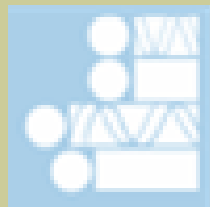




Our Voice



....never forget to, "Plan as if we have HD and live as if we don't."

A Few Words from the President....

I became involved in our chapter because my father had been diagnosed with HD. I wanted to offer any expertise I might have while our family supported each other and began to navigate many new issues. It was a scary and emotional time. Quickly, we moved past the scary and emotional part and began taking action. Simply put, this is the way that our family works best. Dad began making many decisions for his and the family's future, Mom moved into the "I'm here for you" mode, I became very task oriented and reminded people that we were allowed to "feel", a few of us became pretty angry and we all felt some form of denial. There was no way that this was going to "get" Dad- he was simply too strong and the leader of way, way too many things. HD couldn't have Dad; he was too needed.

Beyond all of these activities, Dad began talking to us. He talked about planning for his future. He talked about our futures and planning for

the possibility of having HD. He talked about financial and insurance issues. He taught each of us about the value of preparation as well as the value of continuing to live our lives. In all of this, he continued to demonstrate love, support and leadership. He continued to be our father and the Patriarch of the Nash family.

We planned for the uncertain health of Dad and the future of all of us. Yet, one thing never occurred to us—we never considered the fact that it might be Mom who got sick first. We didn't plan on anyone but Dad being sick or faced with skilled nursing care. Recently, the uncertainty of life smacked us in the face. It is Mom who has been faced with some short term but very serious

health concerns and is currently in skilled nursing. We sure didn't see that coming.

So, this past week I have been thinking about HD, parents, becoming a caregiver, HD, money, HD and yet another shift in roles. It's been quite a week. All of this is to remind each of us that no single thing can rule our lives. HD is, for many of us, a looming possibility, but not a certainty or a death sentence. We have no way to know what will play out in our lives. Our family is being reminded of this right now via Mom. So we will rally around her, show love and support, fill her role the best we can and put HD away for a bit. Yet, we will never forget to, "Plan as if we have HD and live as if we don't."

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Central Ohio Chapter Meeting Time and Place

Our monthly support group 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

OUR VOICE IS THE OFFICIAL PUBLICATION OF THE CENTRAL OHIO CHAPTER, HDSA
490 City Park Avenue, Suite C
Columbus, Ohio 43215
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Our Voice, a newsletter of the Huntington's Disease Society of America, Central Ohio Chapter, is published four 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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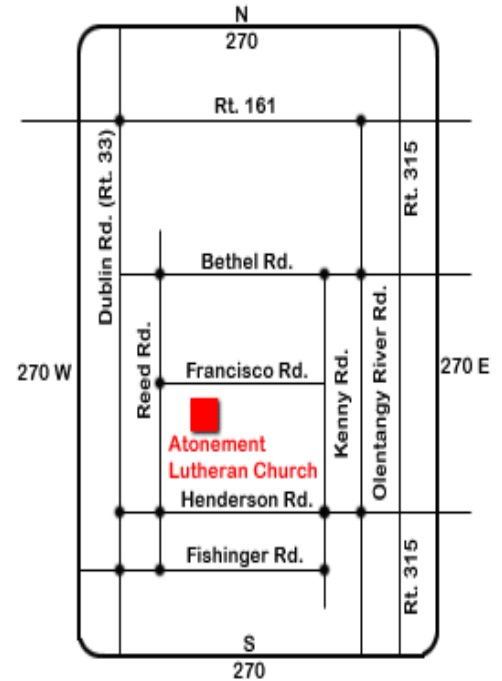
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Theresa Znamenacek Hanson

& Julie Znamenacek, Editors

Please join us at our next meeting. 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.



Annual Meeting

Our chapter is preparing to help you with long-term planning at our Annual Meeting on October 22 at the Der Dutchman. We have invited a financial planner to briefly speak with us about options available for our families, charitable giving, retirement and insurance concerns. She will offer choices for those affected by HD and those who are not. As always, the Annual Meeting will also offer networking and friendship.

The Annual Meeting of the Central Ohio Chapter will be held on Saturday, October 22 at DerDutchmen in Plain City. Family style chicken and roast dinner with dressing, mashed potatoes, green beans, salad, dessert, and drinks will be served at 6:30 PM. The cost is \$12.50 per person. We hope to see you there!

Support Group

Meeting Dates & Times for 2005

If you have any suggestions for speakers or topics of interest please contact Barb Heiman. This is your group and we want it to serve the needs of our HD families. Following is the schedule set for the remainder of the year.

