Central Ohio Chapter

# **Our Voice**

# President's Letter, by Sarah Morrison

There is an old saying that "time flies when you're having fun." In today's fast paced world, I believe that the saying is more succinctly put that "all time flies." How many times have we been planning on doing something but the time got away from us? I keep a list of things to do (my husband calls me the list maker), but it seems that that list never quite gets completed because I run out of time.

As we get into the middle of everyone's schedules summer, seem to get even busier. Kids have various camps to go to, vacations get scheduled, the lawn will not stop growing. Summer is also a busy time for the Central Ohio Chapter of HDSA. We have just wrapped up the 2004 hoop-a-thon and the FBI's John Christie Memorial was recently held at Oakhaven Golf Course. Now, before we can fully recover from these events, the Chapter is already deep into the planning of this year's Celebration of Hope event. I am thrilled to announce that we have three outstanding honorees this year - Bea Wolper, an attorney with the law firm of Chester, Willcox & Saxbe, LLP (with whom I have the honor of working); John S. Christie, President and CFO of Worthington Industries, Inc.; and the Chip Hixson Family, who many of you are familiar with. The Celebration of Hope will be held on September 23, 2004 at the Athletic Club of Columbus the same location as last year. This year, Tina Farley has taken the reins and is acting as the Celebration of Hope Chair. It promises to be another great event.

This takes me back to the issue of time. Sometime during your busy Summer, please make some time for HD. That time could be in the form of visiting a patient with HD. You could tell a friend about the disease and the on-going efforts to find a cure. Solicit a donation from a local business or write your own check. To quote a 1980s band (and to show my age): "Take time to make time, make time to be there."

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Summer 2004



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# Special points of interest:

- New Event Chairs
- Upcoming Fundraisers
- Support Group
   Changes
- Celebration of Hope
- Research Updates
- Advocacy Issues
- Annual Dinner Date

Visit our website: www.hdsacentralohio.org

Our Voice is the official publication of The Central Ohio Chapter, HDSA 490 City Park Avenue, Suite C Columbus, Ohio 43215 Phone: 614.460.8800 Fax: 614.460.8801 Website: www.hdsacentralohio.org

Our Voice, a newsletter of the Huntington's Disease Society of America, Central Ohio Chapter, is published three times annually, 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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#### &

Julie Znamenacek, Editors

# 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.

Please join us at our next meeting. We first get together, discuss upcoming events and make announcements, then divide into 3 groups: caretakers, "at risk," and persons with HD. Each group has its own challenges and it is helpful to talk to others in the same situation. If we have a speaker scheduled, we stay together. There are two basic reasons to attend support meetings. One is to GET HELP. The second is to GIVE HELP. When you lose a loved one or they go into a nursing home, the usual feeling is that you want to distance yourself for a time. You really deserve some "time off" after care giving. But after awhile, please consider coming back--you can be a great help to people just starting on the road you have traveled. No teacher is as helpful as experience and the lessons you learn one by one can mean an easier time for new caretakers.



Our **teen group** would like to meet every 2 or 3 months at the Atonement Lutheran Church. If you have interest in attending, please contact our Social Worker, Barb Heiman at (614) 292-9960, or check the web site at www.hdsacentralohio.org for future dates and information on this group.

# **Changing of The Guard**



The Chapter would like to recognize some changes in event organization and to thank all participants in both First, after several events. vears of dedication to the Hoop-a-thon, Randy Rhinehart has (temporarily we hope) hung up his gym shoes as event chair. Randy has done a superb job on the event, making our hoop-athon one of the best in the country. Marty Vaughan stepped in and organized this year's hoop-a-thon, carrying on the tradition. Thank you

Randy and Marty for your hard work and dedication, we appreciate it.

Also taking a break this year is Wendy Vaughan. As many of you know, Wendy created the Central Ohio Celebration of Hope and made this event a huge success. It is hard to believe that we are only in our fourth year – Wendy makes it seem like the Celebration of Hope has been on our calendars for years! Wendy decided to take this year off and recruited Tina Farley to Chair the 2004 Celebration of Hope. Thank you to both Wendy and Tina, we can't wait until this year's event!

