



Huntington's Disease Society of America Central Ohio Chapter Fall 2001

Our Voice



A Letter from the President, Marty Vaughan



Good News for the fight against HD in Central Ohio! Andrea Pearson has just accepted the position of Executive Director for the Central Ohio Chapter of HDSA! We now have a full time expert from the charitable world to help us be more effective in our efforts. Andrea has a proven record as an Executive Director, and has already begun to develop plans to move us forward. Increasing public awareness of HD through events, promotions and helping bring more volunteers into our group will be among her more important goals. Andrea will work out of an office downtown in the near future, which should help improve our visibility in the community.

Three important events are coming up. The Celebration of Hope Dinner is September 19th at the Hyatt Regency, near the Convention Center Downtown. The Dinner will help us raise dollars for the Center of Excellence at OSU, as well as honor three prominent individuals in Columbus, Dr. Paulson, Nancy Kramer, and Doug Kridler for their contributions to the Community. Secondly, our Annual Meeting at

Der Dutchman is being held in October. This is always a wonderful event. Last, but not least, is the National HDSA's annual convention to be held in Columbus this June. Potentially over one thousand people from around the United States will attend the convention held at the Columbus Convention Center, in Downtown Columbus. **Please plan to attend all events if possible.**

I have been trying to encourage our members as much as possible to enroll in research programs related to HDSA. One current research program known as PHAROS, is still enrolling individuals. Those individuals between the age of 35 - 50, who are at risk, but are presymptomatic, and have not taken a genetic test to diagnose HD, can enroll. The requirements of PHAROS are not time consuming at all and participation is easy.

Contact Dr. Kostyk at our OSU Center of Excellence for more details. If we are a leader in the country in enrollment in PHAROS it will directly improve our chances for more HD research dollars originating from many places to land in Columbus. So jump in and help us find a cure!!!

2001 Annual Meeting, October 27, 2001

The **Annual Meeting of the Central Ohio Chapter** will be held on **Saturday, October 27, 2001** at the DerDutchmen in Plain City. Family style chicken and roast dinner with dressing, mashed potatoes, green beans, salad, desert, and drinks will be served at **6:15 PM**. The cost is \$12.50 per person. The program will

include our annual report for the year 2000-2001, election of board members, and recognition's. Principal speaker will be announced at a later date.

We must guarantee reservations. Please call Norm Baldwin at 614-871-4301 to make your reservation.

Our Voice

Our Voice is the official publication of the Central Ohio Chapter, HDSA, Suite 371, McCampbell Hall, Ohio State University Hospitals, 1581 Dodd Drive, Columbus, OH 43201 614-292-9960

Our Voice, a newsletter of the 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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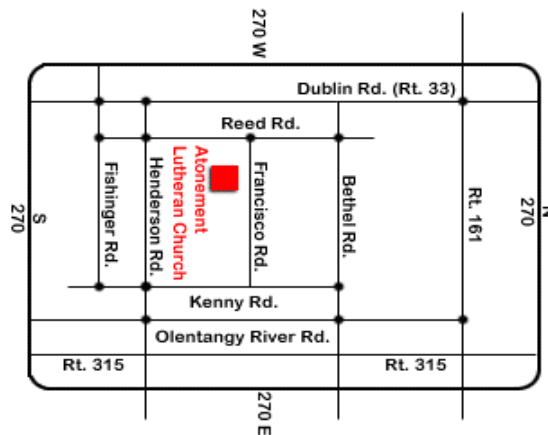
CENTRAL OHIO CHAPTER MEETING TIME AND PLACE

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.

Our meetings have grown over the past several years and we have between 22 to 32 people at each meeting. **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!



Change in Meeting Time of the Columbus Support Group

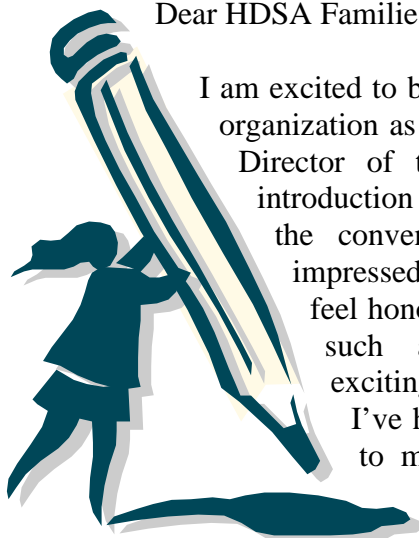
The meetings begin at **7:00 P.M.** This early time will allow those attending to get home at an earlier hour and still avoid the rush hour traffic in coming to the meeting. The meeting will continue to be on the second Thursday of each month at Atonement Lutheran Church. Please note your calendars.