- September 8: Discussion/Support Group
- October 13: "Savy End of Life Planning" Decisions for yourself and your loved one." Marie Lorz, Speaker\
- November 10: Discussion/Support Group
- December 8: Christmas Wrapping/ Card Signing

Huntington's Disease One Day Caregiver Conference, October 8

About the Speakers

Jim Pollard, a special education teacher and healthcare administrator has worked with people with HD for the last 18 years. Jim is the editor and author of "A Caregiver's Handbook for The [*Advanced Stages of Huntington's Disease*](#)." Jim also authored the brochure "[*CNA's First Shift*](#)."

Dr. Kostyk is the medical director of the HDSA Center of Excellence at OSU Medical Center.

Suggested Audience

This program focuses on topics of special interest to family members caring directly or indirectly for loved ones with HD and those who oversee their care in nursing homes or residential settings. This program is not recommended for children as we address some practical topics.

If you have HD yourself, we ask that you pass up this day. The risk of unintentionally offending you or hurting your feelings in

some way tends to inhibit us as we try to figure out ways to become better partners in your struggle with HD.

Conference Topics follows:

A Caregiver's Introduction to HD , Less Apparent Aspects of Movement Disorder, Why the Cognitive Disorder is so Difficult, A Basic Review of the Signs of Depression, Huntington's Disguise, The Importance of Routine, The Importance of Proper Positioning, How To Give A Shower, Keeping Folks Engaged in More Advanced HD, and Research and Clinical Trials.

Location

Ashland Inc., Building #2, 5200 Blazer Parkway, Dublin, Ohio 43017

Fee

\$30.00 Professionals; \$15.00 Caregivers / Family Members.

Fee includes breaks, box lunch and continuing education credit for LSW, RN, LPN. Professionals must attend the entire conference and complete the evaluation. Must have license number for registration and continuing education credit.

Registration—Please RSVP by September 22, 2005.

Make checks payable to: Central Ohio Chapter HDSA.

Send to:

Barb Heiman LISW, 1060 Olmstead Road, West Jefferson, Ohio 43162. Also include your name, address, phone number, and agency that you are with (if applicable).

2005 Convention Report



The 20th Annual HDSA Convention was held in Atlanta Georgia June 24^t-26 .

Numerous workshops and plenary sessions were offered in areas including HD research, symptom management, care-

giver support, genetic counseling, testing issues, living at risk and more.

Professional training was offered on the following: in-service programs for long-term care facilities; genetic discrimination; caregiver burden; issues surrounding advanced planning for

HD families and social security disability issues for HD. Thirty social workers and other professionals from around the country benefited from this training. Next Year's Convention will be held in Milwaukee Wisconsin from June 9th – 11th. Plan now to attend the 21st annual National HDSA Convention!

A Celebration of Hope



THE MARTINI BLAST

A Jazzy Evening with a Twist!

All fundraisers are not created equal. This year, the Huntington's Disease Society of America hosts their annual Celebration of Hope event, however this year's "Martini Blast" theme is sure to stir things up! On Friday, September 30th, top business leaders, community officials and other notable guests will gather downtown for one of Central Ohio's premiere charitable events.

The evening will commence at 7 p.m. on the 2nd Floor of The Hartman Building, as guests sample a bevy of specialty martini cocktails and bid on the extensive silent auction packages. Heavy hors d'oeuvres and carving stations will be located throughout the space for guests to nibble as they mingle at this jazzy affair. The highlight of the "Rat Pack"-inspired evening is sure to be the live entertainment, a tribute to Frank Sinatra and friends by Michael Sutherland, leading guests with his classic crooning ballads as they hit the dance floor.

Before night's end, a special moment will be taken to honor Pat Meeker and Dolores Meeker as our HD Humanity Award recipients and those sponsors who generously support the HDSA's Center of Excellence medical facility located at the Ohio State University Medical Center. All proceeds from the event will be donated to the research and treatment of individuals living with Huntington's Disease.

Special Thanks Go To Our Most Generous Sponsors as of 8/8/05:

- Made from Scratch Catering
- 3 Olives Vodka
- Spice Lounge and Restaurant
- WWCD 101.1 FM
- Digital Interiors
- Pat Dorrow, Coldwell Banker King Thompson Realtor
- Shawn Marquis Insurance Agency
- Maxine Vaughan

An official after party will take place at Spice Restaurant & Lounge allowing guests VIP access to the venue beginning at 10 p.m. After party wristbands will be sold at the event and through HDSA committee members.

The Hartman Building is located at 150 East Main Street, Columbus, Ohio, 43215. Spice is located at 491 N. Park Street in the Arena District.

Considering Long-Term Care Insurance?

