



Huntington's Disease Society of America Central Ohio Chapter Spring 2001



Our Voice

A Letter from the President, Marty Vaughan



It is hard to believe we are now in the year 2001. Time moves so quickly. The past year (2000) was a strange one. Weren't all of our computer systems headed for Y2K self-destruction? Of course, nothing was more fitting to wrap up the year 2000 than the strangest presidential election of all time!

In the HD World, it was in fact a good year. The national and local chapters are growing and research is expanding. Sometimes we all wonder if we are making headway? Well, consider these facts:

- One hundred thirty years ago George Huntington discovered and observed HD.
- Eight years ago the gene was discovered allowing for effective diagnosis.

- Four years ago international researchers formed the "Coalition for the Cure."
- In the last two years treatments have started showing potential.

In the computer world, computer speed doubles every few years. It appears in the HD research world, some similar laws apply. I encourage all of you to increase your involvement in our chapter. Fund-raisers like the Hoop-a-thon, the Center of Excellence Dinner, and the Walk-a-thon, can all use more participation. Also, for those who have not been to support group meetings, please give it a try. We have fun and engaging meetings.

Have a wonderful 2001!

2001 National Convention, June 29-July 1



The 2001 National Convention will be held at the Town & Country Resort and Convention Center in **San Diego, California**. The Town and Country Resort is located on 32 beautifully landscaped acres in Mission Valley. To receive Early Bird rates you must register by April 30th.

Several members of the Central Ohio Chapter are planning to attend the convention. **Sheri Nash** (Central Ohio

National Convention Chairperson), **Pat Meeker** and **Ginny Harris** have starting the planning for the **2002 Convention to be held in Columbus** and will be leading our contingent at the National Convention in San Diego.

For more information on the 2001 Convention, you may contact the HDSA National Office at 212-239-3430 or visit the National Website at www.hdsa.org.

2001 Cure HD BMW Sweepstakes

Grand Prize: A Model Year 2001 BMW Z3 Roadster or \$25,000 CASH

Second Prize: \$5,000 CASH

Third Prize: \$2,500 CASH

Fourth Prize: \$1,000 CASH (2 winners drawn)

Please make all checks payable to: HDSA for \$100 per entry.

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 San Diego, California on June 30th. Entries must be received at the National Office by June 22nd – and tickets are limited to 2500.

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 Norm Baldwin, 5826 Ravine Creek Drive, Grove City, Ohio 43123, or you may return the formal entry form directly to the HDSA national office. Visit HDSA Website at: www.hdsa.org



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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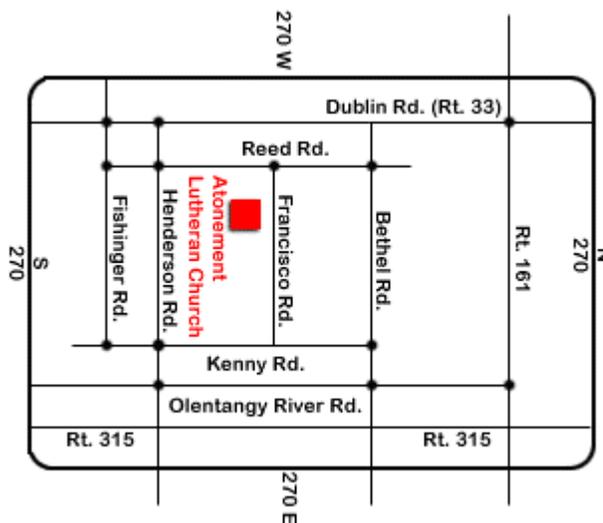
CENTRAL OHIO CHAPTER MEETING TIME AND PLACE

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

The meetings begin at **7:00 P.M.** This early time will allow those attending to get home at an earlier hour and still avoid the rush hour traffic in coming to the meeting. The meeting will continue to be on the second Thursday of each month at Atonement Lutheran Church. Please note your calendars.

The **April Support group meeting** will be held on April 5, 2001 instead of April 12th due to Holy Thursday, a Christian holy day.