# SAVE THE DATE!!

# 2004 Annual Meeting, October 16!!

Call Pat Meeker for more details: 614-460-8800

# First Annual Dance Auction was a Success!

The first annual HD Dance was a huge success! Thanks to the many new faces that were present at the event as well as the continued supporters of Huntington's Disease. It was a great way to raise money while having a good time. We raised a total of \$7,000 and that money was sent to National where it will be tripled by an anonymous donor, bringing the total raised to \$21,000. A special thanks to all of the businesses and sponsors who generously donated wonderful silent auction items. We are looking forward to next year being an even bigger success!

Laura Bamberger



# **Circleville Bowl-A-Thon**

Tammie Wetherell, a friend of Randy Rhinehart's, came up with a Bowl-a-Thon fundraiser last year here in Columbus. Tammie decided to move the location to Circleville this year and on March 14, 2004 they bowled their hearts out for Huntington's Disease and for Randy and his family. When she sent the money she raised she wrote "Thank you for giving me the opportunity to help raise a little money ... I have enjoyed meeting each and every one of you. I would like to wish you all the best of Luck! God bless. I pray that there is a cure found soon. You are all wonderful people and deserve the best has to offer!" AND inlife cluded were checks totaling \$1,000.00!!!! Tammie, we thank you and all your wonderful friends for magnificent event!

Pat Meeker

# this

# Buy Groceries and Help HD

The grocery certificate program continues to be a viable fundraising program for the Columbus chapter. There is no cost to you, but our chapter benefits from your efforts because your participating local grocery store will donate 5% of your purchases made with certificates to HDSA.

Our chapter currently offers Kroger and Giant Eagle certificates. Anyone who wishes to purchase certificates should send checks and a selfaddressed, stamped envelope to Sheri Nash, noting which type of certificates

> you prefer. The gift certificates are returned to you, along with an envelope for your next order.

> > Please send your checks to: Sheri Nash, 1751 Ramblewood Avenue, Columbus,

Ohio 43235. Phone: 614-457-8480.

Meijer allows members to participate without mailing checks to HDSA. Meijer asks each participant to register for a Meijer Guest card thru HDSA. Each family registers via our chapter or on the Meijer website so HDSA can receive the rebate on purchases. Depending upon the amount our supporting families spend, our chapter will receive a reward check monthly. If a family spends \$100-\$399 while using their card, HD will receive 1% in reward money. As a family spends \$400-\$799 or \$800 plus our reward will be 2.5% and 4%. Please participate in this opportunity- it is a foolproof way to support your chapter.

Sheri Nash-Pittman



# Support Groups of Ohio

**Toledo**: meets every third Sunday from 2-4 p.m. in the fellowship hall at Our Savior Lutheran Church, 2820 W. Alexis Rd., Toledo, 43613. For more information, please call Robin VanGorder at 419-691-8940.

**Dayton**: meets at 7:30 p.m. on the second Wednesday of every month at Fairview Methodist Church (on the corner of Fairview & Cataba). For more information please call Cincinnati Chapter Social Worker, Mary Beth Bialic at 513-741-4372.

**Cincinnati**: caregiver group meets every third Saturday at 11 a.m. in the Drake Hospital. For the patient and At-Risk groups call Mary Beth Bialic at 513-741-4372.

