Huntington’s Disease Society of America
Central Ohio Chapter
Winter 2001

Our Voice

A Letter from the President, Marty Vaughan

Partnerships

The last three months bring many thoughts to mind; disaster, hardship, fear, but also positives such as resolve, commitment, faith, courage, unity, and national and worldwide partnerships.

In our HD world, a great partnership has evolved between National HDSA in New York City and local chapters. Our Central Ohio chapter, which commenced thirty years ago, has developed a close working relationship with the National office. One of our local members, Roger Vaughan, is on the National Board of Trustees and a National employee, Andrea Pearson, is now working in Columbus assisting our chapter with fund raising and developing more community exposure.

This closer link with National is necessary as we increase research funding and Center of Excellence financing. In addition, as we ready for treatment, we need to be more visible and accessible to those who will need treatment in the future.

The many changes from opening an office, adding more fund raising events, developing the Center of Excellence and increasing their financial support, increasing visibility and connecting HD patients and at risk people with OSU for clinical trials and treatment all are vital to our success.

Without a strong tie to National, neither National HD nor local HD members will be as effective. National needs us to create local awareness and fund raising and maintain support groups; we need National for their worldwide network of researchers and connections with NIH federal funding opportunities.

I am proud to be part of a dedicated chapter and National organization and look forward to sharing a future with my friends free of Huntington’s Disease.

“TAX*ing Toward a Cure,” written by Marty Vaughan*

Join us in **“TAX***ing Toward a Cure.”* If you make your **“TAX***ing 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.

Please respond by return email and if you choose to participate make your check payable to HDSA and send to: **TAX**ing 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, 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.

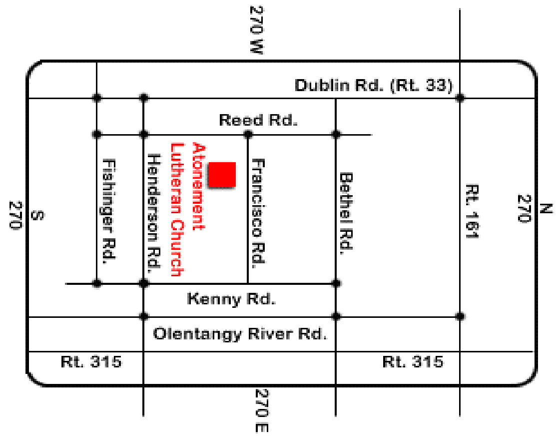
CENTRAL OHIO CHAPTER MEETING TIME AND PLACE

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!



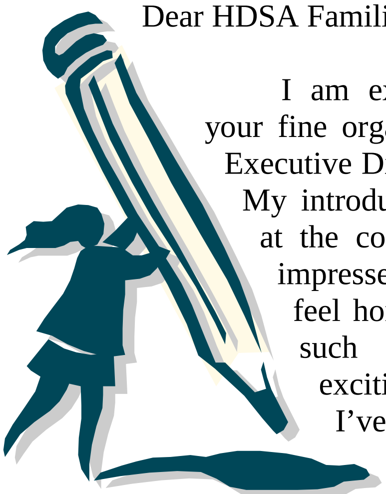
The Columbus Support Group

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.

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-Thon's 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!

Save the date!

Mark your calendars now for these important upcoming dates and events:

December 27th	Midnight Glow Bowling
March 22nd	HD Grand Prix
April 6th	Hoop-A-Thon
September	Golf, Dayton

HD Grand Prix

Teams of four compete in a one-hour endurance race to see which will successfully chase down the winner's trophy! Each driver runs one leg of the trek; team members swap during the pit stop. Open to corporate or family teams, individuals will be placed on teams. It promises to be lap after lap of indoor go carting excitement

.**Midnight Glow Bowling**

This all night lock-in provides the perfect safe activity for middle school kids to do over break from school. Kids will dance, bowl, eat and participate in a special auction. If you miss the first one in Columbus on December 27, we'll be doing it again over Spring Break and would love to come to your area!

Mansfield, Chillicothe, Toledo and Dayton area volunteers – we're looking for you! To help coordinate an event with friends in your area, please give us a call.

Convention 2002, written by Dolores Meeker

Planning for the convention is underway and of course we want it to be a great one, meeting the needs of caregivers, persons with HD, or at risk, family members and interested professionals. Our family service committee is hoping to set aside some of our budget to help families needing financial help to attend.

I will never forget my first convention in Dallas, Texas. My husband was diagnosed and beginning to show some symptoms. I was wondering how our family would be affected, whether I had what it takes to be a caregiver, and a million other questions going around and around in my head. I had attended a few support meetings and asked a lot of questions, but in general, I was very uninformed about HD.

Our chapter social worker, Gladys Cummings (whose husband also had HD) told me about the convention. I thought it would be impossible for me to go, but with some financial help from the chapter and from family members, I was able to attend. I shared a room with Gladys, attended every session I could schedule, and received a lot of information in a very short time!! I also learned from watching families living their lives positively; not without problems, but going forward with hope. I decided if they could do it, so could I!

Because of the empowerment I felt, I want everyone to be able to get that same kind of help. I hope you will do everything possible to take advantage of having the convention in Columbus. It is the very best place to get answers for the questions that we all have when faced with a life altering illness.