Visit our website at: www.hdsacentralohio.org

Taking An Active Roll in Family Functions

People with Huntington's Disease have a genetic disorder, which affects certain motor functions (just as a common cold can cause uncontrollable coughing or sneezing). Otherwise, they are no different from anyone else. They love their families and friends, have hobbies or favorite pastimes, and enjoy the feeling of accomplishment, which comes from doing a job well.

While the onset of Huntington's Disease may prompt some changes in lifestyle, it in no way diminishes the individual's desire to need to be a full, active participant in the day-to-day working of the family.

In fact, the continued increase of participation in household chores and family activities may reinforce the sense of self-worth and maintain a positive attitude.

Taking part in meal preparation, going for walks or drives, group discussion of current events, gardening and caring for pets are activities which are well-suited to

participation by two or more family members. They can offer countless hours of pleasure, physical recreation, and companionship.

Such activities are continuing and self-developing in the sense that there is always something new to do: a section of garden to be weeded or crop of vegetables to be harvested; a pet's coat to be groomed; a new growth of flowers to observe on a walk; a new recipe to try; a new political event to discuss.

You can even combine activities: talk about current events while sharing household chores; grow herbs or vegetables and use them in your recipes; take the dog along on your daily walk.

These functions may even have been the family or household norm before the onset of HD. There is no reason why they should change.

(Reprinted from the HDSA New Jersey Chapter "A Family Handbook").



ELSIE ZNAMENACEK & HENRY "CHIP" HIXSON

With great pride and pleasure the Huntington's Disease Society of America, Central Ohio Chapter recognized two of its members for their personal courage and their dedication to HDSA and the Central Ohio Chapter.

Elsie Znamenacek is an active and inspirational member of the Central Ohio Chapter. She and her husband Larry are blessed with five children **Karen, Julie, Jani, Theresa, and Michael**. They have regularly attended our support group meetings and other chapter activities over the past several years.

Chip Hixson is also an active inspirational member who enjoys keeping our meetings lively. He and his wife **Marilyn** are blessed with two children Jane and Hal. They also regularly attend support group meetings along with Marilyn's parents **Bob and Joanne Meese** from Mansfield, Ohio and Marilyn's sister **Jane Meese** and brother **David Meese**.

These two families produce our chapter newsletter. Julie and Theresa are the

editors and Jane Meese handles the labels and mailing. Many other family members and friends participate in and support our chapter fund-raisers and are major contributors to the recent success of the chapter.

Elsie and Chip are both wonderful people. They inspire us at our support group meetings with their courage, wit, and humor. They are a pleasure to be around as they offer encouragement to their friends and family.

The Znamenacek family and the Hixson family bring a special attribute to our Chapter. The emphasis is on family. They attend Chapter functions as a family and they attend our support group meetings as a family. It is rewarding to all in attendance at our support meeting to see and share in the love that is so evident between Elsie and her family and Chip and his family. The tie that binds is a beautiful expression to behold. Thank you Elsie and Chip for being such special people and for sharing your wonderful families with us!

Historical Facts You Should Know – Written by Ginny Harris

Dr. George Huntington first presented his paper describing Hereditary Chorea on February 15, 1872, before the Meigs and Mason Academy of Medicine at Middleport, Ohio. His paper was the most accurate and eloquent description of Hereditary Chorea put forth until that time. This Chorea then became known as Huntington's Disease.

In March 1972, the first International Symposium on Huntington's Disease took place in Columbus, Ohio. It was known as the Centennial Symposium, which celebrated the centennial of the classical description of Hereditary Chorea by Dr. George Huntington. It was held in the Center for Tomorrow (now known as The Fawcett Center), College of Medicine, at The Ohio State University. The proceedings of the Symposium were published as

Volume 1, Advances In Neurology edited by Dr. George Paulson, A. Barbeau, and T.N. Chase.

The following is a direct quote from the book Mapping Fate by Alice Wexler:

“This was the largest gathering ever devoted to the disease, with 146 researchers from 14 countries presenting some 85 papers. Among them was a Venezuelan psychiatrist, Dr. Ramon Avila-Giron who showed a startling 20 minute black and white film of several communities around Lake Maracaibo that were ravaged by the disease - a film that would have powerful repercussions in years to come.”

