Findings bring hope at HDSA

New markers for HD and potential for stem-cell research discussed at largest national convention in society history

Sean Thompson
HIND-Sight Editor

A record-setting 750 people shared stories, experiences, research findings, and a rewarding weekend at the 2009 Huntington’s Disease Society of America 24th National Convention this June in Phoenix.

With so many people filling the Hyatt Regency conference rooms, the sense of community often felt at HDSA conventions permeated.

“[Convention] gives us an opportunity to form friendships that last a lifetime with people facing the same issues that you face everyday,” said HDSA Board of Trustees Chair C. Walt Johnston during the opening ceremony.

Attendees not only left with friendships, but also a plethora of information on HD research. Introducing a research forum, NBC News Correspondent Charles Sabine commented that though a cure has yet to be discovered, drugs and other therapies have proven effective at treating symptoms and improving quality of life.

“ImPLYing anything but a cure is failure is of course counterproductive,” Sabine said. “Nothing enriches your environment more than hope.”

Before therapies can be tested, researchers first must know what the earliest markers of HD are well before a motor diagnosis has been reached, so the disease can be treated at its earliest stages, said Jane Paulsen, University of Iowa professor of psychiatry and neurology and principal investigator for PREDICT-HD.

One marker Paulsen spoke specifically about during a PREDICT-HD update was MRI scans. Brain scans of participants have shown many changes in the brain as people move closer to HD diagnosis, especially in the caudate, which can show up to a 40 percent neuron loss for those nearest to HD onset. With that knowledge, researchers can design clinical trials to try and “rescue” neurons.

Additionally, because of PREDICT findings, the number of participants needed for a clinical trial has dropped from 2,100 to 800, Paulsen said.

“The amount of money that you have saved because of your contributions and the amount of treatments that we can test has really increased because of your efforts,” she said.

Another topic of interest at the convention was the use of stem cells in HD research and treatment. According to Leslie Thompson, professor of psychiatry and human behavior and director of the Interdepartmental Neuroscience Program at the University of California, Irvine School of Medicine, stem cells can potentially be used to engineer the neurons that are susceptible to HD. Stem cells can also test the effectiveness of drug treatment in HD cells.

The research findings kept the convention buzzing, as attendees soaked up information with a thirst for more. Sabine reminded them that without their contributions, none of the encouraging research findings would exist.

“We have many exciting new weapons to carry on the battle field,” he said. “But the most important of all are you.

“A better world created by a vision of hope really is in our hands.”

On the Web
For more information on the 2009 HDSA National Convention, including selected presentations visit www.hdsa.org/index/2009convention.html
Forum focuses on family

Conversation kicks off program at HDSA Convention in Phoenix

Anne Leserman
Social Worker and UI HDSA Center of Excellence Coordinator

Instead of the usual table-and-chair setup on stage, imagine three comfortable, overstuffed orange chairs. This is the setting for the “Decision Making in HD: Uncertainty, Awareness and Denial” HDSA Family Forum this year in Phoenix. The atmosphere allowed speakers to talk to each other as well as the crowd. Featured were Dr. Randi Jones, a neuropsychologist and the clinical director from the Emory University HD Center of Excellence; Marsha Miller, editor of the Lighthouse and research sections for the HDSA Web site; and myself.

Jones spoke of uncertain aspects of the disease for those at risk, partners of persons with HD, caregivers and the affected individual. She explained the difference between denial, which is unconscious, versus anosognosia or unawareness of symptoms, which occurs because of changes in the brain. This should be remembered when facing decisions like: taking keys away from an HD person who is too impaired to drive; an at risk person talking to a genetic counselor to be more informed about their testing decision; or a couple seeking counseling to assist with changing roles in the marital relationship.

I focused on unawareness issues of persons with HD by talking about issues that arise like driving, living alone or reluctance to bathe. Understanding that family interactions may need to become more contentious and that there may be changes in traditional family roles can aid in coping with the inevitable changes that go along with HD. Expecting an HD person to have insight about their disease may be unreasonable as the disease progresses.

Marsha Miller offered practical advice, speaking from her experience caring for her husband with HD. Her goals changed as her husband’s disease progressed. Her suggestions include: remembering that no one is perfect; start as you mean to go (this has to do with setting limits); every good day with HD is a victory; knowledge is power; plan for the future; be comfortable talking about HD; take care of legal issues; keep on top of paperwork; become an advocate for your HD person; and learn about the stages of being a caregiver.

Feedback about the forum was quite positive and you can expect future conventions to include similar forums.

On the Web
For more advice from Marsha Miller, visit www.hdsa.org/images/content/1/2/12021.pdf

HD Support Groups:
Des Moines
Valley View Village Conference Room
2571 Guthrie Avenue
Third Sunday at 1:30 p.m.
Mark Hillenbrand
(515) 208-3511

Omaha, Nebraska
Perkins Restaurant
108 L. Street
Second Monday at 6 p.m.
Cathy McNeil
(402) 537-0739

Iowa City
University of Iowa Hospitals and Clinics
Della Ruppert Conference Room
Fourth Sunday at 1 p.m.
Anne Leserman
(319) 353-4307

Area HDSA Walks
Get your sneakers and track suits ready for two upcoming local HDSA walks to raise money for HD research.

10th Annual Huntington’s Disease Research Support Walk, Omaha, Neb.
When: Sunday, Aug. 30, registration begins at 8 a.m., walk at 9 a.m.
Where: Zorinsky Lake Park, 156th and F Streets.
What: Optional 1-4 mile walk/run. Also featuring music, door prizes, raffle, and bouncy castle.
For more information: Contact Mike DeBolt at (402) 933-1986 or Theresa Langer at (402) 896-3491.

