

Huntington's Disease Society of America Central Ohio Chapter Fall 2000

Our Voice

A Letter from the President, Marty Vaughan



Congratulations to all of you for recent successes for our local chapter. At the National Convention, our Central Ohio Chapter was awarded Chapter of the Year, plus the national board confirmed that Columbus would be the site for the year 2002 HDSA National Convention! Way to go!

The Chapter of the Year award is a unique honor considering there are over 30 chapters competing. Our secret to success was a combination of top-notch care giving support for our HD community, plus successful fund raising as well. Many of our chapter members have put in hard work and long hours, all of which have added to our success!

But what do these accomplishments mean? Does the chapter's success change our lives, on how we feel as people fighting HD on a daily basis? Personally, it is complicated when I start evaluating my feelings about HD. Feelings of job, expectation, impatience, fear, worry, depression, hope, and resolve all are there. These recent accomplishments help enhance some of the positive, hopeful side of these feelings, but only a treatment or cure can really make a change in our emotional lives.

My hope is that we continue to progress as a group, whether awards are won or lost. If each of us push a little harder, and challenge ourselves to do the hard things for each of us, we will make it. The effort is worth it.

Vaughan's Lead Fund Raising Campaigns

The Central Ohio Chapter received a \$30,000 grant from the Columbus Medical Association to help fund the Center of Excellence at Ohio State University Hospitals for the next three years. Credit for obtaining this grant goes to **Wendy Vaughan**, wife of **Roger Vaughan, Jr.**, member of the Central Ohio Board and the National HDSA Board and to **Kathleen Edwards**, member of the National Staff.

Wendy and Kathleen did an outstanding job of writing the request in a short period of time. Without their efforts, the grant would not have been obtained. Our thanks to **Wendy and Kathleen** for their excellent work!



Raising funds for charitable organizations is nothing new for the Vaughan's. **Wendy** chaired a successful campaign earlier this year raising over \$50,000 for the Goodwill.

Roger is co-chairing the **HDSA's Generation 2000 Campaign**. The goal started at \$500,000 two years ago and has been increased to raise \$2,000,000 by the end of this year. To make a donation to Generation 2000, the last generation of Huntington's Disease, contact **Roger**, the National office, or the Central Ohio Chapter.

As Roger stated, "We have the opportunity to make something happen in curing HD, lets take advantage of this opportunity and get involved now!"

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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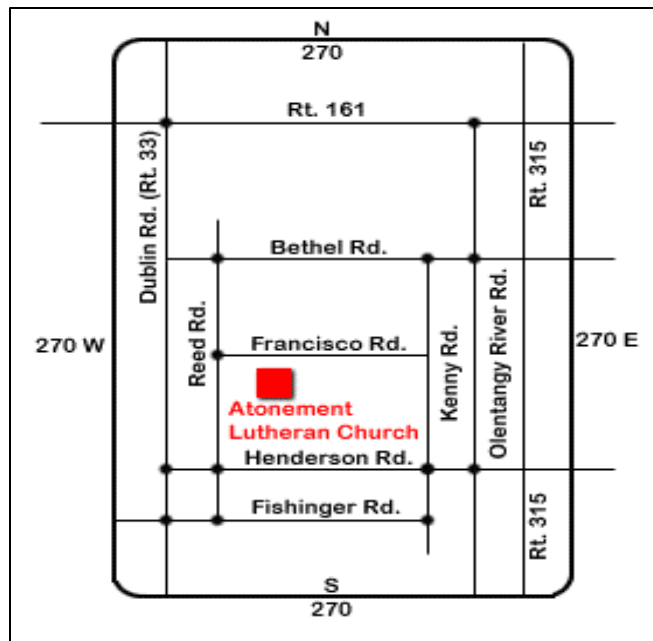
CENTRAL OHIO CHAPTER MEETING TIME AND PLACE

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!