Visit our website at: www.hdsacentralohio.org

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.

Meet Our New Executive Director Andrea Pearson!

Dear HDSA Families and Friends:



I am excited to be joining your fine organization as the new Executive Director of the chapter. My introduction to HDSA was at the convention, and I was impressed by it all. I truly feel honored to be a part of such a dedicated and exciting group of people.

I've had the opportunity to meet with many of the volunteer leaders of the chapter, and would like to thank them for making me feel so very welcome. Those of you who are reading this are the true backbone of our chapter, and I'm looking forward to working together. I'm eager to meet as many families as I can to see how we can successfully meet all of our goals.

What I found upon my arrival at the chapter was outstanding. To have such an outstanding Center of Excellence at OSU is remarkable. We're lucky to have such a resource right here in our backyard. The Center staff, chapter volunteers and committee chairs have been doing a wonderful job of raising money and

providing fantastic support, and I know you want to do more. It will be my pleasure to work alongside the volunteers of the chapter to grow our precious research and support services dollars.

We have an exciting year coming up as we bring a large Walk-a-Thon to the chapter as well as several other new events. In addition, with your help, we'll continue having successful Hoop-a-Thons and Celebration of Hope Dinners. We'll be opening a chapter office outside of the Center of Excellence very soon to provide a place for volunteers to come together and work on various committees or office jobs. Everyone in the chapter is aiming high, and we need you to make things happen. There are plenty of ways to get involved!

I'd like to invite you to email me at apearson@qn.net and share your ideas on future fundraisers and let me know what is going on in your part of the state. I hope to see you at the Annual Meeting!

Warmest Regards,

Andrea Pearson

Are You A Federal Employee?

You can help win the fight against HD through the Combined Federal Campaign (CFC). Each fall, between September and November, eligible employees of the U.S. Postal Service, the Armed Forces and all other branches of the Federal Government are given pledge cards on which they can designate both their charity of choice and their charitable contribution, paid either by check or through payroll deduction. Help us win the battle against HD by writing the number assigned to HDSA, 0526, on your pledge card.



“The Celebration of Hope” Awards Dinner

September 19, 2001, 6:00 p.m.

Hyatt Regency

“Care ~ Commitment ~ Cure”

HDSA Central Ohio Chapter will present our first inaugural awards dinner on Wednesday September 19, 2001 at the Hyatt Regency, in Downtown Columbus. This signature event is the primary fundraiser to support the Huntington’s Disease (HD) Center of Excellence at the Ohio State University Medical Center and it’s clinical research for the cure of HD. We will be honoring distinguished members in our community who have made significant contributions in the areas of medicine, business and the arts.

HDSA is proud to announce that **Governor Bob Taft** as our 2001 Honorary Chairman. **Cabot Rea of WCMH 4** will be our Master of Ceremonies.

In addition, HDSA will pay tribute to **Doug Kridler**, President of Columbus Association for the Performing Arts (CAPA), **Nancy Kramer**, CEO and founder of Resource Marketing, and **Dr. George Paulson**, Professor Emeritus at the Ohio State University’s Department of Neurology. These talented and generous individuals have made significant contributions in their areas of expertise and to the lives of all whom live in Columbus. In the spirit of relentless dedication and compassion of which HDSA was founded, we acknowledge the honorees professional and personal commitment to

their work, families and community. We are also pleased to announce that the “Huntington’s Disease Humanity Award” will be given to the **Harris family**; A family that has demonstrated courage and conviction in the battle against HD.

The evening is designed to be a warm and personal tribute to the honorees. The evening itself will begin at 6:00 p.m. with a cocktail reception and Silent Auction, followed by dinner and awards presentation. Tickets are \$125 per person.

Join us in paying tribute to these award winners and colleagues by becoming a gold, silver or bronze sponsor or purchasing a ticket to the dinner.

Sponsorship opportunities are available for you, your organization, or company to convey your good wishes towards the honorees and support HDSA. Each contribution made will help to advance HD research and bring us much closer to solving the HD puzzle and provide families affected the best possible care for their loved ones. **Give “Hope” today.**

Feel free to contact Wendy Vaughan, at (614) 488-0346 or email at wvaughan@columbus.rr.com should you have any questions. Thank you.

