

# Huntington's Disease Society of America Central Ohio Chapter Winter 2000

## *Our Voice*

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### **A Letter from the President, Marty Vaughan**



This past year has been the most important ever in our collective fight against Huntington's Disease. Nationally more researchers are working on a cure, with better financing than ever before. Drug trials are in progress and several compounds show promise in animal and human trials. Yet still a cure and a significant treatment remains allusive. Maintaining patience through this process of discovering a cure for HD is so difficult. But we must continue to do our part and not grow weary as we come closer to our goal.

Our Central Ohio Chapter of HDSA for the second straight year raised approximately \$60,000! This is an accomplishment considering two major grants obtained in Columbus that are not included in the total because they went directly to National. It is encouraging seeing so many new people involved in our chapter's support group's and fund raising efforts. All of our main events: the Hoop-a-thon, Walk-a-thon, Amaryllis Sale, FBI golf outing, membership mailing and the Kroger program have equaled or exceeded previous efforts! Thanks to all who gave of their time and resources.

On a National level, consolidated revenue has quickly rolled past last year's mark of \$5 million and are now nearing \$8 million! A substantial share of this \$8 million has been given, or committed to research.

Perhaps the two most exciting items for our chapter are the new Center of Excellence at OSU, and Columbus's selection as the site of the 2002 National Convention for HDSA!

The New Center of Excellence at OSU, headed by Dr. Sandra Kostyk, has taken OSU's HD clinic to a higher level of care. The Center of Excellence is made possible through a \$50,000 annual grant from the National office of HDSA. An additional financial boost came from the Columbus Medical Association Foundation. CMAF provided a \$30,000 grant for Center seed money, spread over 3 years. More comprehensive care, including services from different medical specialist, improved outreach programs and many other services are now accessible through the new center.

Columbus has been officially chosen as the site of the 2002 HDSA National Convention. Twelve hundred attendees are anticipated to attend this inspirational conference. Our chapter will be asked to assist the National office in organizing the event. Columbus has been chosen in part due to the years of dedicated work of chapter volunteers since our inception. Also I think Norm Baldwin and Pat Meeker's persistence helped National's selection committee realize that Columbus was a great convention site!

All of our local chapter board members and chapter members, past and present should be proud of the progress we are making. Thanks to all!

**Our Voice**  
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[www.hdsacentralohio.org](http://www.hdsacentralohio.org)

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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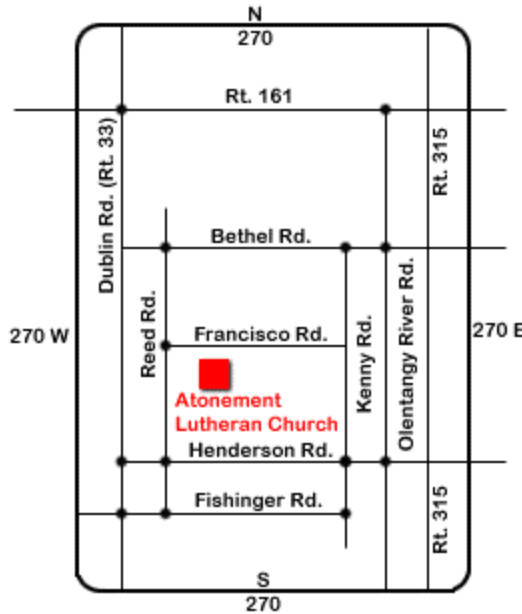
# CENTRAL OHIO CHAPTER MEETING TIME AND PLACE

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!



## 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 box 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. These flowers will make a great gift for teachers, gift exchanges, and are especially nice for the homebound. It would be difficult to find a \$10.00 gift that would be more appreciated!

## Annual Meeting

Seventy-nine people attended and enjoyed the Central Ohio Chapter's Annual Meeting at the Der Dutchman Restaurant in Plain City, Ohio, on October 21<sup>st</sup>. The meeting was a celebration of the accomplishments of the past year, research reports of the most recent advances in the quest of the cure, and preparation for challenges in the coming year.

Chapter President, **Marty Vaughan**, noted the chapter increased its total income from \$58,033 in fiscal 1998-99 to \$68,468 in fiscal 1999-2000. An additional \$30,000 grant was received from the Columbus Medical Association for the new Center of Excellence at Ohio State University. The Central Ohio Chapter was chosen national Chapter of the Year by HDSA and the national convention will be held in Columbus in 2002.

