



Huntington's Disease Society of America Central Ohio Chapter Spring 2002

Our Voice



Celebrities Galore at 2002 Hoop-a-thon

The 2002 Hoop-a-Thon will be something special! Last year was a great day and this year promises more of the same with special added attractions. Plan now to attend, spend the whole day, support HDSA, have some fun, and rub elbows with some very special guests and some very special people.

Clark Kellogg has very generously agreed to come back for a 3rd year to help us in the fight against HD. Clark is a special person and cares deeply about our cause. He will just be completing his national appearance as lead analyst for CBS and the NCAA March Madness Basketball Tournament. He will be heading for the NBA play offs as the announcer for the Indiana Pacers. Please come and thank him in person. Clark will shoot at 11:00 am. Let him know how much we appreciate him. Make a generous pledge!

World Heavy Weight Champion – James “Buster” Douglas will sign autographs and be available for photos with Clark Kellogg at 11:00 A.M. Buster KO'd Mike Tyson in one the most famous fights ever! Don't miss this opportunity to personally meet a Champion and thank Buster for supporting HD.

“The Coach” will appear at 12:00 noon! This will be fun. The Coach is the most famous football coach ever, serving for years at a most distinguished State University. He will give us all a pep talk to be remembered. Don't miss this one!

Mayor Coleman will return to this year's event at 3:00pm. He promises that elusive basket will not escape him this year. Come support the Mayor as he supports HD.

Check the list of celebrities listed separately in this newsletter and check our WEB site at www.hdsacentralohio.org for updated listing as the event draws near.

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

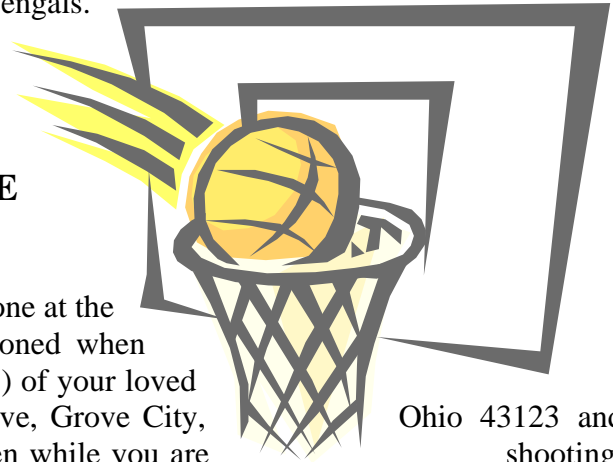
The only thing missing will be you, if you don't come. We really do need **YOU**, plan to attend and support all of the wonderful people who are offering their time and support to HDSA. **Bring your camera and items for autographs!**

HOOPS – SILENT AUCTION. APRIL 6th!

The Super Silent Auction will be going on all day at the Hoop-a-Thon! Great items for sale include: tickets from the Indians, Reds, Blue Jackets, and Crew; autographed items by Archie Griffin, Jim O'Brien, Bobby Rahal, Joe Paterno, Arnold Palmer, A. J. Foyt, Rusty Wallace, Chris Evert, and Terry Bradshaw. We will also have an autographed World Series baseball by Derek Jeter, a baseball bat signed by Kenny Lofton, and many more. We will have sportswear from OSU, Browns, and Bengals. Woodcarvings, knitted afghans and many other great items for bid. Bids are final around 4:00 P.M.

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.



“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.

GROCERY CERTIFICATES, SHERRI NASH

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** 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 hope to expand this program to include **Giant Eagle** and **Meijer**. 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. Phone: 614-457-8480.

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:

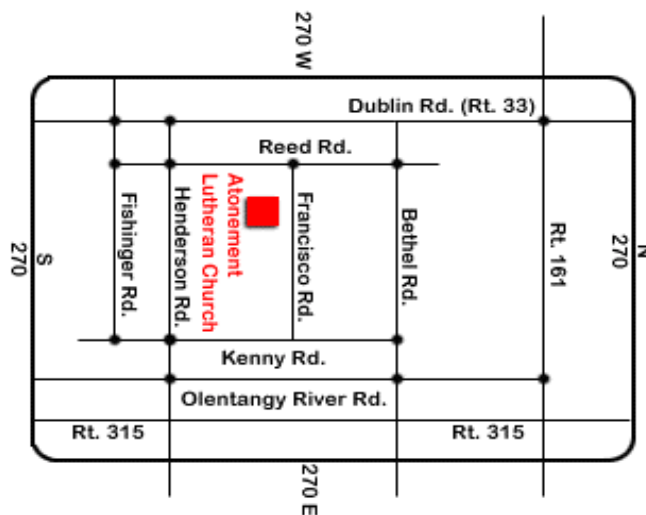
The Atonement Lutheran Church
1621 Francisco Road
Columbus, Ohio 43220

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!