Your contribution will make a difference.



“TAXing Toward a Cure,” written by Marty Vaughan

Perhaps, like me, you have been considering what to do with your tax refund dollars. Certainly there are many considerations, but have you thought about donating those dollars for Huntington’s Disease research?

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.**

Thanks to the \$2.7 million we raised through the first phase of Generation 2000, we’ve dramatically increased our investments in HD research allowing our scientists to get closer and closer each day to

finding the answers to the HD puzzle. So we need to continue what we have begun as the fight is not over.

I hope you will join me, and I encourage you to share this message with others as well.

Please respond by return email and if you choose to participate make your check payable to HDSA and send to:

**TAXing Toward a Cure
HDSA Central Ohio Chapter
2920 Ashby Road
Columbus, OH 43209**

Hoop-A-Thon, Yet Another Success, written by Norm Baldwin

The 2001 Central Ohio Hoop-a-Thon was bigger and better than ever before, raising \$31,203! More celebrities, more shooters, more spectators, more food, more fun!

Randy Rhinehart led the way recruiting 18 celebrity shooters. Including former OSU players **Clark Kellogg, Ken Johnson, Ron Stokes, Troy Taylor,** and **Courtney Bale**; from Capital University **Kendra Meyer**; former Columbus Crew Coach **Tom Fitzgerald**; former pro-basketball player **Val Still**; members of the TV, newspaper, and radio media included **Doug Lessells, Dom Tiberi, Clark Donley, Larry Larson, Brain Rapp, Lee Cockran, Ray Crawford** and **Clay Hall**; and High School Football Coaches **Stan Zody** and **Jim Stimmel.**

The mascots from Columbus professional teams, Louie the Landshark (Landsharks), Stinger (Blue Jackets), Crew Cat (Columbus Crew), and LouSeal (Clippers) were great hits with the youngsters and the oldsters.

The event was held at Resurrection Lutheran Church, in Hilliard. The church donated the facility and several of the

members helped with the event. Proceeds from food sales were donated by **Mike Mavromatis** owner of George’s Coney Island.

The winning team was “**Team Vaughan**” composed of **Marty Vaughan, Christi Vaughan, Jamie Vaughan,** and **Sarah Vaughan,** hitting 470 shots. Cash Money All Stars composed of **Mark Meyer, Jeff Meyer, Ben Losescher,** and **Art Loescher** was second with 410 shots.

Kendra Meyer, Capital University, shattered the record for baskets made, sinking and incredible 205 shots! **Clark Kellogg** equaled his record from last year hitting on 186 shots.

Age group winners were **Jamie Vaughan** 168 in the 12 and Under, **C. J. Gatto** 174 in the 13-18, **Stephanie Thompson** 128 in the 19-35, **Kyle Stanley** 144 in the 36-50, and **Norm Baldwin** 91 in the left over division!

Marty Vaughan was the leading fundraiser, again collecting over \$10,000 in pledges!

Thanks to all who participated in this years most successful Hoop-a-Thon. It was truly a fantastic day.

Volunteers Needed

Volunteers are the backbone of our organization and we need you! HDSA has many types of volunteer work available, so there is something for everyone, and for any amount of time you have to give. We are in need of volunteers to perform a wide variety of tasks, from serving on event committees, general office help and phone work. Some jobs may be done from home.

If you are interested, please contact Andrea Pearson, Executive Director, at 235-5033 for more information.

Kroger Cares, written by Sherri Nash

The Kroger Cares program continues to be a viable fundraising program. We have 46 families participating on a regular basis and this group simply keeps expanding. Many of our families are transferring their prescriptions, purchasing stamps and trying to do the majority of their grocery shopping with HDSA gift certificates. Remember, there is no negative to this program. There is no cost to you and **Kroger will donate** 5% of all proceeds to HDSA.