**Cleveland**: meets every third Monday at 7:00 p.m. at the corporate offices of Realty One, 6000 Rockside Woods Blvd., Independence, Ohio (I-77 and Rockside Road). HD patients, family members and care givers welcome. For more info call Cece Cornell, Chapter Social Worker at 216-844-8572 email cscornell@ameritech.net or Chapter Office at 440-423-HDSA (4372). Chapter President is Don Barr <u>dbarrhome@aol.com</u>

**Mansfield:** meets at 7:00 p.m. the first Monday of every month. Home of Charlotte Dourgherty, 671 Weller Ave, Mansfield, OH 44904. Call Charlotte at 419-774-9761

**Akron:** New Location! Please see the website for updated information: <u>www.lkwdpl.org/</u> hdsa



# 10 Tips for Family Caregivers

- Choose to take charge of your life; don't let loved one's illness or disability always take center stage.
- Be good to yourself! Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- Watch out for signs of depression and don't delay in getting professional help when you need it.
- When people offer help, accept the offer and suggest specific things that they can do.
- Educate yourself about your loved one's condition. Information is empow-ering.

• There is a difference between caring and doing, be open to new technologies that improve your loved one's independence.

- Trust our instincts. Most of the time they will lead you in the right direction.
- Grieve for your losses, and then allow yourself to dream new dreams.
- Stand up for your rights as caregiver and a citizen.
- Seek support from other caregivers.
   There is great strength in Knowing you are not alone.

# Grandview Heights High School Hosts 19<sup>th</sup> Annual HDSA Hoop-A-Thon

The tradition continued May 22<sup>nd</sup> when our central Ohio chapter of HDSA held their 19<sup>th</sup> consecutive hoop-A-thon fundraiser, raising over \$25,000! In recent years the chapter has held the event in different locations including Grove City, Hilliard, and now Grandview Heights. As a result of rotating our venue, thousands of people in these different communities have been exposed to our event and many of these people have learned about HD for the first time.

Our chapter was again very fortunate to have local T.V. coverage. Channel 4 news provided live shots for their morning show with Mindy Drayer and Marshal McPeek, while Channel 10 news talent Ryan Miller showed footage on their evening news segment. Special guests at the event included Simon Fraser and Anthony Schlegel from OSU football as well as Shun Jenkins and Shaun Smith, seniors from the OSU basketball team. As in past years we had surprise appearances from several sport mascots to the delight of the kids.

Special thanks go to our food ven-

Sheryl Karnemaat Inspires Major Gift

The following is quoted from a newsletter sent to families of children who attend Mom's Day Out, a ministry of Dublin Baptist Church:

"Sheryl Karnemaat has been our wonderful MDO Art Teacher for many years. In 1993, her husband, retired FBI agent John Karnemaat, was diagnosed with Huntington's Disease (HD). HD is a mysterious inherited malady in which portions of the brain atrophy and die. HD is incurable and usually results in death. In 1997, researchers discovered what causes HD and today they are dors. Food was donated by George's All American Grill and Velvet Ice Cream. Also a special thank you goes to our MCs, Randy Rhinehart, Larry Larson, and Brian Phillips from CD 101.

A celebrity guest from California, Billy Aaron Brown, arrived late Saturday due to a plane delay but attended dinner at Spagio's Restaurant in Grandview with several raffle winners from the Hoop-A-Thon. Billy is a Hollywood T.V. and movie star who has had family members affected by HD and came to Columbus to help with our event. We raised several hundred dollars in raffle ticket sales for the chance to have dinner with Billy. Those who attended dinner enjoyed getting to know Billy. He has attended many Hoop-A-Thons nationally the last couple years and has lent his Celebrity status to help.

Our chapter and families were blessed to have such a successful event and enjoyable day working together to raise money for HD. As always, it was loads of fun!

Marty Vaughan, Hoop Chair

working on developing a cure for this disease."

"This year, our MDO staff would like to encourage you to make a donation to the Huntington's Disease Society of America IN LIEU OF purchasing gifts for the teachers at the end of the MDO school year. Many of you ask what store, restaurant or items the teachers may like to receive. Making this donation would be more than they could ever ask for."

Sheryl was presented \$4,440 for the Central Ohio HD Chapter to be used for research!

