



Huntington's Disease Society of America

Central Ohio Chapter

Fall 2002

Our Voice



A Letter from the President, Marty Vaughan



Our Central Ohio Chapter continues to find successes in our battle with Huntington's Disease. Our connection with OSU has strengthened the work of Dr. Sandra Kostyk and Dr. Kari Hoyt, as they have been invaluable in care and research. Additionally, National HDSA continues to provide funding for the OSU Center of Excellence, directed by Dr. Kostyk. Patients are seen weekly through the Center, providing very specific care for HD patients, as well as at risk individuals in research studies.

On the fund raising front, our annual list of events and fundraisers has grown to include a Center Dinner, Hoop-A-Thon, FBI/HD Golf

Outing, Walk-A-Thon, BW-3 Event, Grocery Certificates, and more!

If you have not already, please consider enrolling in research studies through OSU. For more information contact Dr. Sandra Koystk at 614-688-3675. On September 25th, everyone is welcome to attend our Celebration of Hope Dinner, honoring Cheryl Krueger, Geoffrey Nelson and Dr. Donald Higgins. Contact Wendy Vaughan for more information at 614-487-9711. Proceeds go to help fund the Center of Excellence.

On October 25th we will have our Annual Meeting at Der Dutchman restaurant in Plain City. This is an enjoyable, relaxing time for all of us. I look forward to seeing you at both of our dinners!

2002 Annual Meeting on October 25th

The **Annual Meeting of the Central Ohio Chapter** will be held on **Friday, October 25th** at the DerDutchmen in Plain City. Family style chicken and roast dinner with dressing, mashed potatoes, green beans, salad, dessert, and drinks will be served at **6:30 PM**. The cost is \$12.50 per person. The program will include

our annual report for the year 2001-2002, election of board members, as well as recognition's. The principle speaker will be announced at a later date.

We must guarantee reservations. Please call Pat Meeker at 460-8800 or Marty Vaughan at 457-0235 to make your reservation.

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. Every bit counts toward finding a cure!

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:

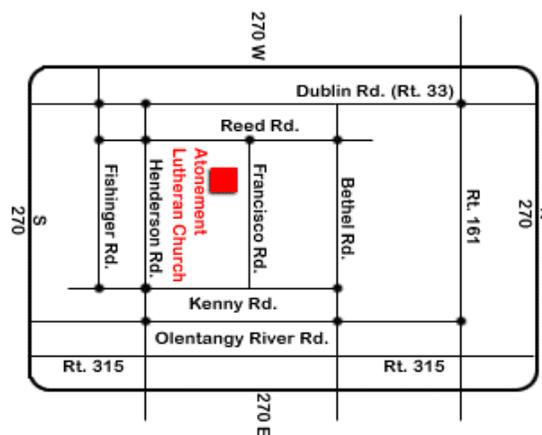
The Atonement Lutheran Church
1621 Francisco Road
Columbus, Ohio 43220

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!

Teen Support Group: Our next teen support group meeting will be held on September 22nd at 3 p.m. at The Atonement Lutheran Church.

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 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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Amaryllis Sale!!! *Written by Dolores Meeker*

Dear HDSA Families and Friends:

I am hoping to have a successful sale of our amaryllis bulbs this year. Last year we fell behind our goal, but with your help we should do much better this year. I am hoping any of you will take delivery of a case (16 or 27) and sell them to your family and friends. Send me your names and addresses and I can have them delivered straight to you from our supplier.

Ask your hairdresser or barber if they would sell a case for you. My friend, Pat Burwell from *Chic Impression* in New Rome, has taken delivery of a case for three years--she puts them on display and they simply sell themselves! Where can you buy such a great gift for \$10? Pat Meeker sold more than 5 cases to members of her

church—she would love someone to challenge her title of Amaryllis Queen!! We will also fill individual orders in the Columbus area, but it is too expensive to mail any quantity less than a full case outside of Columbus.

Make your checks payable to HDSA and send your orders to: Dolores Meeker, 6440 M. V. High Rd. Plain City, Ohio 43064 or call (614) 879-8165. Remember--every dollar we earn brings us closer to a cure for HD!!!!



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, to general office help and phone work. Some jobs may be done from home.

If you are interested, please contact Pat Meeker, at 460-8800 for more information.

Office workers needed for:

Phone calls, Typing, Mailing, Copying, Errands, Volunteer Coordination

Committee members needed for:

2003 Celebration of Hope Dinner, 2003 Walk-a-Thon, speaking engagements, advocacy, 2003 Hoop-a-Thon, Tributes and Memorial Committee and many others!