By the time the annual National Convention is held in Columbus, Ohio, 2002, it will have been thirty years since the Centennial Symposium and 130 years since Dr. Huntington's paper was presented.

HD Care Meeting, May 20th

The Huntington's Disease Society of America, **Northeast Ohio Chapter** has invited the members of the Central Ohio Chapter to participate in its semi-annual forum for HD families, professionals, and all others interested in the care and cure of HD. HDSA members from the Ohio Valley, Toledo, and the Pittsburgh area are also expected at this meeting.

Barb Heiman, Social Worker for our Central Ohio Chapter, will speak on the Center of Excellence at The Ohio State University. Cleveland area physicians and nurses will report on local efforts as they relate to other chapters. The NE Ohio Chapter Board has not yet finalized the entire program, but states that the focus will be on HD families and the team approach for HD care. There will be panel discussions with ample opportunities for questions and answers.

- **When:** Sunday, May 20, 2001. Registration Noon – 1:00 p.m. Program 1:00-4:30 p.m., followed by an informal reception. Refreshments will be served.
- **Where:** The Health Museum of Cleveland, 8911 Euclid Avenue, Cleveland, Ohio. Telephone (216) 231-5010.
- **Cost:** None. No admission fee. Free and easy parking.

The Central Ohio Chapter Board of Trustees encourages attendance at this meeting. The information at the meeting promises to be informative and helpful for all dealing with HD. This meeting will also provide the opportunity to meet other people and doctors dealing with HD.

Joint transportation may be arranged for those wishing to travel together. Please contact **Norm Baldwin at 614-871-4301 if you plan to attend.**

From Our Social Worker: Barb Heiman, LISW

ATTENTION! ATTENTION! The April Support group meeting will be held on April 5, 2001 instead of April 12th due to the 12th falling on Holy Thursday, a Christian holy day. Please mark your calendars. Also, remember we have moved the starting time of the support meetings and Board meetings to 7:00 p.m. If this causes you to be a little late due to work and travel schedules please don't worry about it – arrive when you can.

TEEN SUPPORT GROUP: The next Teen Support Group is scheduled for Sunday March 4th at 3:00 p.m. at Atonement Lutheran Church. The age range is from 10 – 18 years old. Any teen living in a H.D. family system is encouraged to attend. There is no pressure to participate if you are not comfortable doing so, just listening to others in the group can be helpful and supportive. If you feel more at ease, please feel free to bring a friend with you. Adults transporting the teens are welcome to have refreshments and conversation during the teen group or use the time to do errands. For more information, please call the help line at 614-292-9960 and I will get back with you.

CLINIC: The H.D. patient Clinic day has been changed from Monday to Thursday beginning February 15th. The location is also changed from The Clinic building to McCampbell Hall (right across the street) 3rd floor. To schedule an appointment with Dr. Kostyk call 614-293-4974.

“I Have HD”: **Wallet Cards.** HD wallet cards are 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. You may also contact Barb Heiman with the Central Ohio Chapter.



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

EDUCATIONAL SEMINAR: Our Educational and Service Committee will not be sponsoring an Educational Seminar this spring. Time, effort, and energy will be directed toward the Celebration of Hope Dinner scheduled for October 4th and Hosting of the National Convention 2002 which will be held in Columbus Ohio. **HOWEVER**, we have been talking with members of the Cleveland Chapter who plan to sponsor an educational seminar on May 20, 2001. We have agreed to support and take part in this event and we encourage our Central Ohio members to attend. Details for this event are on page 5, but feel free to contact me on the Help line if you need any additional information.

HAVE YOU COMPLETED AN ADVANCE DIRECTIVE? Everyone, regardless of H.D. status, should have an advance directive. Your advance directive dictates specifically what measures (mechanical ventilation, feeding tube, etc.) should be taken in the event that you become incapacitated. Simple forms are available through any health care agency or hospital or our Chapter. The assurance that your wishes will be carried out according to your directive can give you and your loved ones peace of mind. Completing these forms does not have to cost you anything. Please call me if you have any questions or need a form, 614-292-9960.