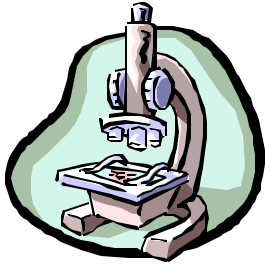


Change in Meeting Time of the Columbus Support Group

Note a change in the meeting time of the Columbus Support Group. The meeting will begin at **7:00 P.M.** vs. 7:30 P.M. **effective with the October 12th meeting.** 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

More Hope – NIH Research Money - Written by Norm Baldwin



The following are comments by Senator Spector from the records of the U.S. Senate relating to a discussion about Huntington's Disease and Departments of Labor, Health and Human Services, and Education and Related Agencies, Appropriation Bill 2001.

Senator Spector responded to remarks of Senator Mikulski who spoke in support of funding for Huntington's Disease research.

"I am familiar with the horrible effects of Huntington's Disease. In my state, 1,200 people are affected. But I am optimistic about a cure. HD research is

advancing rapidly and could be the Rosetta stone to treatments for Alzheimer's, Parkinson's, and other neurodegenerative disorders that together strike millions of people and their families."

"I am hopeful that through public and private medical research funding, we will soon approach a better understanding of, and perhaps even a cure for, this terrible disease." "In Fiscal Year 1999, the National Institute of Neurological Disorders and Stroke at the National Institutes of Health (NIH) dedicated \$62.5 million to the Huntington's Disease research. Also commendable is the commitment of the Huntington's Disease Society of America, which this year will allocate an estimated \$2.8 million to research in the area."

Annual Meeting - October 21st - Written by Norm Baldwin

It was so good last year; we have decided to do it again! The 2000 Annual Meeting of the Central Ohio Chapter will be held on **Saturday evening, October 21, 2000**, at the **Der Dutchman Amish Restaurant**, Plain City, Ohio. A family style Amish dinner will be served at **6:15 p.m.** followed by an evening of celebration, hope, and special entertainment.

A brief business meeting will be held after the dinner. We will celebrate the past year and elect board members for the coming year. **Dr. Lawrence Elmer** from the Toledo Medical College of Ohio will update us on the most recent research developments and **Dr. Sandra Kostyk**, Director of our new Center of Excellence at Ohio State University Hospitals will talk about the programs at our Center. Our

chapter is indeed fortunate to have doctors with so much knowledge about Huntington's Disease. Their dedication, enthusiasm, and empathy for HD patients is unsurpassed. There is new information every month. Come and learn from the experts!

We must turn in guaranteed **reservations by Sunday, October 15th**. Therefore, it is necessary that you call in your reservation. The cost is **\$12.25 per person**, please pay at the door. We are limited to 125 people, so call early. Make your reservations by calling **Norm Baldwin at 614-871-4301**. If there is no answer when calling, please leave the total number of people attending along with their names.

Please join in the celebration and share fellowship with others. **We need you!**

"I Have HD": Wallet Cards. HD wallet cards are now in stock! If you would like more information about these cards, or would like to place an order, please contact Anita Mark-Paul at the national office, ext. 19, or by e-mail at amarkpau@hdsa.org, or contact Barb Heiman with the Central Ohio Chapter.

HDSA Convention 2000 – Written by Delores Meeker

The first national convention of the new millennium surpassed all three I had attended previously. All aspects of HD were covered. There were sessions on nutrition, medication, legal issues, long-term care, juvenile HD, behavioral issues and help for caregivers. I learned something new in each session.

Best of all, from doctors and researchers, we received information about new medications being tested that instilled hope that treatment will soon be possible.

The facilities in Orlando were great and after the daily session ended, we could find restaurants nearby or go for a swim in a large pool adjacent to the hotel lobby. Many

people stayed for a few extra days and took advantage of the Disney complex, Universal Studio and Sea World.

The highlight of the conference for Barb and I was being called to the podium at the Awards Night dinner. We were completely surprised (and very thrilled) to accept the “Chapter of the Year” plaque in behalf of the Central Ohio Chapter.

I hope everyone in our “HD Family” will try to attend a national convention. Next year (2001) it will be held in San Diego. We will have a booth there to encourage attendance at the 2002 convention, which will be held in Columbus, Ohio!

From Our Social Worker: Barb Heiman

SERVICE COMMITTEE: A reminder from the Service Committee that the offer of an evening out, a trip to the Zoo, COSI, the movies etc. for any of our HD families is still available. The chapter will cover the cost and help with child-care or patient care if necessary. To make arrangements or for more information, please call Delores Meeker at 614-879-8165 or the Hotline at 614-292-9960.