**Barb Heiman**, Chapter Social Worker, reported on another successful year in outreach to HD patients and families. Reporting that she handled over 450 contacts last year, and her activity has increased as she is now on the interdisciplinary team at the Center of Excellence. She and **Ginny Harris** completed seven in-service training programs in central Ohio nursing homes and completed a HD care program presented by **Jim Pollard** and attended by 70 people.

**Dr. Sandra Kostyk**, Director of the Center of Excellence at OSU, reported the center is off to an excellent start. Progress has been made in organizing the various disciplines in providing medical services to HD patients. Requests for

medical care and information about HD have increased dramatically since the Center has been announced and opened to the public.

**Dr. Larry Elmer**, Toledo Medical College of Ohio, discussed the most recent research information. The research continues to advance and Dr. Elmer expressed confidence that a cure or treatment will be found for HD and that HD will most likely be the first of the major neurological diseases cured. The target is clear; the researchers must find answers to hitting the "bull's eye". Throughout his positive research report he stressed the HD families must use caution in taking drugs and supplements until they are tested in human trails.



Two very special people, **Elsie Znamenacek** and **Chip Hixson**, were recognized for their fight against HD and their contributions to the Central Ohio Chapter. Please see the Special Recognition article contained elsewhere in this newsletter.

Retiring Board Members recognized were **Dee Williams**, **Dr. Donald Higgins**, and **Dr. Larry Elmer**. **Maxine Kidwell** and **Evelyn Shay** were recognized as the chapter's only director emeritus. New board members elected were **Dr. Sandra Kostyk** and **Theresa Hanson**.

Special music was provided by **Barbara Wills**, the opening prayer was given by **Dee Williams** and the closing prayer by **Laurie Pecuch**.

## Huntington's Disease 19<sup>th</sup> Annual Walk-A-Thon



The weather was great and the walkers spirited for the Central Ohio Walk-A-Thon at Antrim Park on October 7<sup>th</sup>. The walkers enjoyed a potluck dinner prepared by some of the best cooks in Central Ohio!

The Walk-A-Thon continues to be one of our best social events and an important fundraiser. **Dave Fisher** reports he had received \$4268.50 from the walkers and some pledges still outstanding. This was another great effort! Thanks to everyone who participated and contributed!

## Kroger Cares

Don't forget to purchase your Kroger certificates. **Kroger** is donating 5% of 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. To purchase your Kroger

Cares Gift Certificates, please send your check or money order to: **Sheri Nash-Pittman**, 1777 Willoway Circle North, Columbus, OH 43220.

Hint: a self-addressed, stamped envelope helps for a quick return!



## From Our Social Worker: Barb Heiman

**TEEN SUPPORT GROUP:** On November 5, we had our first attempt at establishing a support group for teens living with family or friends affected by H.D. It was a good beginning with seven young people participating. I hope to schedule another meeting after the holidays. I urge you to call if you have anyone between the ages of 10 and 18 in your family who would be interested in participating. Future meetings will depend on the response: the location will be determined by those participating to make it as convenient as possible for them. Currently all those who attended are from West of Columbus.

**MT. VERNON SUPPORT GROUP:** I am happy to report that Amy Lewis LSW in Mt. Vernon has recovered sufficiently from her accident to continue with the support group at Country Court Nursing Home. Call 740-397-4125 for time and date.

**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 HD 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.

**HEALTH FAIRS AND VOLUNTEER OPPORTUNITIES:** We have recently been invited to participate in three Health Fairs

around the Columbus area. This is a good opportunity to educate and inform the public about H.D. We need volunteers to man the booth, hand out literature and answer questions at these events. If you can give a few hours periodically, please call the Helpline at 614-292-9960. A big "THANKS" to the following people who have given their time at recent Heal Fairs: Norm Baldwin, Maxine & Dick Kidwell, Dick & Jeanette Lee, Georgia Bruce, Ginny Harris, Dolores Meeker, and the Pilot Club members.

### PROJECTED SUPPORT GROUP SCHEDULE FOR 2001:

January: Support/Discussion.  
February: Marsha Van Riper R.N.  
(Genetic Studies).  
March: Support/Discussion.  
April: Dr. Sandra Kostyk or  
Clinic Coordinator.  
May: Support/Discussion  
June: Speaker (to be announced).  
July: Convention Report.  
August: Support/Discussion.  
September: Video/Discussion  
October: Support/Discussion.  
November: To Be Announced.  
December: Holiday card signing and gift-wrapping for Patients.

I wish you all a wonderful, joy-filled Holiday Season. Thank you for all you do in the name of the H.D. community. With your continued help, prayers, and support we will celebrate together the year of the cure!

