA Center of Excellence. Our chapter pays for one day a week of patient and family care. A new treatment technique pioneered by HDSA

## FTD

As many of you know, FTD has partnered with HDSA so that whenever an order is placed with FTD, and you mention either HDSA or use our promotional code, a percentage of the profits will go towards HD research.

Please be advised that the promotional code for this program has

spread care over several specialties; nursing, social work, genetics, psychiatry, speech and work place therapy and neurology. This technique also impacts Parkinson's and Alzheimer patients that have similar problems. Therefore, when we work together to raise money for HD we help many families afflicted with OTHER horrible illnesses.

Recently, there have been many television shows, such as ER, The District and The Guardian, highlighting this disease, and the effects that occur to the patients as well as their families. Since this is an "orphan disease" we receive little assistance from our federal government, and thus, have to utilize our own time and energy toward raising funds for this disease.

Before and during the Dream Date auction, we have a "Silent Auction", as another way to achieve our goal. So come to Buffalo Wild Wings and spend your MONEY on our Auction Items or Bid on a DREAM DATE. Either way don't miss out on a GREAT night of FUN!!

We look forward to hearing from you, or see you at Hilliard Buffalo Wild Wings at 1710 Hilliard-Rome Road at 7 p.m. on April 9<sup>th</sup> for a night of fun memories. Join us in our fight to have this be our last generation with HD.

The Nash Family

changed and the new number is 3015. Please update this information in your databases, websites and newsletters.

If you have any questions or comments, please do not hesitate to contact me. Thank you for your cooperation.

*Micaela, Coordinator of Field Operation*



## DNA Direct, By Andrea Zanko, M.S., [azanko@itsa.ucsf.edu](mailto:azanko@itsa.ucsf.edu)

Reproductive decisions are always complex – couples weigh their income, careers, schedules, space, relationships and desire to become parents. Add to that the knowledge of risk, either to a parent and/or to the fetus, and you might imagine the cascade of emotions faced by our families.

For example, a couple was hoping to have their first biological child, but the at-risk partner decided he did not wish to learn his own HD status. Non-disclosing DNA linkage studies were not possible, as the relevant family members were deceased. Advances in technology have provided another option – albeit an expensive, time consuming, physically challenging option – Preimplantation Genetic Diagnosis (PGD). Diagnosis of the embryo can literally take place prior to implantation, with the use of assisted reproductive technologies: *In Vitro* Fertilization (IVF) and PGD. PGD is currently offered at ~50 centers worldwide, with several hundred babies now born. It is a complicated technology that requires numerous medical steps to achieve accuracy and reliability, as well as ongoing psychological support.

Briefly, PGD is possible because a ~ three to ten-celled embryo (sometimes called a “pre-embryo”) can undergo micromanipulated biopsy of one to two cells (blastomeres) for DNA analysis, while the embryo remains in the culture medium. The DNA from the single cell is amplified by a process called polymerase chain reaction (PCR), which allows the interpretation from such a tiny sample. The selected embryo(s) can then be transferred back to the mother’s uterus, and continue developing. The cells in the embryo are still

at a stage of “indeterminate cleavage,” and can compensate for the cell removed.

The primary advantages of PGD, according to interested HD families, are: 1) they are not faced with a decision regarding continuation or interruption of the pregnancy based on the fetal DNA status; and 2) they do not have to learn the at-risk partner’s DNA status. The couple would not be informed about the number of eggs retrieved, the number of embryos formed or the number in which diagnosis were made. No revealing information would be provided which would allow the couple to infer whether embryos with the HD gene were detected.

The disadvantages include: 1) the cost (~\$7,000 to \$10,000 per attempt); 2) location of PGD center may necessitate travel; 3) physical discomfort (~mild to moderate); 4) the procedure may require multiple attempts before a successful pregnancy is achieved (average 2-3 IVF cycles are required to achieve a live birth); and 5) a normal pregnancy outcome cannot ever be 100% guaranteed, either due to an inaccurate diagnosis, other unanticipated birth anomaly or as a result of the embryo manipulation itself.

This is yet another deeply personal decision with no right or wrong choice. PGD is state of the art technology to produce a biological child. Remember, parenting is loving a child unconditionally, whether via biology or adoption or technology. Entering a loving home, where he/she is wanted and adored, puts any child way ahead of the game.

Reprinted with permission from **Nucleus**  
HDSA Northern California Chapter

## THE 2003 NATIONAL CONVENTION

This year the National Convention will be held in Houston Texas, from June 6<sup>th</sup> through June 8<sup>th</sup>! The Central Ohio Chapter is pleased to announce the availability of Scholarship assistance to enable our H.D. individuals and caregivers to attend the National HDSA Convention to be held in Houston, Texas from June 6 through June 8, 2003. The Scholarship will cover the cost

of convention registration and possibly the cost of the room.