MT. VERNON SUPPORT GROUP: I regret to inform you that Amy Lewis, the Social Worker leading the HD group at Country Court Nursing Home in Mt. Vernon, has been in an accident and will be out of work for several months. During that time the support group will be "on hold". If you are not registered with this group and would like to attend when they resume meeting, please call the nursing home to put your name on their mailing list (740-397-4125) or call the HD hotline at 614-292-9960.

We all wish you a successful and speedy recovery, Amy! You mean so much to the people you serve and those who care about you!

CENTER OF EXCELLENCE: The Buckeye Center of Excellence is a reality! Dr. Sandra Kostyk, Director, is doing an excellent job of coordinating services for our H. D. families. Anyone wanting to schedule an appointment with Dr. Kostyk can call 614-293-4974. Appointments can also be arranged with our Genetic Counselor, Sharon Linard, M.S.; Occupational Therapist, Sandra Rogers, PHD; Social Worker, Barb Heiman LISW; as well as other disciplines such as Speech and Physical therapy. Please call the above number or the Hotline at 614-292-9960.

FAMILY SERVICE: This will be the last newsletter before we begin our preparations for Christmas. If you have family members who are homebound or in nursing homes be sure they are on our mailing list. Send names and addresses to: Delores Meeker, 6440 N.V. High Road, Plain City, Ohio 43064-9512. You can also call (614) 879-8165.

We sign cards and wrap packages at our December meeting so we need to have the new names in November.

Reflection and Hope: Sunday, November 5, 2000

An afternoon of "Reflection and Hope" is planned for Sunday, November 5, at Atonement Lutheran Church from 2:00 p.m. to 3:30 p.m. This will be a time to quiet ourselves in the midst of the constant demands, insecurities, fears and frustrations, in our lives and turn our thoughts to a deeper meaning, new hope and a fuller appreciation for the gifts and wonders that surround us. If you have a picture that holds special memories for you -- family, babies, wedding (yours or a family member's) happy times, good memories of any sort that you would like to contribute for a special part of

the program please send them to Delores Meeker at 6440 M.V. High Rd. Plain City, OH 43064. Any pictures sent will be returned to you unharmed. Please also remember your loved ones who have died. As the holiday season approaches, this will be a special time to remember them, and "pictures are worth a thousand words"!

Refreshments will be served after the program. Please plan to join us for this special afternoon and bring a friend if you wish. RSVP will be helpful - 614-292-9960. Thanks!

Teen Support Group: Sunday, November 5, 4:30 - 5:30 P.M.

I will be offering the opportunity for a support group for teens from our HD families. Often our young people are the "forgotten ones". We would like to provide an open, caring setting for them to voice their concerns and questions, talk with others their own age who are experiencing similar family situations, and find support. Age range can be from 10 to 18 years old. This initial meeting will be a trial to

establish interest, best time and day of the week, etc. Please call the hotline if you have any questions. This meeting will follow the above "Reflection and Hope" program on the same day (above). You are encouraged to come for both events, however, the teen group will be restricted to teens only -- parents can have a cup of coffee and "chat".

Barb Heiman, LISW

In Search Of The Family Tree

Randall Martin, a member of the Dayton support group, is searching for family information. Randy indicates his great-great grandfather; **Elmer Martin** married **Elizabeth Roberts**, daughter of **Irenus B. Roberts** and **Martha (Dugan)**.

The family branches including the **Johnson**, **West**, and **Atkeson**. (Muskingum, Zanesville, Dresden areas). If you can help Randy trace his family tree, you can call him at 937-969-8226 or e-mail him at Randall_Martin@reyrey.com

Kroger Cares



The Kroger Cares program has been a big hit for our Central Ohio Chapter. **Kroger** is donating 5% of all dollars spent using HDSA certificates to our organization! There is no extra charge for purchasing these certificates and they are equivalent to cash. These

certificates are becoming a regular part of a number of families monthly shopping. We currently have earned a \$1,750 profit and to date we have had a total of 33 families purchase gift certificates and as each month passes the number grows. To purchase your Kroger Cares Gift Certificates, please send your check or money order to: Sheri Nash-

Hoop-A-Thon Raises Over \$25,000

Clark Kellogg's participation at the 2000 Hoop-a-thon made the event another huge success! Thanks to all who donated to the financial success, thanks to all who attended and shared in the fellowship, thanks to all who worked so hard on the event. Special thanks to Randy Rhinehart, from radio station 920 AM for his work on the PA system. Randy adds a special touch to the event that only Randy can do with his golden voice and his gift of g-- , make that communications.