Currently, we have raised \$4797.50 due to the Kroger Cares program. If each of us can ask one friend or family member to begin purchasing these gift certificates this amount will double and triple! Our chapter has also recently expanded this same opportunity to those who prefer Big Bear. We now offer **Big Bear** gift certificates

Office workers needed for:

Phone calls, Typing, Mailing, Copying, Errands/bank deposits, Volunteer Coordination

Committee members needed for:

2002 Celebration of Hope Dinner, 2002 Walk-a-Thon, speaking engagements, advocacy, 2002 Hoop-a-Thon, Tributes and Memorial Committee and many others!

and they, too, will donate 5% of all purchases to our organization. Anyone who wishes to purchase Big Bear, Kroger or 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. We expect to expand this program to include **Giant Eagle** and **Meijer** within the next 6-8 weeks. Thank you for the continued support of this great fundraising opportunity. Please send your checks to:

Sheri Nash, 1777 Willoway Circle
North, Columbus, Ohio 43220
614-457-8480

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.

SOME GUIDELINES FOR CAREGIVERS

- **Promote Security.** Establish and maintain consistent routines and rituals so that our relative knows what to expect each day and can count on something familiar and meaningful. Remember, most disruptive behavior comes from fear – not knowing what will happen next.
- **Celebrate remaining capacity.** Reinforce what your relative can still do well and don't exaggerate impairment.
- **Don't struggle to make your relative behave in old familiar ways.** Instead, make time for fun and togetherness. Make pleasure in the moment a goal in itself.
- **Substitute for lost ability.** Do things *for* instead of *with* your relative if he or she can no longer do them, but be discreet in offering help. Protect self-esteem. Don't argue with, test or test your relative in public.
- **Make up for the fact that your relative may no longer be able to control impulses.** Try to divert him or her or get the person to think about something else if he or she is about to do something embarrassing, disruptive, or harmful like taking off clothes, accusing an innocent person or lashing out.
- **Watch out for situations that trigger disruptive behavior.** For instance, do not expose your relative to large crowds or too many choices if these scare, upset or frustrate him or her.
- **Build self-esteem.** Let your relative feel productive by finding tasks that he/she can do, such as carrying grocery bags.
- **Listen to your relative.** Learn to hear and respond to the feelings behind the words. For example, a confused, frightened person may ask for his or her mother who died years ago. Instead of saying, "Your mother has been dead for twenty years," which is new information and initiates a grief reaction every time you say it, say something like, "You must really miss your mom," or "Your mother was a wonderful lady."
- **Know where to get help.** Ask your doctor to help you find assistance. Find out what your community has in the way of education, support, counseling and respite care.



When your relative behaves badly, the best approaches are indirect:

- **Try to divert or reassure your relative.** Do not explain, argue or try to reason because this does not work. You can't change your relative's thinking, but you can change the way you respond.
- **Try to handle your own discomfort by taking some time out.** Ask yourself whether the behavior is really a problem. Can you ignore it? Remind yourself that the behavior is a symptom of the disease: Your relative is not trying to upset or manipulate you or to avoid responsibility. Don't take his or her frustrations and criticisms personally.
- **Change your routines to prevent further problems.** Schedule difficult activities for a time of day when your relative is feeling best. Also, schedule frequent breaks, treats or familiar activities.
- **Change the environment whenever possible to prevent problems.** If your relative turns on the stove when you are asleep or at work, for example, remove the knobs. If he or she leaves the house and wanders, install double locks on the doors.

Visiting Your Loved One In A Nursing Home

- IT IS IMPORTANT TO ALLOW YOUR LOVED ONE TO HELP DIRECT THE PLANS OF THE VISITS.
- Pictures of the past.
- Pictures of what's happening now.
- Report cards and school work from the kids.
- Meet with the activities and social services departments about age-appropriate activities.
- Visit during scheduled activities.
- Encourage their friends to visit so your loved one can maintain friendships.
- Bring the kids along.
- Have lunch or dinner with your loved one at the facility.
- Don't say, "oh, you remember, don't you."
- If your loved one likes to be outside, go outside. Most facilities have outdoor seating areas.
- Encourage him/her to do things that he or she enjoyed in the past; puzzles, reading, playing cards, games, etc.
- Ask your loved one about the facility, friends, a tour, etc.
- Find out the proper procedures/rules about taking him/her out, for lunch, for family activity, shopping, hair appointment, fishing, whatever.
- Be sure to continue recognizing special occasions.
- Send mail. Encourage friends, family, kids, to send mail; cards, letters, kids drawings, etc. They will likely serve as decorations, as well.
- Participate in family nights, cookouts, and other events at the facility.
- Attend Card Plan Conferences. Ask when they are held and be there. Participate in these conferences.
- Keep a journal of visits.
- Talk to staff, tell them when they are doing something right as well as when they are doing something wrong.
- Use the facility's forms for formal complaints. Follow-up.
- Volunteer some free time there. Most facilities are looking for good volunteers.