# HYMNS OF CELEBRATION

Resurrection Lutheran Church was the scene of an awesome event on the evening of May 16<sup>th</sup>. The church sponsored a program of religious music and drama to benefit the Huntington's Disease, Central Ohio Chapter, to honor one of their members who has HD, Dee Rhinehart and her husband Randy. A 63 voice choir and a 38 piece orchestra conductor by Dr. Rus-Mikkelson with guest conductor sel Robert Nugent who arranged much of the music. It was thrilling to hear from the opening Come, Thou Almighty King to the final number How Great Thou Art. All of the participants volunteered their time

# **Celebration of Hope Awards Banquet**

Please join us at the Huntington's Disease Society of America's *forth annual* "Celebration of Hope" Awards dinner on September 23<sup>rd</sup> at the Athletic Club of Columbus. The event will benefit the HDSA Center of Excellence for Patient Care and Family Services at the OSU Medical Center. We will proudly pay tribute to prominent, community-minded individuals who are genuine leaders and have made significant and generous contributions to the Columbus community in the areas of busi-

and seemed to enjoy the occasion as much as the sold out audience of well over 300 people. The production director was Dave Johnson.



ness, the arts and medicine. It is with great pride that HDSA of Central Ohio will be presenting awards to Bea Wolper, Esq. with the law offices of Chester, Wilcox, & Saxbe LLP; John S. Christie, President & CFO of Worthington Industries, Inc.; and the Henry "Chip" Hixson Family. Master of Ceremonies will be Andrea Cambern, of WBNS 10TV. For additional information, please call Tina Farley, event chair at 614-460-8800.



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# One of Our Own Honored

For years Randy Rhinehart has been doing the announcing and color commentary for the Whitehall Athletic Department and their various sport activities. As a surprise at an October Football game, they honored Randy and his wife Dee presenting them with checks from the Whitehall Lady Rams Boosters, The Ram Touchdown Club, Whitehall Baseball Boosters, Ram Basketball and the Band for a total of \$275.00 given to our chapter.

WOW! Congratulations to Randy & Dee Rhinehart.

PLEASE JOIN US ON THURSDAY, JULY 1

AT 7PM, AT LITTLE BROTHER'S ON 1100 N. HIGH ST - COLUMBUS W/ JERRY DECICCA, HAL HIXSON, BTKB 4 (BUCKTOWN KICKBACK), HOUSTON'S HAND, FRAME-BY-FRAME VISION & SHELDON MARSH.

\$5 PER TICKET, WITH ALL PROCEEDS BENEFITING HD!

# **Clipper Ticket Give-Away!**

The Central Ohio Service

Committee is donating 4

Box Seats to Clipper Games

on the following dates:

Huntington's Disease Society of America

Call Dolores Meeker: 614-879-9069.

# PARKING IS FREE!!

- July 20
- August 12
- August 24
- August 25





# Research Update: Fasting Could Slow HD, Hike Survival Time

ton's disease.

According to new research by investigators at the National Institute on Aging (NIA), decreasing meal frequency and caloric intake delays onset, slows disease progression, and increases survival time in HD mice. The restrictive diet works because it normalizes glucose metabolism and the levels of BDNF, brainderived neurotrophic factor, which likely helps the body regulate metabolism. When the mice were put on dietary restriction, the formation of harmful huntingtin, cell-killing protease activation, motor dysfunction, and tissue wasting all slowed down. The research suggests that HD causes neurons to degenerate by impairing cellular stress resistance. Additionally, the results indicate that body wasting is caused by the neurodegenerative process.

A special diet may help suppress the disease and increase the life span of humans. "If reducing food intake has the same effects in humans as it does in mice, then it may be theoretically possible to delay the onset of the disease and extend the lives of Huntington's patients by prescribing low-caloric diets or diets with reduced meal frequency," said Mark Mattson, Ph.D., chief of the NIA's Laboratory of Neurosciences.

The study was published in the Proceedings of the National Academy of Sciences Online Early Edition the week of February 10 and also summarized in a report by the National Institutes of Health (NIH).

NIA scientists discovered that transgenic HD mice have an abnormal metabolism, a diabetes-like condition also found in humans with HD. The faulty metabolism causes the mice to progressively lose weight despite having good appetites.