HD Grocery Certificates

Our **Kroger** Cares program has proven to be a viable fundraising program for our chapter. Therefore, we have recently expanded this great opportunity to those who prefer **Big Bear, Giant Eagle, and Meijer** gift certificates. These stores will also donate 5% of all purchases to our organization! Anyone who wishes to purchase certificates should continue to send

checks to Sheri Nash, noting which gift certificates you prefer. The gift certificates are returned to you with an envelope for your next order. Please send your checks to:

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



“The Celebration of Hope” Awards Dinner

September 25, 2002, 6:00 p.m.

“Care ~ Commitment ~ Cure”

I am writing to invite you to join us at the Huntington’s Disease Society of America’s *second annual* “Celebration of Hope” Awards dinner on September 25th at the Hyatt Regency Columbus. The event will benefit the HDSA Center of Excellence for Patient Care and Family Services at the Ohio State University Medical Center. The center provides world-class care to individuals with Huntington’s Disease and their families and is one of just sixteen centers nationwide with this prestigious distinction.

At the 2002 “Celebration of Hope” Awards Dinner, HDSA will proudly pay tribute to prominent, community-minded individuals who are genuine leaders and have made significant and generous contributions to the Columbus community in the areas of business, the arts and medicine. It is with great pride that HDSA of Central Ohio will be presenting the “Distinguished Leadership Award” to Cheryl Krueger Founder/CEO of



Cheryl&Co.; Geoffrey Nelson, Artistic Director of the Contemporary American Theater Company (CATCO); and Don Higgins, M.D. Ph.D., former Medical Advisor to the HDSA Center of Excellence and Associate Professor at Albany Medical College. Gary Nash and his family will be receiving the “HD Humanity Award” for their continuous courage and conviction in the battle of against HD.

Please join us in paying tribute to these award winners by becoming a gold, silver or bronze sponsor or by placing an ad in the dinner journal. I hope that we can count on your support of this special event and most worthy cause. For additional information, please call Wendy Vaughan at 614-460-8800. Thank you again.

~Wendy Vaughan

What Are You Doing For Fun? Written by Frank Nieto, LCSW

You probably remember with great detail what you thought and felt when either you or your loved ones was first diagnosed with HD. While each of us deals differently with unpleasant news, it is likely that you experienced a roller coaster ride of emotions, especially in the first six weeks after diagnosis. Eventually, you settled into a lifestyle that has helped you adapt to the knowledge that there is no cure and that the symptoms will only progress. So where does the FUN come in? It may seem an absurdity that life can still be fun, but it can be, with a few necessary preliminary steps.

First, you and your loved ones need to prioritize yourselves about HD ...despite any of the limitations. You are you, **YOU ARE NOT THE DISEASE.**

Second, you need to be creative and rethink what fun is. Perhaps it is having

visitors, or going for a walk, or putting together photo albums of precious memories.

Third, you need to be able to sensor negative or unpleasant thoughts from your mind. This is accomplished by having a plan to shift into a ready-made daydream that captures your imagination then making the decision to shout NO! to the unpleasant and intruding thoughts that will interfere with your fun.

Fourth, you need to educate those around you by informing them that you only talk about the unpleasant aspects of HD by appointment!!!

Fun exists when we make room for it in our lives, despite the obstacles. Fun and laughter are part of the human spirit and it takes more than HD to keep you down...so, 1,2,3,4 take these steps and have FUN in your life!

Research & Writings of Jeff Meyer, *written by Norm Baldwin*

Jeff Meyer graduated with honors from Amelia High School (Cincinnati Area) this past June. Jeff's family is rightfully proud of him for his many accomplishments. Those who support HDSA can also be very proud of Jeff.

As a year long senior project, Jeff researched and wrote a paper on Huntington's Disease. His paper not only covered the usual description of HD and the search for a cure, it went much further. In addition to articles concerning research, Jeff read books, such as the "Faces of Huntington's", poetry, music, and scripture from the New Testament of the Bible.

His paper related how these artistic and inspiring writings may intertwine with the struggles of those affected by HD and how they can provide spiritual answers, answers as to how many people not only cope with HD but they grow stronger in faith when confronted with suffering and pain. As a part of his project, Jeff conducted an interview with his aunt, Bonnie Baldwin. He poignantly described her reading scriptures to her mother, Verna Meyer, during her last living moments, and how

Grandma Meyer reflected a sense of peace in those final moments after years of suffering with HD. A tribute to her silent suffering and her Christian faith that she passed on to her children.

Jeff's statement of faith in his paper on Huntington's Disease is inspiring and refreshing. Most of the time we hear only the medical, research, and care of HD. Too many times the spiritual aspects of living with HD are omitted. Perhaps we need more statements of faith to help carry us through life with HD.

As a part of Jeff's senior project he conducted a "Hoop-a-Thon" at his high school and raised \$181.50, which he forwarded to HDSA. Jeff has been a "regular" at the Central Ohio Hoop-a-Thon leading a team from his high school basketball team.