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 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: 419-893-01

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. 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.

HOOPS – 2001 BIGGER AND BETTER THAN EVER!

April 7, 2001 promises to be a big day for HDSA here in Central Ohio! The 16th Annual Hoop-a-thon will be held at Resurrection Lutheran Church, 3500 Main Street, Hilliard, Ohio. Check the flyer in this newsletter for details.

Randy Rhinehart has done an excellent service for HD in lining up a host of celebrity shooters. Check the achievements of the celebrity shooters; bring your cameras and items for autographs!

If you are wondering what you can do to help, here is the list. Do one or more of the following and make this the best Hoops yet.

- **Be a shooter.** Solicit pledges from friends, relatives and places of business .
- Make a **generous pledge** to one or more of our celebrity shooters.
- Help the day of the event. Call Norm Baldwin and sign up to **work**.
- **Spend the day** at the Hoops. It promises to be another circus!

We are continuing the team event. This year simply get 4 shooters from your place of

work or your family to form a team. A total of \$400 needs to be raised in order to be eligible for the traveling trophy. Last year Jeff Meyer's team from Cincinnati won the trophy. Can they repeat in 2001 or will a new team name be engraved?

Age group shooters will be awarded trophies for the most shots made. Prizes will be awarded for various levels of funds raised;

the more money raised the better the prize! Jay Burson is donating a Nike warm up suit to the person making the most shots and Nike T-shirts to age group winners. Free HDSA Hoops T-shirt to all shooters!

Food will be available throughout the day, featuring Coney Dogs.

George's Coney Island is donating the profit from all food sales.

We have more community support than any previous HD event. We have several confirmed celebrity shooters and several more invited. Let us show our appreciation and support. Give generously, come, and enjoy this special day!

Need more information, call Norm Baldwin at 614-871-4301.





Memorials

Dale Meyers

*Norm and Bonnie Baldwin, Grove City, OH
Gloria Meyers, family, relatives, & friends, Kalida, OH
Mr. And Mrs. George J. Knippen, Delphos, OH*

Doris Curtis

Norm and Bonnie Baldwin, Grove City, OH

Roger Vaughan, Sr.,

Randee Ross, Scottsdale, AZ

Cheryl Kennedy

Cloyce and Mary Myers, Canal Winchester, OH

Walla Chase

Norm and Bonnie Baldwin, Grove City, OH

Gene Blankenship

*Michael & Betty Obert, Columbus, OH
Lillie Kelly, Columbus, OH*

Bobby Noe

*Don & Ginny Harris, Westerville, OH
Staff of Ohio Depart. Of Nat. Resources;
Div. of Real Estate & Land Management, Cols. OH
Norm & Bonnie Baldwin, Grove City, OH
Mr. And Mrs. Clifford Baker, Columbus, OH
Ohio School Net Commission Employees, Columbus, OH
Jill I. Kasai, Worthington, OH
Mrs. Pat Meeker, Columbus, OH
Debbie McMahon, Columbus, OH
Kathy Waltz, Columbus, OH*

Dr. Clarence Gallagher

Michael & Betty Obert, Columbus, OH

MEMBERSHIP/PUBLIC DONATIONS

*North Franklin County Branch 8200 of Lutheran
Brotherhood*

M/M Richard Kidwell

David & Betty Meyer, Defiance, OH

William & Betty Ball, Powell, OH

Keith B. Moses, Washington, DC

Gloria Meyers, Kalida, OH

Mr. And Mrs. Douglas S. Hossink, Byron Center, MI

WWWCD 101.1 FM, Columbus, OH

Pilot Dogs of Columbus, OH

16TH ANNUAL
HUNTINGTON'S DISEASE SOCIETY OF AMERICA
Hoop - a - Thon

SHOOT FOR THE CURE
April 7, 2001

Resurrection Lutheran Church
3500 Main Street
Hilliard, Ohio

Schedule of Stars

9:30	Stan Zody	Coach Hilliard Darby
9:30	Jim Stimmel	Coach Hilliard Davidson
10:00	Ron Stokes	OSU 82-85 - Radio/TV
10:00	Troy Taylor	OSU 82-85 - Coach Mifflin
10:15	LouSeal	Columbus Clippers Mascot
12:00	Tom Fitzgerald	Coach Columbus Crew
12:15	Crew Cat	Columbus Crew Mascot
1:00	Clark Kellogg	OSU 80-82 - CBS TV
1:30	Louie the LandShark	LandSharks Mascot
2:00	Stinger	Blue Jackets Mascot
2:30	Val Still	Columbus Quest
2:30	Dixie Jeffers	Coach Capital University

