

# HIND-Sight

## *Huntington's Disease Information & New Discoveries*

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## CONVENTION NEWS

The 15th Annual HDSA National Convention was held June 9-11 in Orlando, Florida, with the theme *The Future is Now*.

Some of the workshops presented were: family planning, living positively with HD, genetic testing, and legal planning.

This was a great opportunity for HD families and caregivers to meet and support one another.

For those of you who were unable to make it to this year's conven-

tion we definitely encourage you to start planning a trip to attend next year's convention. It will be held at the Town and Country Resort in San Diego from June 29-July 1.



## Local Stores Support HD

Did you know that your area stores support Huntington's Disease?

We would like to thank **Cub Foods, Econo Foods, Fareway, Hy-Vee in Coralville, Hy-Vee in Iowa City, Movable Feast, Walmart in Iowa City, and Sav-Half Greeting Cards**. These stores have made donations to the monthly HD support group meetings. We are very grateful for their contributions and concern for this devastating disease.

**PLEASE NOTE:** When calling the HD Center of Excellence at **(800) 777-8442 x34307** be informed that the following questions

may be asked of you prior to using the toll free line. Questions you can expect to be asked are:

- 1) **Whom do you want to speak to?** (answer. Elizabeth Penziner)
- 2) **Reason for your call** (answer: to discuss an appointment)
- 3) **Hospital #** (if you have been seen at the U.I.H.C. before)
- 4) **Address and possibly SS# or date of birth**

Please feel secure in providing information to the operators and understand that your information will be kept confidential and that your name will never be given to anyone nor will you be contacted by anyone. If you have any question or concerns, feel free to contact Elizabeth Penziner on her direct line at **(319) 353-4307**.

## RAFFLE

Brian Wignall, wildlife artist, has donated a print to be raffled off at the Iowa HDSA Conference on August 12th.

Tickets are \$1.00 each or 6 for \$5.00. To purchase tickets or to collect tickets to sell contact Lisa Ethridge at (515) 227-3247 or the HDSA Iowa Chapter at (800) 535-4797.

## CoEnzyme Q10

Clinical research continues to examine the efficacy of supplements such as CoQ10. Medical endorsement is awaiting the outcome of these trials. For families who independently choose to take CoQ10, Earth Source may be a cost effective alternative.

Suzanne Wycoff, a mother of and advocate for her two adult children with Huntington's Disease, has worked for three years with a chemist to provide families with an affordable, excellent

quality product. She has recently designed her company, *Earth Source*, for the sole purpose of facilitating access to quality supplements at the most reasonable price.



Contact her at:

1631 140th Avenue,  
San Francisco, CA, 94122

Phone: 415-759-7262

Email: Earthsource10@yahoo.com

## HD CENTER OF EXCELLENCE FEATURE

**Dr. JUDITH CROSSETT,**

psychiatrist for the HD Center of Excellence, consults and provides diagnosis and treatment for the psychiatric component of HD—often the first symptoms which appear, and which add to the disability at any stage. Dr. Crossett reports, “Psychiatric illness is just that—illness—not weakness, not irreversible. We can treat, at least alleviate the psychiatric illness which is part of HD and improve life for the patient and the family.”

A graduate of Grinnell, the University of Toronto, and the University of Iowa, Dr. Cros-

sett stopped collecting degrees at five. Despite being able to read, write legible and coherently, and spell, she went into medicine, the most desperate ploy of an English Lit PhD trying to stay in Iowa City.

“Psychiatric illness is just that-illness-not weakness, not irreversible.”

“I like taking care of patients, and that is best done with a team. I like working with teams—families, patients, hospital staff of all disciplines, those who work in the community.”

## Upcoming Event

### ◆ Iowa State Convention

When: August 12th, 2000

Where: Marriott Hotel, Des Moines

Keynote Speaker: Dr. Jane Paulsen

**We really hope your attendance is possible. This will be a great opportunity to learn about the recent HD advancements and to connect with the HD community. To register , please call 1-800-535-4797! Plan to attend. You won't want to miss this IOWA event sponsored by the Iowa HDSA Chapter!**



On the personal side, she is very involved in her church. She sings in the choir, is in charge of social events, and is also involved with the Outreach committee. She plays bridge, enjoys her three cats, and loves to go camping.

*"Ain't it kinda funny, at the dark end of the road, that someone lights the way with just a single ray of hope."*

---Alabama, "Angels Among Us"

## CALL FOR RESEARCH SUBJECTS

We are still recruiting for our HD studies! We need:

- Individuals at-risk for HD who are unaware of their gene status, between the ages of 30-55, for the HSG's PHAROS study.
- Individuals who are at-risk for or have already been diagnosed with HD, any age, for our HD Study.
- Individuals with a CAG re-

peat >39 (both pre-symptomatic and diagnosed), showing few movements, for our imaging studies.

- Pairs of brothers or sisters who are full siblings, both known to be showing motor signs of HD

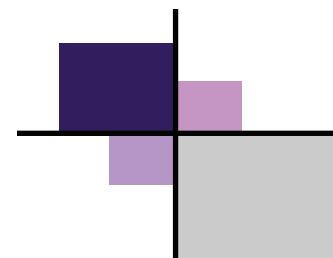
Every individual that participates in research makes a difference, and it is a way to show support for those individuals living with

HD, their family and friends.

IF YOU ARE INTERESTED PLEASE CONTACT:

**Katie Hall: 319-353-4131 or 319-353-4307**

**katie-hall@uiowa.edu**



since my joyful marriage to Andrew Penziner. I am so pleased to be able to share all of this with you. It is great working with the HD community again and I am looking forward to an exciting future together. Beginning in August, I will be leading the HD support groups and hope to meet those of you I haven't yet had the pleasure to meet, along with all of you who can attend. See you all soon,  
Elizabeth Penziner

## ANNOUNCEMENT OF RETURNING STAFF

For those of you who were avid readers of our newsletter back when Liz Agresta was writing, I am so pleased to share that after successfully completing graduate school, I am back working with Dr. Paulsen again. All of this comes just in time for HDSA's designation of the University of Iowa as an HD Center of Excellence. Dr. Paulsen's lab has grown quite a bit and I am really fortunate to join a team of such dedicated and compassionate people. No

sooner was I back before Katie and I boarded a flight to the HDSA national meeting in Orlando. It was fantastic seeing familiar faces and reconnecting with old friends. I was trained for my position working for the HD Center and attended several insightful workshops and lectures. Anyone interested in further details on the meeting should feel free to contact me here at the lab. And okay, one further bit of exciting news, I am now Elizabeth Penziner,

## SUPPORT GROUP MEETINGS

Our July HD Support group meeting will feature Jacqueline Croat. She will demonstrate massage therapy and relaxation techniques. All meetings are held the forth Sunday of each month from 1:00-3:00 p.m. at the U of I Hospitals and Clinics

Adult Outpatient waiting room near Elevator I on the 1st floor of JPP. If you have any questions contact Elizabeth Penziner at 319-353-4307. Please check our web page for information about the upcoming support



group meetings: <http://>

[www.medicine.uiowa.edu/hd](http://www.medicine.uiowa.edu/hd)

For information about other HD support groups held in your area please contact Mike Fisher at 800-535-4797.

**"With the new day comes new strength and new thoughts."**

---Eleanor Roosevelt

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



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*Mail this form to: **Elizabeth Penziner, University of Iowa College of Medicine, Psychiatry Research MEB 1-145, Iowa City, Iowa, 52242-1000.***