Team Hope Walk and Iowa Chapter Picnic, Des Moines, Iowa
When: Saturday, Sept. 12, registration begins at 7 a.m., walk at 8 a.m.
Where: Gray’s Lake Park, Fleur Drive and George Flagg Parkway.
What: Walk to be followed by family picnic at noon with free food and massages. Staff from University of Iowa Center of Excellence will be available to answer questions about current HD studies.
For more information: Contact Jenna Carnahan (jennacade@hotmail.com) or Lori Wesack (johnsonlorianne@msn.com). Or, pre-register at: www.firstgiving.com/hdsateamhope.

From the Editor
Welcome to your redesigned HIND-Sight! As the new editorial associate for the HD Center, I’ll be taking over editorial duties. You’ll notice changes as the newsletter continues to evolve.
As is always the case, feel free to contact me with feedback at sean-thompson@uiowa.edu or (319) 384-4094. Also, if you want to write something for HIND-Sight, please contact me with your ideas!
Sean Thompson, HIND-SIGHT Editor
HD Research Opportunities Abound

As NBC News Correspondent and well-known HD advocate Charles Sabine emphasized at this year’s HDSA National Convention, research volunteers are whom allow for the breakthroughs toward fighting this disease. That’s why the University of Iowa HDSA Center of Excellence continues to ask of you to give your time and your input to the various ongoing research studies.

If you or someone you know is interested in participating in any of the following studies or would like more information, please contact the person listed or contact Anne Leserman, UI HDSA Center of Excellence Coordinator at (319) 319-353-4307 or e-mail at anne-leserman@uiowa.edu

Observational Studies:

PREDICT-HD
What? The UI’s chief HD study investigating the earliest signs of HD in pre-symptomatic individuals. Participation lasts for five years (with the intention of extending the study).
Who is it for? Individuals at risk for HD, who have been tested for the HD gene and are either positive or negative, and have not been diagnosed with HD symptoms. Must be age 18 or older.
Contact: Stacie Vik, (319) 353-3716, stacie-vik@uiowa.edu.

COHORT:
What? A long-term study with the goal of collecting clinical information from HD families to learn more about the natural history of HD. Participation lasts for as long as volunteers are able and willing to participate.
Who is it for? Adults and children who have had a genetic HD test, and adults who are part of HD families.
Contact: Anne Leserman, (319) 353-4307, anne-leserman@uiowa.edu.

Clinical Trials:

CIT-HD
What? An investigation of the effect of Citalopram vs. a placebo on attention, thinking ability, muscle movements and daily activities in participants with HD. Participation lasts for 20 weeks.
Who is it for? Individuals who have tested positive for HD or have received an HD clinical diagnosis. Participants must also notice a change in their level of attention, focus and/or thinking ability, and must be age 18-65.
Contact: William H. Adams, (319) 353-4411, william-h-adams@uiowa.edu.

2CARE
What? An investigation of Coenzyme Q-10 vs. a placebo for the treatment of HD symptoms. Participation lasts for five years.
Who is it for? Individuals who have mild HD, and who are age 16 or older.
Contact: Nancy Hale, (319) 353-4537, nancy-hale@uiowa.edu.

HART
What? An investigation of ACR16 vs. a placebo for the improvement of voluntary motor function in persons with HD. Participation lasts for 16 weeks.
Who is it for? Individuals who have clinical features of HD, and who are age 30 or older.
Contact: Nancy Hale, (319) 353-4537, nancy-hale@uiowa.edu.

GINA protections now in effect

Portions of the bill that Sen. Ted Kennedy, D-Mass called “the first major new civil rights bill of the new century” are now in effect.

The Genetic Information Nondiscrimination Act of 2008 (GINA) protects against the misuse of genetic information by employers and insurance companies. The provisions that prohibit insurers from obtaining genetic information or using such information to determine eligibility or premiums took effect on May 21.

The provisions of the bill that protect individuals from genetic information being used against them in the workplace do not go into effect until November 21.
Friends for life, friends for your health

“The consistent message of these studies is that friends make your life better.”

Karen A. Roberto, director for the center for gerontology at Virginia Tech

The prescription: coffee with your best friend, poker night with the guys or maybe a little Facebook time. Recent research has shown that having friends can help fight illness and depression and prolong life.

According to a New York Times article by Tara Parker-Pope published April 20, an Australian study found that older people with a large circle of friends were 22 percent less likely to die during the study period than those with fewer friends. A recent Harvard study reported strong social ties could promote brain health.

Additionally, Parker-Pope reports a 2006 study of nearly 3,000 nurses with breast cancer showed that women without close friends were four times as likely to die from the disease as women with 10 or more friends.

In the new book “The Girls From Ames: A Story of Women and a 40-Year Friendship,” author Jeffrey Zaslow chronicles 11 childhood friends from Iowa who eventually scatter to 8 different states. Despite the distance, the New York Times article says the friendships endured, and the role of friendship in the women’s health is evident throughout.

When two of the friends learn they have breast cancer, they turn to their longtime friends for support, more so than their doctors or even their families.

The article says people with strong friendships are even less likely to get colds, possibly due to lower stress levels.

“People with stronger friendship networks feel like there is someone they can turn to,” said Karen A. Roberto, director of the center for gerontology at Virginia Tech.

“Friendship is an undervalued resource. The consistent message of these studies is that friends make your life better.”

Source: www.nytimes.com