Jeff will be attending Defiance College next year. HDSA extends sincere congratulations and heart felt thanks for his inspiring paper and his personal efforts in the fight for the cure.

Rhinehart Shoots Hoop to New Highs! *written by Norm Baldwin*

Under the leadership of **Randy Rhinehart** the Central Ohio Chapter's 2002 Hoop-a-Thon reached new highs. The total funds raised exceeded \$34,000! The event attracted a record number of people, the only problem during the event occurred when the Resurrection Lutheran Church parking lot was full and participants had to search for a parking space!

Clark Kellogg made it a "three peat," coming back for a 3rd consecutive year as our lead celebrity shooter. Clark is a gentleman and an inspiration. HDSA extends special thanks and appreciation to Clark for his support.

It was a first ever for the five major team mascots to appear at the same time.

Back for the 2nd year was **Crew Cat** (Columbus Crew), **Lou Seal**, (Columbus Clippers), **Louie** the Landshark (Columbus Landsharks) and **Stinger** (Columbus Blue Jackets). Joining them was **Brutus** (Ohio State Buckeyes). Special appearances by the **Bone Lady** (Cleveland Browns) and **Steve Biro** as the one and only "Coach".

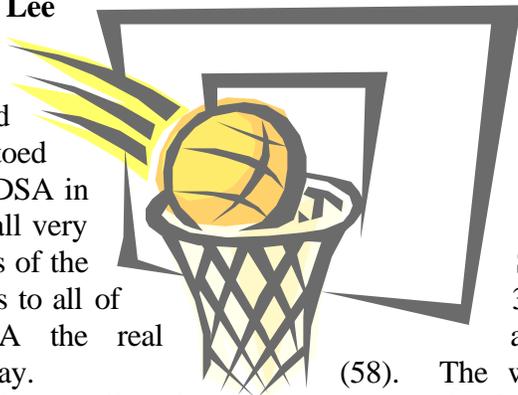
From the Ohio State Men's Basketball, were seniors **Will Dudley** and **Tim Martin** and from the OSU Women's program was past stellar performers, **Jami Lewis**, **Toni Roesch**, and **Lisa Cline**.

The list goes on! Former heavyweight champion, **James "Buster" Douglas**; former OSU quarterback, **Greg Frey**; Crew Coach, **Greg Andrulis**; radio,

TV, and newspaper personalities, **Joe Weasel, Mike Wyant, Clay Hall, Clark Donley, Larry Larson, Ronnie Hunter, Mike Raymond, Lee Cochran, Tim Feran,** and **Anthony Rothman.**

All total, a record 119 dedicated shooters toed the line to help support HDSA in the care and cure of HD, all very special people in the hearts of the "HD Community". Thanks to all of them for making HDSA the real winner on this wonderful day.

Thanks to others who contributed: **Mike Mavromatis** from George's Coney Island, **Bryan Wagner** providing horse drawn wagon rides, **Greg Davis** for rides on a Hovercraft, **Laurie Ruggles** face painting, and all who donated to the super silent auction, and the members of Resurrection Lutheran Church for allowing the use of



their church and the 100 plus members who helped the day of the event!

The leading fund-raiser again this year was **Marty Vaughan**, accounting for over \$10,000! The leading shooters in the age brackets were: 12 and Under, **Kali Basenback** (158); 13-18, **Jeff Kolenski** (158); 19-35 **Stephanie Thompson** (136); 36-50, **Bruce Whitley** (113); and over 50, **Mike Vaselick** (58). The winning team was DaDawgs composed of **Jeff Kolenski, Jeff Meyer, Ben Loshier,** and **Anthony Collini**, from Cincinnati. The most inspirational team were the shooters from **Carlton Manor** nursing home, thanks guys!

Great effort, great day....thanks **Randy!**

Support Groups of Ohio



- **Mt. Vernon:** meets every third Wednesday of the month at 7:00 p.m. at the Country Court Nursing Center, 1076 Coshocton Ave., Mt.Vernon, 43050. For more information please call Bob Lyall, LSW at 740-392-1533
- **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 Robin VanGorder at 419-691-8940.
- **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.
- **Mansfield:** meets the first Monday of the month at 7:00 p.m. in the house of Charlotte Dourgherty, of 671 Weller Ave, Mansfield 44904. For more information, please contact Charlotte at 419-774-9761
- **Chillicothe:** Social worker Trish Fry has agreed to lead a support group in Chillicothe. Please call Barb Heiman 614-292-9960 if you are interested in attending in this area. Meetings will begin sometime this fall after the organization is complete. The day, time and place will be announced.