Some statistics say the average nursing home stay is 2.6 years and the national annual cost of a semi-private room is \$52,000. Nursing home costs go up about 5% a year and by the year 2030 they are estimated to reach nearly \$200,000. Long-term care insurance may not be the best choice for everyone so it is important to consider how beneficial it may be for you before committing to the monthly premiums.

Remember, long-term care insurance claims may be

paid 10 or 20 years after the policy is written. That's why it is important to choose a stable insurance company with a history of writing such policies.

Check with ratings services before making a choice. Look for a policy that you can customize with the right combination of benefits for you such as:

- ✦ Location of care: in your home, in a nursing home, in an adult day center or in an assisted living facility.
- ✦ Type of care; skilled nursing care, custodial care,

home health aides.

- ✦ Options for benefits (pay monthly or daily) and length of coverage.
- ✦ Flexibility in applying benefits.
- ✦ The number of days that you pay before your policy benefits begin (ranging from 30 – 365 days).
- ✦ Coverage of mental illness such as Alzheimer's.

Consider all the options (Medicare, Medicaid, personal finances) and choose wisely.

First Time Fundraising Event Wins National Award

Congratulations Maureen Nash for winning the HDSA national award for "Best New Fundraiser" for her organization of the gala held April 2004.

This first time fundraising event took place at the Ramada Inn Ballroom. The 125 attendees arrived in cocktail attire ready to "dance the night

away," also the theme for the event. Along with a night of dancing, the guests were

**The event raised \$9,000
which was tripled by an
anonymous donor....**

able to bid and browse the extensive variety of silent auc-

tion items donated to the event.

The evening was completely coordinated by chairperson, Maureen Nash along with several friends and volunteers. In total the event raised \$9,000, which was tripled by an anonymous donor!

Thanks for everything that you do for our chapter Maureen!



Free Samples Make Excellent Gifts! Do you have samples of lotion, shampoo or conditioner you have saved from hotel stays? If you are like me, you never use them. If you have a collection, bring them to support meeting. Our committee will make "care bags" for nursing home residents and HD clients who come to the clinic. Thanks in advance!

Amaryllis Sale

Help HDSA/Central Ohio raise funds for patient and family support and research. Sell for \$10 each!! The Chapter earns \$5.65 on each one sold. These make great Christmas gifts! Buy individual amaryllis kits in small quantities (less than 16) for yourself or to sell. I will deliver or you can pick them up from my home or at an agreed upon place. Be sure to include phone number below.

Mark how many of each color:

_____ Red Lion _____ Apple Blossom (soft pink) _____ White Christmas _____ Cinderella (red/white)

Or if you wish large quantities, order by the case of 16. These will be delivered by UPS to your address. Cases may be all one color, or assorted.

How many?

____ Case of 16, assorted colors (8 red, 4 pink, 2 red/white, 2 white)

____ Case of 16, all one color. Specify which:

____ Red Lion

____ Apple Blossom (soft pink)

____ White Christmas (white)

____ Cinderella (red/white)

When do you want delivery? Check one: _____ Before Thanksgiving _____ Early December

Your Name _____ Phone _____

Address _____ City, State, Zip _____

Payment can be sent in with order, or sent to me after you've sold the bulbs. Make checks out to **HDSA**.

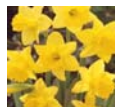
Send this form or contact: **Dave Fisher, 5498 Avery Road, Dublin, OH 43016;**
(614)932-9358; davefisher@wideopenwest.com

Flower Bulb Program

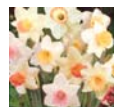
In addition to the usual amaryllis sale, our national HDSA has begun a "Flower Bulb Program." The supplier of the amaryllis is also making available the following bulbs:



- 32 Mixed tulips (11/12 cm size); 16 bags per case



- 32 Daffodils Dutch Master (yellow) 12/14 cm: 8 bags per case



- 32 Mixed pink Daffodils, 12/14 cm: 8 bags per case



- 64 Mixed Crocus, 7/8 cm: 16 bags per case

These are to be sold for \$12 per bag, and the chapter earns \$6.25.

These bulbs are available only from early September through October.

So call now!

Advance Directives/ Healthcare Decisions

When people become ill, they mainly rely on loved ones to make healthcare choices. Some choices are easy, others are difficult.

To assure that your wishes are carried out when you can no longer communicate them, an advanced directive, such as a *Durable Power of Attorney for Health Care* (allows you to appoint someone to make decisions for you) or a *Living Will* (allows you to express your wishes about your medical treatment) can be used to make wishes known in writing.



There are many factors to consider:

- Your present condition
- The proposed treatment
- The side effects or risks involved

- Possible benefits of the treatment
- Possible consequences of treatment if refused
- Available choices

It is extremely important for you to take an active part in decisions about medical care. Filling out Advance Directives with serious thought, the help of your physician and the cooperation of family members or close friends will ensure that you will be cared for according to your wishes when medical treatment is necessary.