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.

Visit our website at: www.hdsacentralohio.org



MONTHLY SUPPORT GROUP TOPICS

March 14: Advanced Directives (Living Will, Durable Power Of Attorney, Do Not Resuscitate)

April 11: Hoop-A-Thon Results And Discussion/Support Group

May 9: Genetic Counselor Sharon Linard To Speak

June 13: Report On The National Convention

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.

**17TH ANNUAL
HUNTINGTON'S DISEASE SOCIETY OF AMERICA**

Hoop - a - Thon
SHOOT FOR THE CURE

April 6, 2002

**Resurrection Lutheran Church
3500 Main Street
Hilliard, Ohio**

SHOOT WITH THE STARS

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

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

Join the fun – Shoot for the Cure

SHOOTING TIMES MAY BE SCHEDULED

From 8:00 AM to 5:00 PM

Contact: Norm Baldwin 614-871-4301

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

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

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
		TOTALS	\$	\$

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

Questions? Contact Norm Baldwin, Hoop Co-Chairman at 614-871-4301

THANK YOU FOR YOUR SUPPORT!

Schedule of Special Guests
HDSA Hoop-a-Thon Saturday April 6th
Resurrection Lutheran Church
3500 Main Street
Hilliard, Ohio

9:30	Kathy Lindsey Brent Bower Stan Zody Jim Stimmel	Girls Coach Hilliard Davidson Girls Coach Hilliard Darby Boys Coach Hilliard Darby Boys Coach Hilliard Davidson
10:00	Greg Andrulis Greg Frey	Head Coach Columbus Crew OSU Quarterback
11:00	Clark Kellogg Buster Douglas	OSU Basketball – CBS Sports World Heavyweight Champion
12:00	“The Coach” Todd Yeagley	You will know him when you see him! Columbus Crew
1:00	Brutus Stinger Crew Cat LouSeal Louie the LandShark The Bone Lady	Ohio State Mascot Blue Jacket Mascot Columbus Crew Mascot Columbus Clippers Mascot Columbus LandSharks Mascot Cleveland Browns fame
2:30	Toni Roesch Val Still Lisa Cline OSU Women’s Basketball Player(s)	OSU Basketball – OSU & Big 10 Basketball Analyst Columbus Quest & Worthington Christian OSU Basketball
2:45	Tim Feran Clay Hall Anthony Rothman Ray Crawford	Columbus Dispatch WSYX 6/FOX 28 WSYX 6/FOX 28 WSYX 6/FOX 28
3:00	Mayor Michael Coleman	Mayor of Columbus
3:00	Mark Wyant Clark Donley Larry Larson OSU Basketball Player(s)	WBNS 1460, The Fan Sunny 95 610 WTVN
3:15	Lee Cochran Ronnie Hunter Mike Raymond	This Week Newspaper New Rock 99.7 The Blitz ONN

Schedule as of March 1st. For updated information check our WEB Site

www.hdsacentralohio.org

BRING YOUR CAMERA AND ITEMS FOR AUTOGRAPHS!
 EXPRESS YOUR APPRECIATION TO THESE STARS FOR SUPPORTING HDSA!!!!

**Pledge to
Huntington's Disease
17th Annual Hoop-a-Thon**

**Saturday, April 6
8:00 a.m. – 5:00 p.m.**

**Resurrection Lutheran Church
3500 Main Street
Hilliard, Ohio**

YES, I want to join in the fun when **Clark Kellogg** shoots hoops for support of the Huntington's Disease Society of America! Help put a little pressure on Clark as he shoots free throws for 10 minutes; pledge for each shot he makes. Clark will be at the event at 11:00 a.m.

Your Name	Address	Phone	Pledge per Basket
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Ask a friend to join the fun, register pledge below.

Proceeds of pledge to Central Ohio Chapter _____% directly to research _____%

Make each shot count for Clark and the Huntington's Disease Society.