If you would like to apply for this scholarship assistance please complete the following application and return it to: Central Ohio Chapter HDSA, c/o Barb Heiman LISW, Suite 371 McCampbell Hall, OSU – 1581 Dodd Drive, Columbus, OH 43210-1296

### APPLICATION FOR SCHOLARSHIP

#### PERSONAL INFORMATION:

NAME \_\_\_\_\_  
ADDRESS \_\_\_\_\_  
CITY/STATE/ZIP \_\_\_\_\_  
PHONE \_\_\_\_\_ (day)  
\_\_\_\_\_ (evening)  
E-MAIL \_\_\_\_\_

#### APPLICANT IS:

\_\_\_\_\_ A Person with HD  
\_\_\_\_\_ A full time caregiver for a person with HD  
\_\_\_\_\_ At-Risk for HD

#### PREVIOUS ATTENDANCE:

\_\_\_\_\_ Have never attended  
\_\_\_\_\_ Have attended \_\_\_\_\_ times  
Last time attended \_\_\_\_\_

*SIGNATURE* \_\_\_\_\_ *DATE* \_\_\_\_\_

The HDSA National office also offers a limited number of scholarships to those who are in need of some financial help. For more information on how to apply please call 1-800-345-HDSA or on line at <http://hdsa.org/events/ConventionAgenda.html>

## SUPPORT GROUPS OF OHIO



- **Mt. Vernon:** temporarily on hold.
- **Toledo:** 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 Alma Mueller at 419-893-0174.
- **Dayton:** meets at 7:30 p.m. on the second Wednesday of every month at Fairview Methodist Church (on the corner of Fairview & Cataba). For more information please call Cincinnati Chapter Social Worker, Mary Beth Bialic at 513-741-4372.
- **Cincinnati:** 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 the above number.
- **Cleveland:** meets every fourth Monday at 7:00 p.m. at the Independence Public Library, 6361 Selig Drive, Independence, Ohio. For more information, please contact Don Barr at 1-440-423-0506 or [dbarrhome@aol.com](mailto:dbarrhome@aol.com), or Cece Cornell, SW at 1-216-844-8572.

### Teen Support Group

The Teenage support group has been meeting every two months throughout the year. The age range for inclusion in the group is from 10 to 18 years of age. We meet on Sunday afternoons from 3:00 p.m. to 4:30 p.m. at Atonement Lutheran Church (the same location as our adult support group). We encourage all teenagers living in an HD affected family to consider attending this support group. No one is pressured to speak if he/she is not comfortable doing so.

The purpose of the group is to share information about HD; educate attendees on

current research breakthroughs; and establish friendships with others who understand the challenges of living with H.D. Parents or guardians bringing their son or daughter to the group are invited to visit with the other adults while the teens meet separately. It can be a helpful learning experience for all. For more information please call Barb Heiman at 614-292-9960. The next teen meeting is scheduled for Sunday, March 16, at 3 p.m. Please check the web site [www.hdsacentralohio.org](http://www.hdsacentralohio.org) for future dates and information on this group.

### Grocery Certificates

The Kroger Cares program continues to be a viable fundraising program. There is no cost to you and **Kroger will donate 5%** of all proceeds to HDSA.

We now offer **Big Bear, Meijer and Giant Eagle** gift certificates and they, too, will donate 5% of all purchases to our organization. Anyone who wishes to purchase any combination of these should

continue to send checks to Sheri Nash, noting which checks you prefer. The gift certificates are returned to you with an envelope for your next order. Thank you for the continued support of this great fundraising opportunity. Please send your checks to: Sheri Nash, **1936 Willoway Circle South**, Columbus, Ohio 43220. Phone: 614-457-8480

## **Family Service Report, by Dolores Meeker**

This year, we are able to obtain free tickets to the Ohio State Fair for those with HD and their family members. The chapter will pay for ride tickets for children and also for parking. We received several notes and

calls from families who enjoyed the experience. Outings, such as this, are good for the whole family! For tickets please call Dolores Meeker at 614-879-8165.

### **Denial is not a River in Egypt**

Denial can take many forms and is both challenging and frustrating for all concerned. The most familiar form of denial is the psychological form of denial: the inability to accept a painful reality, such as the death of a loved one or the diagnosis of a debilitating disease. This is not an uncommon reaction and is one of many defense mechanisms we use in dealing with difficult situations. Denial can even be therapeutic in that it allows an opportunity to adapt, adjust and accept the unpleasant reality over time. If an individual continues in a state of denial, never coming to terms with the reality, then it is a maladaptive defense that limits the ability to cope.