Caregiver Stress Indications

- Denial about HD and its affect on the person with HD.
- Anger at the person with HD or others.
- Anger that no effective cure exists currently.
- Anger that other people don't understand what's going on.
- Social withdrawal from friends and activities that once brought you pleasure.
- Anxiety of facing another day and what the future holds.
- Depression breaks your spirit and affects your ability to cope.
- Exhaustion makes it nearly impossible to complete necessary daily tasks.
- Sleeplessness caused by seemingly never-ending list of concerns.
- Irritability leads to moodiness and triggers negative responses and reactions.
- Lack of concentration makes it difficult to perform familiar tasks.
- Health Problems begin to take their toll both mentally and physically.

Paraphrased From: *Caregiver Stress; Signs to watch for.. Steps to take*, published by the Alzheimer's Association

From The Social Worker, Barb Heiman LISW

I would like your input on a few of our services so that we can better plan to meet your needs. Please answer the following questions and return your answers to me at Central Ohio HDSA, 1581 Dodd Drive, Suite 371 McCampbell Hall, Columbus OH 43210, Thank you for your help.

1. HDSA materials, books, brochures & newsletters:

- How useful are they to you?
- Are they easily available to you? (Support Group, libraries, internet)

2. Location, date, time of support group meetings:

- Do you attend one? If yes, which one?
- Comments or suggestions on content?
- Topic areas you would like to hear discussed?

3. Thoughts and suggestions on Fund-Raising Activities:

- Hoop-A-Thon
- Walk-A-Thon
- Amaryllis Sales
- Celebration of Hope Dinner Event
- Other

4. Any other comments or suggestions to improve our Chapter's Activities

A SAD NOTE:

Our good friend and support group member Jim Frim died Tuesday, Aug. 7th. Bev's address is 5829 Lockbury Lane, Dublin 43016-3276. I am sure she and the family would appreciate hearing from you.

REMEMBER:

THE NATIONAL CONVENTION WILL BE HELD IN COLUMBUS OHIO NEXT YEAR FROM MAY 31, THRU JUNE 2. MAKE PLANS TO ATTEND.

HUNTINGTON'S DISEASE 18th ANNUAL WALK-A-THON Saturday, October 13, 2001 1:00 – 5:00 p.m.

Sponsored by The Central Ohio Chapter, Walk-A-Thon will be held at Antrim Park Shelter House (located on the east side of Olentangy River Road, north of Bethel Road, and south of Rt. 161). The HD family picnic will start at 3:00 p.m. Please bring a covered dish.

Here's what to do:

- 1. Sign up supporters and list the amount they pledge per mile made on this form (you may use another piece of paper if needed) and bring it the day of the event.**
- 2. After the event, collect pledges.**
- 3. Free T-Shirt to all walkers!**



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Memorials

Paul Fleming

Karen Zeedyk, Defiance, OH

Bud Lovejoy

Dolores Meeker, Plain City, OH

Lillie Kelley

**Gary & Karen Ruff, Columbus, OH
Harold & Helen Blankenship, Columbus, OH
Mike, Becky, & Megan Obert, Columbus, OH
Thomas & Jennifer Payne, Grove City, OH
Volleyball Girls, Columbus OH**

Bobby Noe

**Dolores P. Meeker, Plain City, OH
Lisa Meeker
Phil Meeker and Family
Julie A. Fox, Hilliard, OH
Dennis & Deborah L. Holmes, Columbus, OH**

Jerald G. Rodriguez

Brad R. Taylor, Paulding, OH

Joe Crabtree

Lillie Kelly, Columbus, OH

Patrick Berger

Barbara & Gary Heiman, Plain City, OH

John Walter Reece

Motorists Mutual Insurance Company

Bernard Karnemaaat

Norm & Bonnie Baldwin

Memberships

Pilot Club of Columbus, Inc.

FRIENDS: The 2001 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.**

**Central Ohio Chapter, HDSA
Suite 371, McCampbell Hall
The Ohio State University Hospitals
1581 Dodd Drive
Columbus, OH 43210-1296**

Address Service Requested

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
THERESA HANSON, 548 STOCKBRIDGE ROAD, COLUMBUS, OHIO 43207**