## 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 S.W. Mary Beth Bialic at 513-741-4372.

**Cincinnati:** caregiver group meets every third Saturday at 11:00 a.m. in the Drake Hospital. For patient and At-Risk group call Mary Beth Bialic at the number listed above.



**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

## A Local Radio Station is Helping Fight HD

CD101.1 FM hosted one of the most exciting fundraisers yet! On November 4<sup>th</sup> CD 101 gave the proceeds of the Ohio State-Michigan State tailgater to the Central Ohio Chapter. A group of HD supporters put on their

Ohio State sweatshirts and helped battle Michigan State by selling drinks! Our group had a wonderful time! If you would like to volunteer next year please call Theresa Hanson 614-492-0311.

## Donations & Memberships: (As of August 23, 2000)

Wendy Gerber, Fremont, MI  
Janet E. Fulk, Bellevue, OH  
Mrs. Marie Shawber, Leipsic, OH  
Sonnenberg Trucking Inc., Hamler, OH  
Ms. Joan K. Hurst, Upper Arlington, OH  
M/M Geoff Hornbeck, Grove City, OH  
Don & Patti Wooddell, Westerville, OH  
Marty Vaughan, Columbus, OH  
Natalie Richardson, Wooster, OH  
Mrs. Louise Carmichael, Powell, OH  
M/M Arnold Jack, Columbus, OH  
Martha M. Baldwin, Defiance, OH  
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Janice Overzet, Fremont, MI  
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William Bates, Marion, OH  
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M/M Robert Meese, Mansfield, OH  
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Barry & Marilyn Buzogany, Gaithersburg, MD  
Janette Sheets, Columbus, OH  
William T. Neal, Cape Coral, FL  
Bern Karnemaat, Fremont, MI

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*M/M Brad Taylor, Paulding, OH*  
*James & Gail Myers, Paulding, OH*  
*Marion & Doris Bidlack, Grover Hill, OH*  
*Mark & Helen Bidlack*  
*Dean & Betty Bidlack & Family*  
*Todd & Karen Bidlack & Family*  
*Roger & Mike Miller, Hicksville, OH*  
*Mr. & Ms. Charles F. Hart, Bellevue, OH*  
*Mr. & Mrs. Kenneth Anspach, Van Wert, OH*  
*Kent & Karen Badders, Fort Wayne, IN*

*Carol Shattuck, Fort Wayne, IN*  
*Rudy & Carolyn Straley*  
*Mr. & Mrs. Jay Covil*  
*Mr. & Mrs. Ronald Bendele, Sr.*  
*Mr. & Mrs. Harold Philipot*  
*Bob & Ruth Reinhart*  
*Mr. & Mrs. Kevin Philipot*  
*Mr. & Mrs. Jerry Bortel*  
*Mr. & Mrs. James Bissell*  
*Jane A. Hart, Fort Wayne, IN*

### **Frances Hart Bauer & William "Bud" Hart**

*Mrs. Leah Ann Hart, Paulding, OH*

### **Gene Daugherty of Mansfield, OH**

*M/M Michael Lefever, Ashland, OH*  
*M/M Leslie E. Pierce, Lexington, OH*  
*M/M Chris Nedelkos, Lexington, OH*  
*M/M Albert J. Sigg, Mansfield, OH*  
*M/M William S. Shay, Lambertville, MI*  
*Dorothy Elsasser, Mansfield, OH*  
*Michele Foster, Mansfield, OH*  
*Charlotte A. Daugherty, Mansfield, OH*  
*M/M Milton L. Jones, Mansfield, OH*  
*M/M James J. Carcione, Mansfield, OH*  
*Feliz and Rosina Pascual, Port Charlotte, FL*

*Karen L. Jaworski, Louisville, KY*  
*Debra Houserman, Mansfield, OH*  
*Patricia Goode, Mansfield, OH*  
*Marcia K. Bond, Mansfield, OH*  
*Betty A. Leppert, Mansfield, OH*  
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*Mildred J. Wheeler, Mansfield, OH*  
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*M/M Bernard M. Hallabrin, Lexington, OH*

### **David Hampp**

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*M/M Ralph A. Jones, West Jefferson, OH*  
*Carleton Manor, Chanda D. Calentine, Washington Court House, OH*

### **Wilda Sammet**

*Richard Young & Shirley Feasel, Fostoria, OH*  
*Greg & Beth Collins & Family, Upper Sandusky, OH*  
*David & Jenny McCleary, Upper Sandusky, OH*  
*Dr. & Mrs. D.P. Smith, Sycamore, OH*  
*Dan & Sue Shepherd & Family, Upper Sandusky, OH*

### **Patric Peter Berger**

*Dolores P. 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," 0 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!!**

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**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**