Professional Training

HDSA will be conducting its Professional Training at the annual Convention. The training is a chance to learn more about HD as well as to network with other HD health care professionals. Participants will primarily be social workers employed by HDSA's Chapters and Centers of Excellence. However, we would like to invite nurse educators, genetic counselors, speech pathologists, and other members of the multidisciplinary health care team from hospitals and long-term care facilities to attend.

The training will be held on Thursday, May 30,at the site of the 2002 Convention at the Hyatt Regency. The registration fee is $55. Please contact the National Office for more information on registering for this professional training
1-800-345-HDSA.

The Central Ohio Chapter of HDSA

…. 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 Columbus Ohio from May 31, through June 2, 2002. The Scholarship will cover the cost of convention registration and/or room cost. The Convention will be held at the Convention Center, Hyatt Regency Hotel downtown.

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.

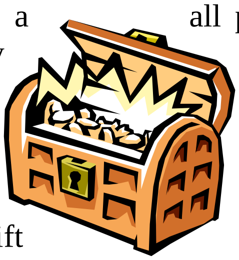
Hoop-A-Thon, APRIL 6, 2002…. written by Norm Baldwin

Mark your calendar now for **April 6 for the 2002 Hoop-a-Thon!** Plan now to attend, join the fun and help raise funds for our Central Ohio Chapter. The event will again be held at the Resurrection Lutheran Church, Hilliard, Ohio.

Over the holidays talk with the members of your family and make plans to enter the team event. Last year **Marty Vaughan** captained his family members to a team win over the 1999 winners captained by **Jeff Meyer** and his high school friends from Cincinnati. Put together your team and take a shot at the traveling trophy.

Randy Rhinehart and **Norm Baldwin** are looking for help with the event. We could use help with items for the silent auction. The sports memorabilia, tickets, etc. were a big hit at last years hoops and raised over $1500. Let us know if you can help. **Call Norm at 614-871-4301**.

Grocery Certificates, 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 nothing negative about this program. There is no cost to you and **<u>Kroger</u>** <u>will donate</u> 5% of all proceeds to HDSA.

If each of us can ask one friend or family member to begin purchasing these gift certificates this amount will double and triple!

We now offer **Big Bear** gift certificates 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.

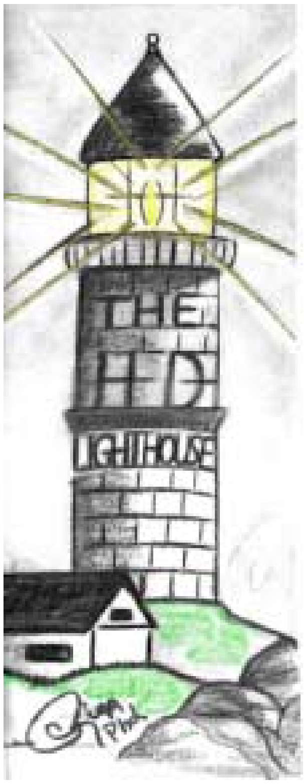
Support Groups of Ohio

- **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.

Jerry's Lighthouse (**http://hdlighthouse.org**) by Gayle Tinnerman

Comment from a frequent HD Lighthouse website visitor:
"I don't think I could have survived this year without this website. I couldn't find ANY information on what I could do to help myself until I found this place. This website is where hope for people with HD lives. Thank you, Jerry, from the bottom of my heart."

The Lighthouse Keeper (webmaster), Jerry Lampson:
"In 1997, I started the HD Lighthouse website when I found out that a nurse and two aides who cared for my wife, Peggy, at the Meadow View Manor in Grass Valley, CA were connected to the internet. I wanted the site to provide information to healthcare professionals learning about HD.



"After Peggy's death in April, 2000, I wanted to forget about HD. Then I went to a retreat to see a group of folks at risk for HD and maybe say goodbye. I was surprised that so many visited the HD Lighthouse website; and I was moved by their praise and appreciation for the HD Lighthouse as I had been moved by the grace and understanding that Peggy taught me in the last year of her life. I thought if they could teach me so much about HD – actually about life – on a personal level that I should continue the HD Lighthouse as an on-going opportunity to learn with others about HD. I like to think the HD Lighthouse is on the cutting edge of new and effective treatments for HD.

"The first year, the HD Lighthouse website served about 50 documents; on Oct. 5, 2001, the Lighthouse served its one millionth document."

What you will find on the HD Lighthouse website:

- Cutting edge HD-related research from around the world
- The HDL Triad: three areas where you can be proactive in your battle with HD to modify its course
- An informal "EPA Study" documenting HD-affected individuals' experiences with various forms of EPA
- HD clinical trials; the story-behind-the-story on clinical trials
- In-depth information about drugs and supplements
- Inspirational stories about HD families and from proactive individuals like Phil, Lisa, and Carrie
- A "Forum" where you can communicate with other affected individuals
- Information about HD events, like the STAR Retreat for At Risk Persons
- Useful search engines for the HD Lighthouse site AND the Internet

Parting comment from the Lighthouse Keeper (webmaster):
"The joy of my life is proactive folks in the HD community who take and use the information on the HD Lighthouse website. And I always treasure feedback from visitors…"

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**.

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