

# HIND-Sight

*Huntington's Information & New Discoveries*

Volume 1 No. 2

University of Iowa Hospitals & Clinics

March 2000

## HD CENTER OF EXCELLENCE UNIVERSITY OF IOWA

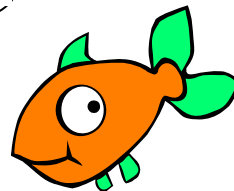
It is with great excitement that we announce the University of Iowa has just been designated as a Huntington's Disease Society of American Center of Excellence! On February 16, 2000, the University of Iowa Hospitals and Clinics was visited by a HDSA national representative for a site visit. Through the efforts of families, individuals, clinic personnel and Drs. Jane and Hank Paulsen/Paulson we came out with flying colors!

The HD Center of Excellence will include a clinic personnel of: neurologists, neuropsychologists, psychiatrists, pharmacists, genetic consultants, social workers, physical therapists, speech pathologists, clinical dieticians, occupational therapists, and research assistants. We believe by combining the efforts and knowledge of health professionals who play an important role in maximizing patients' abilities in the face of this progressive illness, we will be able to help patients and their families understand and cope with this complex genetic disease. Our team approach will provide a full range of HD services, including office visits, follow-up care, and the clinic will also serve as an educational resource for anyone needing HD information. We will work with your local family physician to help you in any way possible.

We would like to thank all of the families, clinic personnel, and those of you who have offered your support and efforts toward the realization of this clinic. Once again, we are now one more step closer to finding the cure for HD!



Tell your family about the HD support group meetings held at the University of Iowa Hospitals and Clinics, Clarinda Regional Hospital, Adair County Memorial Hospital and the Iowa Lutheran Hospital. See page 2 for more details!





## Iowa City HD Support Group Meeting Schedule

Dates	Speakers
Sunday, March 26	Dr. Henry Paulson, neurologist
Sunday, April 16	Jodi Morgan, speech pathologist
Sunday, May 28	TBA
Sunday, June 25	Liz Agresta, health and wellness

**Location:** University of Iowa Hospitals and Clinics, Adult Outpatient Waiting Room, 1<sup>st</sup> Floor John PappaJohn Pavilion, near elevator I, Iowa City, IA

**Time:** All meetings are held from 1:00-3:00 p.m. and snacks are provided.

### Clarinda

**Location:** Clarinda Regional Hospital, 17<sup>th</sup> & Wells, Clarinda, IA

**Time:** Every Third Friday of the month, 7:30 p.m.

### Adair

**Location:** Adair County Memorial Hospital, 609 SE Kent, Greenfield, IA

**Time:** Every Third Friday of the month, 7:30 p.m.

### Des Moines

**Location:** Iowa Lutheran Hospital, 700 East University Avenue, Des Moines, IA

**Time:** Every fourth Friday of the month, 8:00 p.m. (weather permitting)



*"I Have HD"*: These wallet-sized cards are now in stock. If you would like to place an order, please contact Anita Mark-Paul at the national office, ext. 19, or by email at [amarkpau@hdsa.org](mailto:amarkpau@hdsa.org). See example below.

I HAVE HUNTINGTON'S DISEASE

Name \_\_\_\_\_ Tel \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

TAKE ME TO A HOSPITAL OR CALL:

Name \_\_\_\_\_ Tel \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

I HAVE HUNTINGTON'S DISEASE

If I appear to behave strangely it is because I have HD.

I may slur my words, forget where I am going or may even trip over my own feet.

I know that I am doing these things. I am aware of what is going on. Please be patient.

**If I need help**, please contact the person listed on the other side of this card.

Thank you for your understanding and for caring...

Huntington's Disease Society of America



# HDSA 2000 Convention



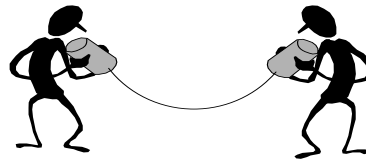
The 2000 Annual HDSA Convention will be held at the Clarion Plaza Hotel in Orlando, Florida, June 9-11. The theme for the Convention is “THE FUTURE IS NOW!”

The opening session and keynote address is schedule for 9:00 am on Friday, June 9. It will end at Noon on Sunday, June 11. The awards banquet and dance will be on Saturday evening. Make your reservations now!

HDSA offers scholarship for individuals and families who would not be able to attend the convention without some financial help. For more information on how to apply for the 2000 convention Scholarship, please call 1-800-345-HDSA extension 23.

Another smaller convention will be hosted by the Illinois Chapter on April 1, 2000, at the Wyndham Hotel in Oak Brook, IL. Call 630-443-9876 for more information.

SPREAD THE NEWS!



Contact Diana Fisher at 1-800-535-4797 for more information on the following events.

**Hoop-A-Thon**, April 1st  
Location: Greenfield High School  
Time: 1:00-5:00 p.m.

**Hoop-A-Thon**, April 22<sup>nd</sup>  
Location: Bedford High School Gym  
Time: 10:00 a.m.

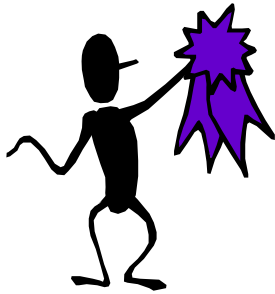
**5K Run/Walk**, May 16<sup>th</sup>  
Council Bluffs  
Time: TBA

**HDSA Iowa Chapter “Cook Outs”**  
Time: 11-1:00 p.m.  
Dates: May 19-20, June 23-24, July 7-8  
Location: TBA

**Indy-Go-Kart**, July 16<sup>th</sup>  
Location: Council Bluffs  
Time: TBA

**Kiss-the-Pig-Contest**, August 16<sup>th</sup>  
Location: Four County Wide

1-800-345-HDSA



# SPOTLIGHT

**In the last issue of HIND-Sight we asked readers to suggest a person who has shown bravery and stood up strong in the face of HD. This issue we are featuring Shane Crossley. His story was sent to us by Bob Hasselbring, a reader from Tennessee. Please submit your recommendations for the upcoming issues.**

Shane Crossley has always kept a bright, cheery outlook on life as Huntington's Disease progressively robbed him of his ability to be independent. Recently he found himself living in a trailer park in Clarksville, Tennessee, on a very limited budget. He didn't always have enough money to buy his medicine and without it his involuntary motions would be more severe. Some onlookers might even think he was intoxicated. Such was the case when he was walking home with a bag of groceries. A car pulled up beside him and the driver jumped out, stuck a gun in his face and demanded his money. Shane complied, and the gunman then pistol-whipped him to the ground and left with his money, billfold, and bag of groceries. With his fighting spirit, Shane crawled to a nearby store where a 911 call brought immediate police help. The patrol officer was surprised that in his injured condition Shane not only was able to describe the assailant, but gave him the make, model and color of his car as well.

Efficient police work quickly found a car meeting that description and took Shane to it to see if this was the man that had robbed and assaulted him. It was, and Shane also noticed his sack of groceries on the back seat of the car. He pointed this out to the police, who asked the suspect to describe what was in the bag without looking. He couldn't. Then they asked Shane and he told them the complete contents including the brands and size of the containers. The robber was arrested and it turned out that he was wanted for other crimes. Shane was called upon to testify at a hearing and the police appreciated his valuable contribution to getting this criminal off our streets.

When Shane realized that he was destined to be one of the fifty percent to inherit this disease he could have been bitter. Yet, his cheerful spirit and optimism is contagious and to know him is to love him. This true story should be an encouragement to us all. See the photo below of Shane.



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 \_\_\_\_\_