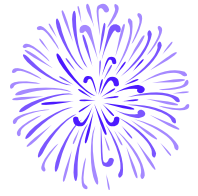


HIND-SIGHT



Huntington's Disease Information and New Discoveries

Huntington's Disease Center of Excellence at The University of Iowa Hospitals & Clinics

Please continue to explore our newsletter for stories about Center fundraisers, alternative HD therapies and updates on past and upcoming HD conferences. during this past year. We wish all of you happy reading and a wonderful summer!

Volume 2, Issue 2: May
2001:

- Conference Updates
- Alternative Therapies
- Celebration of Hope
Dinner
- HD Center Events
- Support Groups

HD CONFERENCE

UPDATES

Iowa State HD Conference **April 28, 2001**

Mike and Diana Fisher of the Iowa HD Chapter welcomed conference attendees to second annual Iowa State HD Conference. Dr. Jane Paulsen presented the keynote address and provided an educational overview of HD Management in relation to care, medications and treatment. Elizabeth Penziner also presented on experimental treatments for HD in clinical research, and a summary of these can be read on page [4].

The 2001 HDSA National Convention

The 2001 HDSA National Convention is in San Diego, CA, at the Town and Country Resort. The Town & Country is situated on 32 beautifully landscaped acres in Mission Valley, with many San Diego attractions only minutes away. Attendees may register for the Convention prior to June 22, 2001 by completing and forwarding the Convention Registration Form to 2001 Convention, Huntington's Disease Society of America, 158 West 29th Street, 7th Floor, New York, NY 10001. You may also fax the registration form (for credit cards only) to 212-239-3430 or use the link at the bottom of this page. After June 22, registrations will only be accepted at the Convention itself.

Program Highlights:

The Convention's opening session will begin at 9:00 am on Friday, June 29. It will be followed by the Family Services and Care Forum and, in the afternoon, by smaller educational workshops dealing with varied issues of the HD community. The Convention's reception will be held Friday evening. On Saturday, the AstraZeneca

Research Forum will be held in the morning and smaller educational workshops will be scheduled throughout the afternoon. Our Generation 2000 gala, featuring dinner, awards presentations and dancing, will be held on Saturday evening. Educational sessions will continue on Sunday morning. The Convention ends at Noon on Sunday.

UPCOMING PLANS AND PROJECTS IN THE HD CENTER:

Please join HDSA in celebrating HD Awareness Month. Each year, HDSA's chapters and affiliates host a variety of fundraising events in their local areas. Events taking place during HD Awareness Month include the Shoot for a Cure Hoop-a-thon and the Cure HD BMW Sweepstakes. All proceeds from these events directly support HDSA in our efforts to find a cure for Huntington's Disease.

During the month of May, and throughout the year, we urge you to support HDSA in our efforts to find a cure for this deadly disease. For more information about Huntington's Disease or HDSA, please contact the Huntington's Disease Society of America at 800-345-HDSA, hdsainfo@hdsa.org, or on the Internet at www.hdsa.org. HDSA is committed to *making this the last generation with HD.*

SUPPORT GROUPS



HD CONVENTION

The 14th Annual Huntington's Disease Society of America (HDSA) convention will be held at the Crystal Gateway Marriott in Arlington, Virginia just minutes away from the capitol, June 4-6, 1999. The theme is *A National Commitment to Care and Cure*. The program will address the needs and concerns of HD families and caregivers. There will also be major presentations on the status of HD research by Dr. Michael Hayden and other professionals, including our own Dr. Jane. Information sessions covering topics such as Juvenile HD, Coping with Psychological Distress, Family and Caregiver Issues, At-risk Challenges, Genetic Testing, and Young Adult issues in HD families will be held. Topics such as the Management of HD (Care, Medication, and Treatment), Nutrition, Speech and Communications, Managing Behavior, Sexuality, Occupational and Physical therapy, and late-stage care giving will be covered during the workshops and panels. Legal matters facing HD families and caregivers, such as privacy, social security disability, health and life insurance, estate/financial planning, marriage, family planning and adoption, financial planning for the future, veterans' benefits, and nursing homes will be addressed. Support groups are available for all individuals: at-risk, juvenile, tested positive and negative, caregiver, family, young adults, and gay and lesbian. Please call HDSA at 1-800-345-HDSA ext. 23 for more information on registration. For those who are unable to attend this exciting convention, don't worry, because we will bring the information home and pass it on to you!