Mail to:
Norm Baldwin
5825 Ravine Creek Drive
Grove City, Ohio 43123
Phone 614-871-4301
normbaldwin@juno.com

GIVE GENEROUSLY!

DNA Direct, By Andrea Zanko, M.S., azanko@itsa.ucsf.edu

A concerned father asks, “When do I explain to the kids what is happening to their mom? How much do I say? How will they ever understand?”

Mike and Cheryl have two children. Their daughter, Liz, is 8 and their son, Ryan, is 10 years old. Liz plays piano and Ryan skateboards. They are busy, delightful, thriving kids with lives full of school, friends and soccer. Mike works full time. Cheryl had been at home to manage the household, chauffeur the kids and volunteer at school. She organized the social engagements and did the laundry, always with a vibrant energy and good nature. There was harmony to the home. Two years ago, however, Cheryl became uncharacteristically distant, less affectionate and chronically angry. She appeared lethargic, with little energy or exuberance. That, combined with physical restlessness, convinced Mike that HD had taken up residence, despite Cheryl’s denial of any problem. At first, the kids were simply confused. They couldn’t understand why mommy often yelled and wasn’t always happy when they arrived home from school. But there were still enough good days for Mike to just say that mommy was having a hard day. But the hard days became more frequent.

Now, after two years, Mike reports the kids have learned to avoid mommy, or to fear her if they have not completed their chores. They sometimes make a mess, are loud and silly and they resent the chores that seem more demanding than those of their friends. They just want to be kids. They ask why mommy sits on the couch so much and why she doesn’t have dinner parties anymore? Why doesn’t she play, why doesn’t she volunteer in the school garden and why doesn’t she drive on field trips? And why is she so angry with them?

Mike is grieving for the wife and partner he is slowly losing. And one of the most painful aspects for Mike is watching his children respond to the changes in their mom.

A recent large-scale study at Memorial Sloan-Kettering Cancer Center examined families coping with the illness and loss of a parent. The report clarified a child’s grieving process from ages 3 to 17 years, and made it very clear that children are incredibly resilient; they can grow and recover, but much of a child’s strength comes from the responses and support of the unaffected parent.

Particularly with an illness such as HD, the grieving and loss is extended over years. It is a process, continually changing as the relationship with the ill parent changes. In the Sloan-Kettering study, the age of the child defined understanding and coping. The 3-5 year olds had a difficult time understanding the irreversibility of loss. They needed very concrete explanations, and they often demonstrated distress through nightmares, stomach aches, bedwetting, and extreme anxiety when separated from the well parent. Children ages 6-8 years could understand permanent changes, but they were often likely to feel responsible for their parent’s illness. They loved talking about their affected parent, telling stories about the parent, and they cherished special shared memories. The 9-14 year olds were more reluctant to talk about their loss; they escaped into their activities and friends. The 12-14 year old adolescents could be shockingly egocentric, worried more about how the illness of the parent would affect social lives. But they also missed the ill parent terribly, as a caretaker and as a roll model. The oldest children, from 15 to 17 years, most resembled adults in their approach to loss. They were helpful and supportive to the well parent, but clearly experienced a sustained grieving.

The study emphasized that children who adjusted most appropriately did so because their parent(s) communicated with them. When there was no communication, or the well parent was terribly burdened by his/her own depression or additional stresses, the children simply experienced more difficulty coping. Interestingly, many ill parents expressed concern that their children would remember only the most difficult stages of their disease, and most often, that was not the case. Children’s images “focused on the positive aspects of the parent.”

A few basic guidelines:

Answer the question asked honestly and directly, without offering more than is needed. Make sure that you understand WHAT is being asked. Simple, reassuring answers are most effective. Your children are sensitive to the changes in their home. Their fantasies and magical thoughts may have created horrifying answers already; your words can soothe and make sense to them.

Remember, there is time to offer information gradually – incremental explanations over time can be modified according to maturity of the child and symptoms of the parent. Your children may benefit from counseling, particularly as they get older and may need a safe place to express their fears, sadness, and anger. The older child will likely need more in-depth discussion, with tolerance for a spectrum of unpredictable emotional responses. Remember, the adolescent is a complex array of contradictions.

Use appropriate resources. An overwhelmed parent will be perceived as inaccessible – let other trusted adult's help. Allow your children to be kids. Helping with chores is great, but keep tasks age appropriate,

with time for homework and PLAY. Home should not feel like boot camp. Kids with loving, accessible parents and/or trusted adults can understand and adjust to incredible hardship. Their questions keep them connected to you. Don't shut them out, don't overwhelm them – aim for balance, simplicity and honesty. Be accessible. Be genuine.