Dr. Mattson previously found that putting rats and mice on low-calorie diets or intermittent fasting-depriving them completely of food every other day-could improve glucose metabo-

Fasting may be a way to slow Hunting- lism and protect brain nerve cells in experimental models of Parkinson's disease and stroke.

> The same appears to be true for the HD mice. HD mice put on an intermittent fasting diet showed signs of the disease about twelve days later than those not on a diet. The dieting mice lived ten to fifteen percent longer. Furthermore, the fasting mice could better regulate their glucose levels and lost body weight more slowly than the other mice.

> NIA researchers found three major differences between the two sets of mice. First, the fasting mice showed fewer degenerated nerve cells. Second, these mice had higher levels of heat-shock protein-70 (HSP-70), which increases cellular resistance to stress. Third, fasting mice had higher levels of the crucial BDNF, which stimulates the growth and survival of nerve cells.

> Dr. Mattson hypothesized that BDNF also has a key role in helping the regulation of energy metabolism. "Were looking at BDNF very care-"We're exploring the fully," Dr. Mattson said. idea that increasing the levels of BDNF in the brain can forestall Huntington's disease without a change in diet."

> According to the NIH report, "since the 1930s, investigators have consistently found that laboratory rats and mice live up to 40 percent longer than usual when fed a diet that has at least 30 percent fewer calories than they normally would consume. So far, caloric restriction has increased the life spans of nearly every animal species studied, including protozoa, fruit flies, mice, and other laboratory animals.

> "Many gerontologists are particularly intrigued by findings suggesting that caloricrestricted diets have prevented or slowed down development of many age-related diseases and age-related changes in animals, including kidney disease, diabetes, several types of tumors...."

> For more on research and the latest updates, go to www.HDSASanDiego.org.

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# Advocacy in Action,

Would you like to take a more active role with HD? How about meeting with your congress person? Members of Congress are happy to meet with their constituents. An easy way of doing this is to meet with them in their home offices during the summer break. These district offices are a better place to meet than in Washington D.C. Here, they are not pressed with committee business or being called to votes. You can visit www.senate.gov to find the address/phone number of the local offices. First, contact the district office to set up an appointment explaining that you would like to discuss some legislative issues involving HD. If you are only able to get an appointment with an aide, take it, he/she can advocate for you with the legislator. Some issues which may be discussed may be to sponsor a bill, assign a member of his/her staff as a liason to the chapter or to attend local events/chapter meetings.

Tell the legislator exactly what HD is and how it affects you or someone you know. This is your opportunity to explain the devastating effects of this disease. The goal is to build a long term relationship. Have reasonable expectations. Remember, different issues are dealt with at various levels of government. Yet, these general quidelines will apply equally well to state and local legislators. Some potential concerns to discuss could be: funding for NIH, social security disability rules and health insurance issues. After each meeting send a thank you note highlighting any issues which were discussed and include information about HD and anything that the individual may have requested.

# Sheri Nash-Pittman

This information has been submitted with the assistance of a training seminar provided by Mike Romansky of McDermott, Will & Emery. His organization has been instrumental in providing HDSA assistance with teaching individuals how to visit with their representatives. He provided training to some of the HDSA leadership and National Convention attendees. Listed above are the steps he recommends.

# Anatomy of a Successful HDSA Visit

- 1. Introduce yourself and HDSA
  - Make it personal and let them know that you represent a national organization with more than 300,000 lives touched.

• HD is a model for other neurodegenerative diseases and research will also assist ALS, Parkinson's, and Alzheimer's

2. Thank the legislator

• for dollars appropriated to NIH and NINDS which supports HD research projects

- 3. HD remains a major health problem
  - lack of funding for clinical trials for rare diseases
  - lack of federally funded community based resources for HD patients due to the youth of affected person
- 4. HDSA recommends that Congress:

•Support increase in NIH budget

•If visiting US Representative, need to support the Genetic Information Non-Discrimination Act (S. 1053) that will protect those who have genetic diseases from discrimination on part of health insurance and employers

5. Cultivate a long-term relationship- be a resource

•Suggest a follow up meeting or phone call, write a thank you note and put the representative on your mailing list.