Clark Kellogg demonstrated he is a special person. Not only for his shooting ability but for his caring attitude, giving of this valuable time, making a person donation for HD research, and his inspirational personal message of faith and our roles as servants to each other. Clark Kellogg is an excellent roll model for all; youngsters, adults, and oldsters.

Kwadjo Steele and Devon Smith, from the Ohio State University basketball team came along with Clark. Our thanks to these fine young men for their participation and support to our cause. It was an exciting

day to see the Scarlet & Gray and hear the Buckeye fight songs and see these exceptional athletes in action.

The total funds received have passed the \$25,000 mark for the second year in a row. Coach Jim O'Brien sent his personal congratulations to the chapter for another successful event. The leading fund-raiser was Chapter President Marty Vaughan. Marty raised over \$10,000!!!

Winners in the various brackets and baskets made were: Up to age 12 Cristi Vaughan (120), 13-18 C. J. Gatto (171), 19-35, William Hanson (158), 36-50 Marty Vaughan (132), 50 and beyond Norm Baldwin (116). The team from Cincinnati "Cash Money All Stars" captained by Jeff Meyer edged out the Grandview Bobcats, captained by Mary Vaughan (533) to (525).

Clark Kellogg posted a record performance. Clark made an incredible 183 out of 202 for a 91% average. For you true sports fans, that is one basket every 3 seconds for the 10-minute period!

See you next year!



Books by Carmen Leal Polk and her CD are available for \$15.00 at our support meetings (held on the second Thursday of every month). The books can also be purchased from Delores Meeker. You can write or call Delores at: 6440 N.V. High Road, Plain City, Ohio 43064-9512.
(614) 879-8165

Amaryllis Sales by Delores Meeker



The Motto on the Amaryllis Box is "Growing a Brighter Future." We aren't just selling flowers; we are "buying research hours to find a cure!"

If you can sell a case of 16 or 27 amaryllis kits, I can have them shipped directly to you. If you need fewer kits, call me at (614) 879-8165 and we will arrange delivery or you can pick them up at the December support meeting. If you live a

distance from Columbus and can't participate in our other fundraisers, this gives you an ideal way to support our group. The amaryllis kits are nicely packaged and will make a great gift for teachers, clergy and club gift exchanges. They are especially nice for the homebound, as they grow quickly and bloom freely. It would be difficult to find a \$10.00 gift that would be more appreciated! Please order early and **SELL! SELL! SELL!**

AMARYLISS BULBS

The Huntington's Disease Society of America, Central Ohio Chapter is conducting its annual amaryllis bulb sale. From the \$10 sale price, the chapter receives \$5. Proceeds are used for care of HD patients and families, and for research for the cure.

These bulbs are wonderful gifts. Adults love the beauty of the flower; children are fascinated at their growth.

Please help! Take orders and deliver, or buy them by the box and sell them. Choice of Thanksgiving or Christmas delivery!

<u>NAME</u>	<u>ADDRESS</u>	<u>PHONE</u>	<u>QUANTITY</u>
_____	_____	_____	_____
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Boxes of 16 or 27 plants will be shipped direct to your home or place of business (variety of colors).

**Place Orders: Dolores Meeker – 614-879-8165
6440 M. V. High Road, Plain City, Ohio 43064**

**Checks To: HDSA, Central Ohio Chapter
Dave Fisher, Treasurer
4835 Avery Road, Amlin, Ohio 43002**

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 info, 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 info please call Cincinnati Chapter S.W. Mary Beth Bialic at 513-741-4372.