Silent Auction Items Needed

Do you have any items that you would like to donate for the auction?



Ideas:

- Sports Memorabilia
- Gift Certificates
- Homemade Items
- Tickets to Sporting Events
- Movie Tickets

Can't afford to buy something? Ask your favorite place of business to donate a tax-deductible item!

In loving memory...

Memorials

Lucy Davis (Wendy Vaughan's mother)

by: Linda Ballard dba Ballard Interiors

Dale Meyers

by: his daughter and her husband Bob and Michelle Fry

John Hindel

by: Lillette Holdren

Coral Toland (Maxine Kidwell's mother)

by: Betty Gaddis

Research Update: RNA Interference



*Raeann Carrier,
Ph.D. Student*

Division of Pharmacology, The Ohio State University
carrier.25@osu.edu

There have been several attempts to delay the disease progression of Huntington's disease (HD). Many of the treatment efforts are based on alleviating the behavioral and psychological symptoms of HD. Prevention of neuron death or the clumping of the mutant huntingtin protein, improvement

of energy metabolism, and increasing production of protective proteins are some of the proposed strategies. Some of these treatments have been studied in animal models that carry variations of the mutant huntingtin gene, and a few studies have been done using human participants. In this article, I will describe a new strategy designed to directly decrease levels of the mutant huntingtin protein. It is possible that if there is less mutant protein, there will be

less brain cell dysfunction and hopefully lessened symptoms of HD.

This proposed new therapy uses small fragments of ribonucleic acid (RNA, very similar to DNA) which can specifically bind to the cellular message that makes mutant huntingtin (called messenger RNA; mRNA) and silence its expression. This new technique is called "RNA interference" (RNAi). Several recent papers (please see end

of article for references) have been published that tested the feasibility of using this technique to treat HD and other polyglutamine repeat diseases. They found that treating cultured cells (cells grown in dishes in the lab) with a specific sequence of RNA that targeted huntingtin mRNA reduced huntingtin mRNA and protein expression in a dose dependent manner. This means that the addition of the RNAi decreased levels of the protein and the more RNA that was added to the cultured cells the less huntingtin present. This research group (at the University of Iowa) also did similar studies in a mouse model of HD and found similar results and determined that the RNAi was present months after it had been introduced to the brain. This treatment also decreased the neuron pathology and behavioral dysfunctions associated with HD. The HD mice, when left un-

treated have clumps of huntingtin in neurons and their motor function slowly becomes impaired. Treated mice had fewer clumps of huntingtin protein and performed better than untreated animals during tests run to measure motor ability.

These results are exciting and suggest a possible method of treatment. However, a few issues still remain. In the studies described above, the mice had mutant human huntingtin as well as normal mouse huntingtin. The RNAi targeted the human huntingtin but had no effect on the mouse protein. Although the purpose of normal huntingtin is unknown, reducing its expression with RNA interference may also be toxic. Also, different people with HD can have variations in the mutant copy of the gene, and these variations could make creating an RNAi sequence to a specific region somewhat diffi-

cult. Finally, the RNAi can not enter the cell directly; it requires specialized carriers (such as a virus) to gain access to brain cells. The techniques for delivering the RNAi to each of the millions of brain cells are still under development. This idea of using RNAi to silence a mutant gene is new and still evolving, but it does provide a mechanism to decrease mutant huntingtin which ultimately may be beneficial in the future.

References:

1. Harper SQ, Staber PD, He X, Eliason SL, Martins IH, Mao Q, Yang L, Kotin RM, Paulson HL, Davidson BL. RNA interference improves motor and neuropathological abnormalities in a Huntington's disease mouse model. *Proc Natl Acad Sci U S A*. 2005 Apr 19;102:5820-5
 2. Chen ZJ, Kren BT, Wong PY, Low WC, Steer CJ. Sleeping Beauty-mediated down-regulation of huntingtin expression by RNA interference. *Biochem Biophys Res Commun*. 2005 Apr 8;329:646-52.
 3. Xia H, Mao Q, Eliason SL, Harper SQ, Martins IH, Orr HT, Paulson HL, Yang L, Kotin RM, Davidson BL. RNAi suppresses polyglutamine-induced neurodegeneration in a model of spinocerebellar ataxia. *Nat Med*. 2004 Aug;10:816-20
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**HUNTINGTON'S DISEASE
SOCIETY OF AMERICA**



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Our Voice Editors:

Theresa Znamenacek Hanson
Julie Znamenacek

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 the address listed above.

Please tear out and return.

Name _____

Address _____

Phone number _____

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