6. Alert HDSA National to the visit and any action items!

# **DONATIONS RECEIVED IN HONOR OF:**

# Bonnie Baldwin

John & Judy Lechner

Paul & Alice Katterhenrich

Grandma Keenor

Luke Lehmar

Steve and Robin Van Gorder

Nate and Jean Eudaly

<u>Larry Dean Sherman</u> Melissa Sherman "May all the families of Huntington's Disease be blessed."

# A Note of Thanks from Dolores Meeker

I would like to thank, on behalf of the Meeker and Shipley myself, families, all those in our HD chapter who sides give rallied to our to support when we lost our dear Lisa in January. Sorrow and grief are still an ever-present part of our lives, but your cards, calls and visits have added a bright moment in our days. An amount over \$5,000 was donated to HD in her memory and we designated it to be used by Dr. Kostyk at the Center of Excellence as a discretionary fund. In this way, Lisa can continue her giving ways, and provide support for those following the steps of her beloved father and brother.

Would you like to send a donation in memory or in honor of someone close to your heart?

If so, please send your donation to HDSA, Central Ohio Chapter, with an attached note or letter including the name of the person to be remembered. Send your information to 490 City Park Avenue, Suite C, Columbus, Ohio 43215.

# MEMORIALS

# Lisa Beth Meeker

William & Cassandra Bishop Jay and Karen Straley Michael & Angelena Mounts Dr. Henry (Chip) & Mrs. Hixson III Patricia and E. B. Rayburn James and Nancy Holtzhauer Don and Ginny Harris Richard and Elaine Valentin Jean and Stan Carpenter-Haycock **Richard Youmans** Richard and Elaine Meeker DRC Marketing Group, Inc. Dorothy Madden Anne Savage William and Charlotte Holt Richard and Judy Stelz Karl and Aloma Krieger Mary Ernst Jean and Joe Cavarozzi James and Mary Schulze Joseph and Joyce Timmons John and Mary Lee Kile Robin & Joe Craft Miles and Kay Patton Roger and Wendy Vaughan Ernest and Kim Crabtree Regina Giles

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# Edwin "Teddy" Meeker

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#### John Batt (Cousin to Norm &

# Bonnie Baldwin)

Norm & Bonnie Baldwin

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Saunders Fetters
Patricia J. Saunders

# Wilmer Meyer

#### (Bonnie Baldwin's Uncle)

David and Helen Deal

Art and Mary Ostertag

# Velma Douglas and Jennings Mollohan

(Sarah Morrison's Grandparents)

Norm and Bonnie Baldwin

Brother: John E. Thompson

<u>Mother: Pauline Thompson</u> <u>Aunt: Carol Tobin</u>

Aunt: Louise Welden

Uncle: Stanley Seymour

# Grandfather: Floyd Seymour

Donna Lewis

"I would like to donate for all of my family members that have passed away from Huntington's".

# Dennis Nash

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Are you moving, or have moved? Let us know where we can find you! Call or mail the Central Ohio office with the form below to change your mailing address.

**The 2004 Membership Drive is now on.** Please note and use the membership form included below. Receipts from Membership help pay for education about HD. Educating the public and training 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 and send your membership donation today.

Please tear out and return.

Name		
Address		
Phone number		
Please direct this donation of \$ to: Care	% Research	%
$\Box$ Please take me off the mailing list. I do not wish to receive upcoming newsletters		
$\square$ I woyld like to help by volunteering.		
$\square$ I have a change of address, as noted above.		
PLEASE RETURN THIS FORM WITH YOUR CONTRIBUTION TO:		
HDSA, CENTRAL OHIO CHAPTER,		
490 CITY PARK, SUITE C, COLUMBUS, OHIO 43215		