SHOOT WITH THE STARS

Autographs - Photographs

Free T-shirts to shooters! - Prizes! - Awards!

Food - Coney Dogs - George's Coney Island

Shooters obtain pledges for free throws made in a 10-minute period
Proceeds benefit the Central Ohio Chapter and research to help find a cure for
Huntington's Disease - **Join the fun** - Shoot for the Cure

OPEN TO THE PUBLIC - SUPPORT HDSA

SHOOTING TIMES MAY BE SCHEDULED

From

9:00 AM to 5:00 PM

Contact Norm Baldwin 614-871-4301

CONFIRMED CELEBRITY SHOOTERS

16th Annual Hoop-a-Thon

Dixie Jeffers is in her 15th year as head women's basketball coach at Capital University. Her teams won the Division 3 National Championship in '94 and '95. She recorder her 400th collegiate win as a coach, Jan. 31, 2001



Clark Kellogg is the CBS analyst for college basketball. He is also the analyst for the Indiana Pacers of the NBA. Played in 86 games with the Buckeyes 1980-1982. Set the HDSA Hoops record of 184 free throws made and raised \$18,400 at last years Hoop-a-Thon. Welcome Clark back!

Ron Stokes is the analyst for Ohio State men's basketball on radio. Also serves as analyst for high school games on Sport TV and works for the Columbus Dispatch. Scored 1,240 points for OSU from 1982-1985.

Troy Taylor is the girls' head coach at Mifflin High School. Scored 1,497 points at OSU from 1982-1985 and 421 career assists. Will go head to head with Ron Stokes at the Hoop-a-thon.

Val Still was a member of the former Columbus Quest and star player at University of Kentucky.

Jim Stimmell is the head coach at Hilliard Davidson varsity boy's basketball team. He and Coach Stan Zody have agreed to a shoot out to open the celebrity shooting at this year Hoops.

Stan Zody is the head coach of the Hilliard Darby varsity boy's basketball team. Stan is donating 12 basketballs to the Hoop-a-thon.

Special appearances by **LouSeal** (Columbus Clippers Mascot), **Crew Cat** (Columbus Crew Mascot), **Stinger** (Columbus Blue Jackets Mascot) and a late entry, **Louie the Landshark** (Columbus Landsharks Mascot)!

Shoot with the Stars at the 2001 HDSA Hoop-a-ton, April 7th.

HUNTINGTON'S DISEASE SOCIETY OF AMERICA

2001

HOOP-A-THON

SHOOT WITH THE STARS – SHOOT FOR THE CURE

PLEDGE FORM

NAME OF SHOOTER _____

NAME OF PLEDGER _____

ADDRESS _____

PHONE NUMBER _____

PLEDGE: PER SHOT MADE \$_____ FLAT AMOUNT
\$_____

THANK YOU FOR SUPPORTING THE HUNTINGTON'S DISEASE SOCIETY OF AMERICA IN ITS EFFORTS IN CARING FOR HUNTINGTON'S PATIENTS AND RESEARCH TO FIND A CURE!

Send to: Norm Baldwin, Hoop Chairman
**Huntington's Disease Society of America, Central
Ohio Chapter**

Ohio State University Hospitals
1581 Dodd Drive, Suite 371
Columbus, Ohio 43210-1296

or

e-mail: normbaldwin@juno.com

or

phone: 614-871-4301

THANK YOU FOR YOUR SUPPORT!

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
THERESA HANSON, 548 STOCKBRIDGE RD., COLUMBUS, OH 43207**

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

Address Service Requested