Cincinnati: caregiver group meets every third Saturday at 11 a.m. in the Drake Hospital. For patient and At-Risk group call Mary Beth Bialic at above number

Toledo Support Group

The HDSA Central Ohio Chapter has an active support group that meets on a monthly basis in Toledo, Ohio. Anyone with an interest in Huntington's Disease: those affected, caregivers, individuals at-risk, health professionals and caring friends, are all welcome to attend. The formats of the meetings are most often an open-forum type discussion. Occasionally there will be a speaker or a specific topic to discuss. Dr. Lawrence Elmer of the Movement Disorder Clinic at the Medical College of Ohio, as our medical advisor, periodically speaks to the group. There is a great deal of Huntington's information available also such as, brochures, articles, informational videos and resources for help and additional information. The support group meets the

third Sunday of the month from 2:00 to 4:00 p.m. in the fellowship hall at:

Our Saviour Lutheran Church
2820 W. Alexis Road
Toledo, OH 43613

The church is located between Douglas Rd and Secor Rd, directly across the street from Whitmer High School. From northbound I-75, take the Alexis Rd exit and head west. I-475, take the Douglas Rd. exit and head north to Alexis and turn left. From US 23, use the Sylvania exit and head east on Alexis Rd.

For more information, contact Alma Mueller at: 419-893-017

Huntington's Disease 19th Annual Walk-A-Thon Saturday, October 7, 2000 1:00 to 5:00 p.m.

Walk-A-Thon 2000 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.



Don't forget that all of the walkers get a **free tee shirt!**

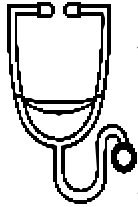
Here's what to do:

- 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. You may also get flat donations if the person prefers.

- After the event, collect all of the pledges.
- Send checks to: Dave Fisher, HDSA Treasurer, 4835 Avery Road, Amlin, Ohio 43002

HDSA Renews Dr. Hoyt's Fellowship Grant



Dr. Kari R. Hoyt, Ph.D. has been awarded a \$25,000 Research Fellowship grant from the Huntington's Disease Society of America. HDSA awarded Dr. Hoyt her initial grant in 1999 and renewed her grant for another year in June at its meeting in Orlando. Dr. Hoyt is studying

the effects of HD in the brains of mice with genetically designed HD, comparing the results to mice without the mutated HD gene. Dr. Hoyt conducts her research at The Ohio State University. Kari is also a board member for the Central Ohio Chapter. Congratulations Kari, on your grant award and for your outstanding work!

Donations & Memberships:

(As of August 10, 2000)

Susan J. Pfeiffer, Chicago, IL
Joseph & Clara Dorozowski, Bethlehem, PA
Christine L. Taylor, Cols, OH
Eloise Kunnen, Fremont, MI
Susan K. Hochgraber, Midlothian, IL
Carol L. Young, Amarillo, TX
M/M John B. Poll, Fremont, MI
John C. Eshoo, Chicago, IL
L. Steven Brooks, Mt. Sterling, OH
Ken & Joyce Frens, Fremont, MI
Dr. Sandra Kostyk, Cols, OH
M/M William D. Kunnen, Fremont, MI
Gary & Barb Heiman, West Jefferson, OH
Pat Meeker, Cols, OH
Robert Postma, Newaygo, MI
M/M William Hughes, Lincolnshire, IL
Julie A. Olson, St. Cloud, MN
Roselia D. Verhoff, Ottawa, OH
Robin L. Black, Marysville, OH
M/M Dennis Shay, Marysville, OH
Joan Hogle, Cols, OH
Mrs. Lillie H. Roy, Cols, OH
M/M Ron Gingrich, Ottawa, OH
Mrs. Maxine Vaughan, Cols, OH
Harvey A. MacIvor, Middleburg Heights, OH
Mary L. Baldwin, Cols, OH
M/M Don Harris, Westerville, OH
Timothy Zinnecker, Houston, TX
M/M Harold J. Workman, Sr., Muskegon, MI
M/M Gary Nash, Worthington, OH
Wilmer Meyer, Napoleon, OH