Caring for the Caregiver

Amy M. Cheshire, CSW-R, MSG (Reprinted from the HD Focus, Upstate New York Chapter)

There is no typical person with HD and therefore there is no typical caregiver that is coping with HD. Families touched by HD often say that understanding HD is the hallmark of a good caregiver, and that understanding often comes in bits and pieces and through trial and error. It is often during this care-giving journey that the caregiver gets burnout and begins to suffer from a variety of stresses, including guilt, isolation, and depression. Over 50% of caregivers will experience an episode of major depression while providing care to a loved one. Yet many caregivers tend to be focused only on the needs of the person with HD. Their own needs get ignored or pushed aside, often until it is too late. There are strategies to provide self care in order to avoid this caregiver burnout. As caregivers often say, HD is a great teacher! As a caregiver you can't control the progression of HD, but you can control how you respond to the progression. Here are some important suggestions:

- Assertively ask for help from others.
- Establish your boundaries; in other words, learn the art of saying "no".

- Take care of your body daily (eat well, sleep and exercise.)
- Nurture your soul daily (music, hobbies, spirituality, and small pleasures).
- Avoid making promises that may be difficult to honor.
- Don't chase ghosts, in other words, focus on what remains, rather than what has been lost.
- Take RESPITE, which is from the Latin word "to breathe".
- Remember to celebrate the humorous aspects of the situation.
- Attend an HD support group for information sharing, problem solving and fun!
- Plan ahead, explore benefits, resources, advance directives and discuss with your loved one their wishes and concerns about the future.

Remember in the face of it all, first and foremost, as caregivers we need to take care of ourselves, in order to continue in the care-giving journey. Find the places where you can draw hope that changes all of our batteries.

"Don't forget to put on your own oxygen mask first."

Adopt a Family

We know how hard it can be living with HD and want to know if your family would like to be adopted for Christmas. Perhaps you know

of a family who needs to be adopted? If you are interested, please provide us with the children's names, their ages, sizes and likes:

Your Name _____
 Address _____
 City _____ Zip _____
 Phone number: _____

Child's Name _____	Age _____	Sex	M	F
Sizes _____	Likes _____			
Child's Name _____	Age _____	Sex	M	F
Sizes _____	Likes _____			
Child's Name _____	Age _____	Sex	M	F
Sizes _____	Likes _____			

*Would you like to adopt another HD family this Christmas Season? ____ Yes ____ No
 For information, please call: (614) 879-8165 or (614) 292-9960 or mail to:
 Dolores P. Meeker, 6440 M.V. High Road, Plain City, Ohio 43064

Memorials

DALE TISH

Phyllis Allmacher & Kurt Allmacher
Avanelle DeCola
Warren Swisher
Joanne Swisher
Joanne Rudisell
Lowell T. & Nancy MacKenzie
Jim & Colleen King
Kathy & Reed Clark
Mr. & Mrs. Michael Izzie
Mike & Connie Whitham
Jerold & Pam Alderman
Ronald & Mary Jane Inkrott
Grace Kindinger
Laura Mirolo
Dick & Candy Deubner
James & Kathleen Schwenker
Pauline Williamson
Dr. Randall Shimkus
Jeannette & Dick Lee
Charles & Nancy Knoop
Dick & Maxine Kidwell
Dr. & Mrs. Darrell Parks
John & Mary Germaine
Mr. & Mrs. Trevor Craig
Carrie Stephenson
Elaine Anderson
Dr. & Mrs. Les Smith
Mr. & Mrs. Paul Hegenberger
Mr. & Mrs. Norman Rask
Marilyn Lucas
Kay Arnold
Connie Kibler
Thane & Stella Thatcher
Helen Lee
Robert Grinch
The Roaring 20 Stock Club
David & Jean Ives
Charles & Margie Headlee
Whetstone Care Ladies – Evelyn Schnittke
Lucy E. Berry
Millard & Phyllis Mundew

Dr. Paul & Jane Morton
Carrie May Jones
Jennifer Reed
Doris Browning
Dolores Meeker

EVELYN SHAY

Tony & Teresa Pusateri
Greg & Leyda Grissett
Norm & Bonnie Baldwin
Bubba & Carey Kidwell
Roland & Betty Geddis
Pat Meeker

DONAVAN POLING

Fred Lindabury, Jr.
Jo Beerman

STEVE SMOUTHERS

Carol & James Rockwell
Keith, Carmen & Brian Taylor
Dolores Meeker

EVANGELINE PANOS

Mr. & Mrs. Christ Mantis

MARY ANN MORROW

Dick & Maxine Kidwell
Norm & Bonnie Baldwin
Dolores Meeker
Ruth & Eugene Neff
Dick & Jeannette Lee
Thelma Morrow
Carlton Manor Committee of Hope

SAMUEL TRIPLETT

Daniel Collins
Karen Kilgore
WRFD Staff
Ang-LLA Farms, Gary & Joyce Warner

FRIENDS: The 2002 Membership Drive is now on. Please note and use the membership form included below. 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**