RAISING \$ FOR HD

The Cure-HD sweepstakes continues to raise thousands of dollars for HD research and care programs. The GRAND PRIZE this year is a 2000 BMW Z3 Roadster along with five runner-up prizes: one \$10,000, one \$5,000, and three \$1,000 U.S. Savings Bonds. Winners will be selected in a random drawing at the 14th Annual HDSA convention in Washington, D.C., June 5, 1999, need not be present to win. Tickets are \$100 and can be reserved by calling Mike Lamma, (212) 242-1968 ext. 12. Entries must be received by June 4, 1999.

1-800-OUR-GIFT is an international floral delivery service which donates 20% of proceeds from your purchases to the Huntington's Disease Society of America. Flowers, plants, and fruit baskets are a perfect gift any time of the year.

IN bookstores this May, The Faces of Huntington's, anthology compiled by HD family member Carmen Leal-Pock. A percentage of the book's proceeds will go to support HD programs. Books can be ordered for \$15.95. Send check payable to Living Hope Inc., P.O. Box 952163, Lake Mary, Fl. 32795-2163.

OUT on Video: "Huntington's Disease: Living with Knowledge" written and narrated by Dr. Jane Paulsen and produced by the Sioux Valley HDSA chapter, can be ordered by sending a \$25.00 check (includes shipping and handling) made payable to the Sioux Valley Chapter, PO Box 1311, Sioux Falls, SD 57101-1311. All proceeds go to HD.

ON the web: check out the web site created by Renette Davis, in Chicago

Ill. It is one of my favorites and includes lots of important information for people with HD and their caregivers. It has great stuff on nutrition, and contains super recipes. It has poems and stories as well as up-to-date links to medical information and conference reports. Renette welcomes contributions from others. The web site address is <http://www.lib.uchicago.edu/~rd13/hd/>

July 13, 2001 and August 10, 2001

HDSA Iowa Chapter HyVee
Cookout!!

From 11am to 1pm we sell hot sandwiches, chips and a soda for a certain price. Depends on what HyVee has scheduled! Then they take out what their cost is and the rest goes to HDSA Iowa Chapter.

Location: 1604 Bent Street, Bedford, IA
- Corner of HWY 148 and HWY 2

How to enter: It takes about three people to do it easier. But could use two if had too! One to cook, one to put the orders together and one to handle the cash.

For more information contact: Mike Fisher 800-835-4797

**ALTERNATIVE THERAPIES AND
TREATMENTS FOR HUNTINGTON'S
DISEASE**



**RESEARCH
VERSUS
RUMORS**

Before concluding that an experiment has shown that a nutrient cures a disease or alleviates a symptom, ask these questions:

- Was there similarity between a comparison group and the experimental (or treatment) group?
- Was the sample size large enough to rule out chance variation?
- Was a placebo effectively administered? (Blind study)
- Was the experiment double-blind (even the investigator doesn't know which group had the treatment)

Donations/Memorials

Donations and memorials for any reason are a source of funding for the Iowa HD Center of Excellence that allow us to continue to serve families affected by HD in Iowa and surrounding states.

All donations or memorials should be sent to our chapter office. Please make checks payable to Huntington's Disease Center of Excellence at the University of Iowa. They may be sent to Huntington's Disease Center of Excellence; 1-145 MEB; The University of Iowa; Iowa City, IA 5224



HD RESOURCES AND CONTACT INFORMATION



To schedule an HD Center appointment: Contact Elizabeth Penziner at (319) 353-4307

For information about genetic testing: Contact Cathy Evers at (800) 260-2065

To learn about research opportunities: Contact Laura Stierman at (319) 353-3716

To receive 24-hour emergency support: Call the helpline at (800) 777-8442 ext. 34307

To reach us by email: hdinfo@uiowa.edu

To connect to our web site: www.uihealthcare.com/huntingtonsdisease/

To reach the national office: Contact HDSA at (800) 345-HDSA

To contact the Iowa Chapter: Call the chapter office at (800) 535-4797

Jane Paulsen, Ph.D.
The University of Iowa
Psychiatry Research 1-293 MEB
Iowa City, Iowa 52242-1000
503260023

**Not getting your own copy?
Moving?**

Know of friends or relatives who would like to receive this newsletter?

- add my name to your mailing list
- change my address
- remove my name from your mailing list

NAME _____

ADDRESS _____

PHONE _____

*Mail this form to: Laura Stierman, University of Iowa College of Medicine, Psychiatry
Research MEB 1-293, Iowa City, Iowa, 52242-1000*