As noted in Understanding HD – A Resource for Families, HD patients may also manifest denial secondary to brain dysfunction. This is known as “anosagnosia” or a lack of self awareness. This is a fancy name describing a condition where neurons die and feed-back loops in the brain become disconnected. Information simply cannot travel from one part of the brain to another.

Whatever the cause of denial it is a difficult behavior particularly when issues of maintaining health and safety are at stake.

Some strategies to consider if faced with denial:

- Educate family, significant others, and caregivers about HD and its many faces.
- Avoid confrontational conversations when addressing concerns with the HD individual but do not discontinue interactions and discussions.
- Consider who explains the concerns. Some individuals respond better to close family members while others often do better with a health care professional or counselor.
- Have a safety net in place in the event a crisis develops. Consider child card, placement options, physician involvement, and even involuntary commitment procedures.
- Remember that HD is a progressive disease, and time brings about its own changes.
- Have a support system in place to meet the needs of caregivers.

(Reprinted from an article by Marybeth Bialick, MSW, Ohio Valley Chapter)

### **A Few Points to Ponder:**

- A true friend can hear a tear drop.
- Life is to most of us a continuous process of getting used to things we hadn't expected.
- Always remember that you are unique, just like everyone else.
- Warning: Dates on the calendar are closer than they appear.

## **The Dedication of the Historic Marker for Huntington's Disease**

The Meigs County Historical Society has set a date for the dedication of the HISTORIC MARKER for HUNTINGTON'S DISEASE. We will have a dedication ceremony for the historic marker in Pomeroy, Ohio on Saturday, April 26, 2003. The ceremony will start **at 1:00**

**p.m.**, in front of Pomeroy City Hall, which is located at 320 East Main Street, Pomeroy. People can just come to the ceremony; they do not need to RSVP. The dedication ceremony will feature speakers from the HDSA Central Ohio Chapter and the Meigs County Historical Society.

### **Understanding Huntington's Disease**

with

**Jane S. Paulsen, Ph.D.**

**A conference for professional and family caregivers at:**

*The Fawcett Center*

**The Ohio State University**

2400 Olentangy River Road.

Columbus, Ohio 43210

*Saturday – May 3, 2003*

**8:00 a.m. – 3:30 p.m.**

**Sponsored by Central Ohio Chapter, HDSA**

(614) 292-9960

This conference offers continuing education credits for the following professionals:  
SWs, RNs and LPNs pending application.

#### *Overview*

Dr. Paulsen is a Professor of Psychiatry, Neurology and Psychology and director of the HDSA Center of Excellence at the University of Iowa, College of Medicine. She has been active in HD research and clinical care for 15 years. She is the author of the book, "Understanding Behavior in Huntington's Disease" which has been translated for use in 6 countries. She is currently the Principal Investigator for a grant entitled "Neurobiological Predictors of HD Onset" (PREDICT-HD) which seeks to detect the earliest brain and behavior changes evident in persons at risk for HD. PREDICT-HD is being conducted at 20 sites throughout North America. Dr. Paulsen serves on the Center Programs and Advisory Board for the HDSA and was 2002 Chair of the HDSA Convention Steering Committee.

The cognitive changes, emotional and movement disorders that comprise Huntington's Disease (HD) present challenges to professional and family caregivers, particularly in the middle and advanced stages of the disease. This conference will focus on causes of difficult behaviors in HD and offer some approaches to solving behavior problems.

This program will be helpful for:

- Social workers, nurses, case managers, LPNs, RNs, CNAs; physical, occupational, and speech therapists.
- Long term care facility administrators and all LTCF staff.
- Neurologists, general practitioners, psychologists and psychiatrists who provide advice to persons with HD and their caregivers.
- Any caregiver to persons with HD at home or in a healthcare facility.
- Any healthcare professional interested in an orientation to HD and care of people with HD.

**There are relatively few healthcare resources geared specifically to people with HD. This program is offered by the Central Ohio Chapter of HDSA in an effort to increase awareness of HD and provide the most up-to-date- information on caring for the HD patient.**

**Fee:** \$30.00 Professionals-- \$15.00 Caregivers, family members.

Fee includes breaks and box lunch. Professionals must attend the entire conference and complete the evaluation. Must have license number and social security number for registration. No partial credit can be given.