John & Carla Mathews, Cols, OH
Ron Benedick, Upper Arlington, OH
Dick & Jeanette Lee, Cols, OH
Gail E. Becker, Cols, OH
M/M William B. Peterson, Mt. Vernon, OH
Donna Lewis, Lakeview, OH
Vernon & Karla Oard, Grand Rapids, MI
Betty N. Geddis, Sunbury, OH
Evelyn Shay, Cols OH
Tony & Brenda Borck, Fredericktown, OH
Norm & Bonnie Baldwin, Grove City, OH
Emerson Lumber Co./Greg Grissett, Cols, OH
Lee & Karen Haberer, Brentwood, TN
Jill & Bob Echenrode, Westerville, OH
Carolyn Taylor, Cols, OH
Greg & Jenny Nijak, Springboro, OH
Richard & Barbara Lowry, Centerburg, OH
Steve & Patti Kunnen, Comstock Park, MI
Eugene & Ruth Neff, Mt. Sterling, OH
Paul & Jane Morton, Cols, OH
Paul & Susan Callaway, Wheaton, IL
Norm & Barb Emmets & Family, Mel Dunn, Hilliard, OH
M/M Robert D. Fisher, Crestline, OH
Susie Nabil, Powell, OH
Mary J. Martin, Marysville, OH
Paul & Mary Jane Daggett, Fairfield, OH
Sarah D. Morrison, Gahanna, OH
Dick & Maxine Kidwell, Cols, OH

Memorials

James Williams

Don & Anita Brown, Worthington, OH
Michael & Jackie Linder, Cave Creek, AZ
Marge DeVault, Pataskala, OH
Dee Williams, Columbus, OH

Grace F. Ferlito

Campbell, Hornbeck, Chilcoate & Veatch, Columbus, OH
M/M Michael Stewart, Marysville, OH
Robert N Mosure, Columbus, OH
Dorothy A. Vaughan, Dublin, OH
M/M Roger A. Vaughan, Dublin, OH
M/M Timothy W. Schenz, Powell, OH
Maxine Vaughan, Columbus, OH
Ann & Charles Stearns, Hilliard, OH
Pe ggy Hughes, West Worthington, OH
M/M Larry Easton, Worthington, OH
Northwest Title, Columbus, OH
M/M Greg Marquis, Dublin, OH
M/M William Harding, New Philadelphia, OH
M/M Stanley P. Fawcett, Columbus, OH
Linda Larson, Dublin, OH
Betty & Vicki Johnson, Columbus, OH
Richard Quattropane Family & Rose Tarantino, Alpine, CA
Pastoral Care Dept., Riverside Hospital, Columbus, OH

Cheryl Kennedy

Norm & Bonnie Baldwin, Grove City, OH
Dolores Meeker, Plain City, OH
Ed, Susie, & Kelsey Kennedy
M/M Donald Harris, Westerville, OH
M/M Dave Fisher, Amlin, OH
Dee Williams, Columbus, OH
Dick & Maxine Kidwell, Columbus, OH
Marge DeVault, Pataskala, OH
Barbara Graham, Columbus, OH
Paula Kennedy, Josh & Kaylee Kennedy, Shirley Stuart, Reynoldsburg, OH
Jean Scott, Tim & Julie Scott, Linda Day, Ron & Donna Scott, Sunbury, OH
Phillip & Cori Walker, Granville, OH

Anna Blizzard

Marge Devault, Pataskala, OH

Clifford Scott

Dolores Meeker, Plain City, OH

FRIENDS: Please help in the fight against Huntington's Disease. The battle goes on by the research people, individuals with HD, people who are "at risk," caregivers, relatives, and friends. Join in May during our annual membership drive. Join in supporting our fundraisers. Join in giving your time. Join in attending chapter meetings. **Join now with a special donation.** **Your donation is tax deductible.**

It is kind of like church; the need does not go away with one donation. **Give regularly!!**

Please tear out and return.

Name _____

Address _____

I would like to help by volunteering _____

Phone number at which I can be reached _____

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

Please indicate if this is your first gift to HD yes _____ no _____

**PLEASE RETURN THIS FORM WITH YOUR CONTRIBUTION TO:
HUNTINGTON'S DISEASE SOCIETY OF AMERICA, INC.
CENTRAL OHIO CHAPTER
DAVE FISHER, 4835 AVERY ROAD, AMLIN, OH 43002**

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

Address Service Requested