For more information on talking to children, please refer to these articles available through HDSA, "Telling the Children," by Shirley Dalby SW, and "Talking with Children about HD in The Family," by Arlette Lefebvre, MD.

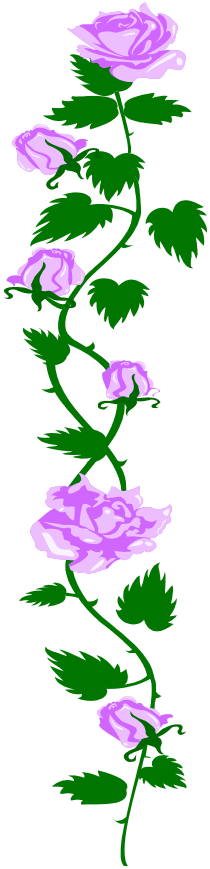
(Reprinted with permission of Andrea Zanko, M.S.)

A POEM WRITTEN BY DOUGLAS SHERWOOD

*Dear Mother,
I do not know what to say
For all I can do to help I will.
But I know it will not go away.
Pain, anger, and sadness too
I know this you feel,
I just wish I could help you.*

*If I could turn the dreary rain to pleasant sunshine
If I could give you cheerful thoughts to help you free your mind.
Whatever I could do to help, you know I would
But it is you who possesses the strength that should.
Set the smallest of goals each and every day,
Don't let anything, no matter how big or small, stand in your way.
You have what it takes to stand tall and proud
But you hide it and don't give yourself the credit you allowed
Look at what I have become, such a successful son.
But I owe all this to you because you were the one.
You were the one to bring me life and guide me each step of the way.
Remember and in my heart you will stay.*

Mother, I love you!



2002 Cure HD BMW Sweepstakes

Grand Prize: A Model Year 2002 BMW C325Ci 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

Purchase 2 tickets for \$100 each and receive the third free!

Please make all checks payable to HDSA, Central Ohio Chapter

Your Name: _____

Address: _____

City/State/Zip: _____

Phone (h): _____

Phone (w): _____

Some restrictions apply. Official Sweepstakes Rules available on request from HDSA. The drawing will be held at the National Convention in Columbus, Ohio on June 1st. The Central Ohio Chapter supports this fund raising effort and the generosity of BMW. You may send your entry to the Chapter by mailing to HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC., CENTRAL OHIO CHAPTER, 490 CITY PARK, SUITE C, COLUMBUS, OHIO 43215 or you may return the formal entry form directly to the HDSA national office. Visit HDSA Website at: www.hdsa.org

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, or Cece Cornell, SW at 1-216-844-8572.

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!

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.

***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.*

Memorials

Bobby Noe

Paul & Victoria Baker

Roger Vaughan

Randee S. Ross

Beatrice Anspach

Leah Ann Hart

Kenneth Anspach

Jim Frim

Theresa Hanson

Roger & Bev Masteller

Bernard Karnemaat

Marilyn Peck & Family

Jarob Design, Inc.

Mart & Dorothy Wiers

Frank, Lisa, Laurie & Alexis English

Steve & Patti Kunren

Alvin & Norma Luchies

Bruce Born

Barbara Vlietstra

Theresa Hanson

Don & Sandy Goossen & Family

Doug & Deb DeRidder & Family

Jerry & Nancy DeGood

Marjory Ann Maynard

Herbert W. Smouther

Deb & Hudson Wouthuis & Family

Steve & Judy Burns & Family

Dirk & Kim Racette

Douglas & Rosalie Hossink

Meredith Gilbert

Mr & Mrs. John Karnemaat

Evelyn Shay

Thelma Jane Koerner

Dolores Meeker

Rodney & Joan Hogle

Dave Fisher

Ginny & Don Harris

Andrew & Betty Shay

Martha Butler

Margaret & Clara Habamav

Polly & Donna Taylor

ODOT Office of Structural Engineering

Bill & Ruth Goldsbury

Beth Edwards

Dick & Maxine Kidwell

Luceille Lester

Mr & Mrs. Richard Lee

Mr. & Mrs. Edward Borger

Addamay Rousculp

Jack England

Fritz & Kate Goss

In Honor of:

Steve & Robin VanGorder

Jean & Nate Eudaly

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**