Make checks payable to: Central Ohio Chapter HDSA and send to: Barb Heiman LISW, 1060 Olmstead Road, West Jefferson , Oh 43162

*Hotel Accommodations*

University Plaza Hotel has designated a block of 10 rooms for the night of May 2nd at a cost of \$85.00. Phone the hotel directly at (614) 267-7461 or toll free (877) 677-5292.

**Directions to The Fawcett Center:**

**From the North:** South on I-71 or Rt.23. Take 270 West to 315 South. Take 315 South to Lane Avenue Exit—east on Lane Ave. Go a few blocks to Olentangy River Rd. Turn left (north). The Fawcett Center is the first driveway on the East (right) side of Olentangy.

**From the South:** North on I-71. Take 315 North to Lane Avenue Exit. Turn East (right) on Lane Ave. Go a few blocks to Olentangy River Rd. Turn left. The Fawcett Center is the first driveway on the East (right) side of Olentangy.

**From the East:** West on I-70 . Take 315 North to Lane Ave. Exit. Turn East (right) on Lane Ave. Go a few blocks to Olentangy River Rd. Turn left. The Fawcett Center is the first driveway on the East (right) side of Olentangy.

**From the West:** East on I-70. Take 315 North to Lane Ave. Exit. Turn East (right) on Lane Ave. Go a few blocks to Olentangy River Rd. Turn left. The Fawcett Center is the first driveway on the East (right) Olentangy.

**Registration Please RSVP by April 19, 2003**

Name \_\_\_\_\_

Address \_\_\_\_\_

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

Phone \_\_\_\_\_ Agency \_\_\_\_\_

\_\_\_\_RN \_\_\_\_\_LPN \_\_\_\_\_SW

Family member \_\_\_\_\_

# Update on Huntington's Disease - *A Decade of Discovery* -

*Presented by:*

*The Medical College of Ohio Movement Disorders Clinic,  
The Huntington's Disease Society of America (HDSA) Central Ohio  
Chapter  
and the Toledo Neurological Society*

**Thursday, May 8, 2003**

Reception 6:00 p.m.

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Dinner

6:30 p.m.

**The Buffet Dinner will be followed by a Panel Discussion  
Dana Conference Center  
On the Campus of the Medical College of Ohio  
3000 Arlington Ave  
Toledo, OH 43614**

A variety of beautiful items will be offered by silent auction – your generous bids will be gratefully appreciated. All proceeds from the auction will directly benefit the Huntington's Disease Society of America for family services and research.

## **Master of Ceremonies**

Jim Tishy  
Sportscaster WNWO – NBC 24 Television

**Scheduled speakers:**

### **Barbara Boyle**

National Executive Director and CEO  
Huntington's Disease Society of America

### **Dr. Roger Albin, M.D.**

Professor of Neurology and Co-Director of Movement Disorders Clinic University of Michigan  
Member of The Huntington Study Group

### **Dr. Sandra Kostyk, M.D., Ph.D.**

Director of HDSA Center of Excellence and Movement Disorders Center  
Ohio State University  
Member of the Huntington Study Group

**Tickets:**

<b>Individual</b>	<b>\$20.00</b>
<b>Professional</b>	<b>\$50.00</b>

**For ticket information – please call Robin VanGorder  
419-693-7822 or 419-691-8940**

## **Daily Schedule Can Be a Valuable Strategy to Combat Apathy & Inertia, By Allan Grill, CRC, MFT 1-888 828-7343**

A daily routine can be a beneficial therapeutic tool in combating apathy and inertia, common HD-related psychiatric and cognitive symptoms. In spite of some of our conditioning to resist and resent routines imposed upon us and to value unstructured time, a written daily schedule of activities can be a most useful external device to encourage initiation when the ability to initiate from inside oneself is impaired. Because of the changes in brain function related to Huntington's Disease, many people have difficulty in initiating activities that were once pleasurable. A schedule can provide structure to an otherwise unfilled day, when the only activity might be sitting around watching television. While Huntington's Disease may rob the affected individual of taking initiative, the use of a written daily schedule or routine is one strategy to seriously consider.

To the right is a sample of a daily schedule, but do note that it is only an example (you'll probably want to be more specific than my general outline). For a daily regimen to work and be effective, it should be modified to suit your personal preferences, needs, and abilities. Of course, be realistic about it. If you tend to be a night owl and go to bed at 2 AM, don't set your alarm clock for 7 AM. Get plenty of sleep and wake up at a reasonable time. Give yourself ample time to accomplish your activities, and perhaps most importantly, schedule in pleasurable activities.

If you can arrange to do so, it is better to eat several smaller meals spread throughout the day as opposed to eating larger meals. This will help keep you from feeling ravenous when it's meal time, and will hopefully slow down how quickly you eat, reducing the risk of choking on solid foods or liquids. Each time you eat or drink is an opportunity for calories, preferably high-quality calories, and particularly if you are underweight. While diet sodas and potato chips might be quite tasty, they are not the best snack foods and can be difficult to swallow if you tend to choke when eating. A speech therapist can do a swallowing evaluation to help you figure out what types and textures of foods are best suited for your

particular needs, as well as offer suggestions about body positioning to reduce the risk of choking when eating.

In addition to preparing your own activity schedule, there are well-structured Adult Day Health Care Centers and other recreational programs that may be available in your community. These programs can provide both structure and an opportunity to socialize with other people during the day.

Ask your friends, family, or health care professionals for help if creating a schedule feels like an overwhelming feat. It might sound corny, but that pad and pen sitting over there on the table could turn out to be a valuable, useful friend.

Sample daily schedule:

8:30 AM Wake up (set your alarm clock Daily!) Personal care (bathing, grooming, dressing, etc.)

9:30 AM Eat breakfast. Be sure to allow enough time to comfortably prepare and eat your meal. Remember: consuming a sufficient amount of high-quality calories is an essential part of treatment for some HD-related symptoms. Also, make sure you consume enough fluids, and remember to take your medications and vitamin supplements.

10:30 AM Do a pleasurable activity. This may be a hobby that you've enjoyed doing in the past, or perhaps something new that you're willing to try out for the first time. This can be done solo or it can be an opportunity to share with a family member or friend. Keep in mind that this should be fun and enjoyable, as well as therapeutic.

12:00 PM Eat lunch. Try to do so in a relaxed environment without multiple distractions. If you have problems with swallowing or choking, watching TV, reading, or talking while eating will distract you from concentration necessary to chew and swallow safely.

1:30 PM Walk around the block. The distance covered and amount of time spent is dependent upon your mobility and safety in walking. If possible, have a regular walking companion for some added safety and



fun. If you find yourself tripping or falling, consult with your doctor about a referral to a physical therapist. I know of one person with HD who regularly and successfully uses a treadmill for both exercise and stress reduction, as an alternative to walking outside. Modify your exercise to suit your ability to do it safely. Ask your doctor for additional suggestions for exercise.

3:00 PM Snack/small meal.  
4:00 PM Quiet time. Listen to soothing music and rest for a while. If you have a garden, sit outside, and maybe even do a bit of gardening. Make those phone calls to people that you've been meaning to call.

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## **MEMORIALS**

### **Roger Vaughan**

Randee S. Ross

### **Bobby Noe**

Paul & Victoria Baker

### **Karl Gathman**

Gary & Dianne Zenz

### **Jewell D. Menke**

Mr. & Mrs. John Menke

Nancy Marino

Mr. & Mrs. Dick Menke

Mary Menke

Patricia Menke

Mr. & Mrs. Harry Heiser

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I.A.T.S.E. Local #66

Barbara Menke & Family

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Evette C. Moody

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Martha & Bob Menke & Family

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Juanita Schultz, (Mike & Diane & Family,

Phil Schultz & family, Chris & Leslie

Schultz & Family, Sharon Schultz & Family, Pat & Karen Wilhelm & Family).

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Charlotte Leeth

Cyril & Judy Frey

William & Debra Sturgeon

### ***In Honor Of:***

**Mr. & Mrs. Steve Van Gorder**

Nate & Jean Eudaly

**FRIENDS: The 2003 Membership Drive is now on.** Please note and use the membership form included below. The separate mailing for our Membership Appeal was not mailed in May as it has been done in the past few years. The non-mailing in May saved time and expense, however, the need is as great as ever. Receipts from Membership help pay for education about HD. Educating the public about HD and especially the education and training of people working in nursing homes is one of our most important functions. Our people in nursing homes deserve the best care possible. Support the work of the Central Ohio Chapter; **send your membership donation today.**

**Please tear out and return.**

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone number \_\_\_\_\_

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

Please take me off the mailing list. I do not wish to receive upcoming newsletters

I would like to help by volunteering Check here:

**PLEASE RETURN THIS FORM WITH YOUR CONTRIBUTION TO:  
HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC., CENTRAL OHIO CHAPTER,  
490 CITY PARK, SUITE C, COLUMBUS, OHIO 43215**

**HDSA Central Ohio Chapter  
490 City Park Ave., Suite C  
Columbus, OH 43215**

**Address Service Requested**