Takeaway from HDSA? Get involved

By Sean Thompson  
HIND-Sight Editor

Researchers, Huntington disease advocates and society officials all had the same message for the attendees at the 2010 Huntington’s Disease Society of America 25th National Convention this year in Raleigh, NC: Thank you for all you do for HD research and advocacy, and don’t stop now.

A record number of about 800 people heard the message June 24-25 to stay active, stay involved and continue to be part of the solution to end this devastating disease.

“What you’ve done has already changed the face of HD,” said UI HDSA COE Director Jane Paulsen, who is also the principal investigator of the PREDICT-HD study. “The key is getting involved.”

In regard to research, Paulsen said during the HDSA Research Forum that because of the 1,000 plus people who have taken part in PREDICT-HD, researchers have identified markers of HD up to 15 years prior to diagnosis. Those markers can be used to design better clinical trials for people prior to HD diagnosis.

HDSA CEO Louise Vetter talked about the recent history of the society and reflected on the last 25 years. She said she is inspired by the amount of progress that has been made, with many success stories in the areas of care, science and understanding of HD, thanks to the tireless efforts of HD families staying involved.

“In some ways, a quarter-century goes by in the blink of an eye,” Vetter said. “We must not get discouraged. We must soldier on. And we must look for new ways to conquer each battle as it approaches.”

Vetter reiterated that observational studies like PREDICT-HD and clinical trials involving drug treatments are in constant need of volunteers, and she asked the HD community to keep up their amazing commitment to research.

“We need more heroes,” Vetter said of those who volunteer for HD trials and studies. “It’s a personal decision, but it’s a powerful commitment. I ask you to think if you can step up and be a hero.”

During the keynote address, attendees heard from one of the HD heroes Vetter referenced. Jeff Carroll is a Ph.D. student and researcher at the University of British Columbia (UBC), and he also has HD in his family. When he tested gene positive for HD in 2003, he told the physician that gave him his results that he wanted to help.

Ever since, he’s been doing HD research in the lab of prominent researcher Michael Hayden of UBC.

“What I’ve found in Michael’s lab is hope,” Carroll said. “The real knowledge that people who are very smart are working hard every day to find a cure.

“Engagement with HD has been a huge blessing for me.”

Carroll encouraged attendees to get involved in research or at a minimum to stay engaged and educated about HD.

“I don’t know if I will die of Huntington disease or in my sleep when I’m 100,” Carroll said. “But what I hope is on that day when I look back, I’ll know that I have done everything I can.

“I have found enormous peace with positive engagement with this disease, and I hope that you can too.”

Thank you to all our Iowa City Hoop-A-Thon donors!

Thanks to around 200 businesses and individuals who donated money, silent auction items, food and their time to the 2010 HDSA Iowa City Hoop-A-Thon. It’s because of you we were able to raise about $5,500 for HD research and care. We cannot thank you enough for making the event a success!

We have our sights set on an even higher total and a better event for 2011. If you would like to get involved, please contact Sean Thompson at sean-thompson@uiowa.edu or (319) 384-4094.
Dr. Gonzalez a fixture at HD Clinic

Patients that come to the UI HDSA COE’s HD Clinic are getting used to seeing another familiar face as part of the clinic staff.

Since January, Dr. Pedro Gonzalez, M.D., has been the clinic’s consistent neurologist, fulfilling the role that had been covered by a handful of doctors who rotated in and out of the clinic. Gonzalez says that consistency helps improve the level of care clinic patients receive.

“Here, you get to know the patient,” Gonzalez said. “You get to know their caregivers, their family members, sometimes the staff of whatever residence they live in. You get to know what they expect in life.”

Gonzalez, 38, is a native of Spain and graduated from the University of Málaga Medical School in Spain. He came to Iowa in December of 1999 and completed a two-year fellowship in movement disorders, working under Dr. Hank Paulson, former co-director of the UI HDSA COE.

Getting to know the clinic patients and working with a team that has a wealth of knowledge about HD has made being the clinic’s neurologist a great experience so far, Gonzalez said. The clinic staff are knowledgeable on every aspect of HD, which is a unique benefit for patients with a relatively rare disease.

“Patients come here and they see everyone they need to see,” Gonzalez said. “We try to answer all their questions.”

Gonzalez, who has three young children with his wife, Dr. Ana Recober (also a neurologist at the UI), enjoys traveling with his family in his free time. He’s also an avid cook of dishes that remind him of his native Spain (which, he proudly pointed out, is the 2010 World Cup champion).

If you’re willing, UI has an HD study for you

Perhaps you think you aren’t eligible to participate in HD research because you tested negative for the HD gene mutation. Or maybe you haven’t even been tested and thought this would prevent you from volunteering for a study.

It turns out there are volunteer opportunities for people in both categories. In fact, if you come from an HD family and are willing to volunteer your time for HD research, there is likely a study that would benefit from your participation.

At the University of Iowa, PREDICT-HD and COHORT are two observational studies that are enrolling volunteers. To be eligible to participate in PREDICT-HD, participants must have tested gene positive or gene negative for HD.

And to take part in COHORT, if you are a member of an HD family, regardless of your gene status and regardless of whether or not you’ve been tested for the HD gene, you are likely eligible for this study.

Both PREDICT-HD and COHORT involve annual visits, and participants can take part in both studies at the same time if they are willing.

Other inclusion criteria do apply, so if you are interested in taking part in either study, please contact Anne Leserman at anne-leserman@uiowa.edu or (319) 353-4307. We have several other studies enrolling, so if you’d like to volunteer, contact us and we will find a study for you.

From the editor

I hope you enjoy our profile of Dr. Gonzalez (above) We are lucky to have him in our clinic. If you’re coming to clinic, try to think ahead of what HD questions you’d like to ask him, in order to get the most out of your appointment.

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 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

PREDICT-HD: Contact Anne Leserman, (319) 353-4307, anne-leserman@uiowa.edu
COHORT: Contact Nick Doucette, (319) 353-5546, nicholas-doucette@uiowa.edu
CIT-HD: Contact William H. Adams, (319) 353-4411, william-h-adams@uiowa.edu
2CARE: Contact Nancy Hale, (319) 353-4537, nancy-hale@uiowa.edu
CREST-E: Contact Nancy Hale (see above)
HDSA walk on Sept. 18 in Ankeny

The third-annual HDSA Iowa Chapter Team Hope Walk for HD features a brand new location this year and a silent auction to raise additional money for HD research. The walk will take place Saturday, Sept. 18, 9-11 a.m. at the Ankeny campus of Des Moines Area Community College in Ankeny, IA. The campus is a great location for the walk, said Walk Chair Lori Wesack.

Registration for adults is $15 or $20 for same-day registration. Children are $10 or $15 on walk day. All money goes toward HD research, and all participants get a free t-shirt!

For more information or to pre-register by Sept. 10, contact Wesack at (515) 314-7262 or loriwesack@gmail.com.

For more information on the UI HDSA Center of Excellence, visit our website at:

www.uihealthcare.com/depts/huntingtionsdisease/

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NYA a network of support

By Elizabeth Speth
Special contributor to HIND-Sight

(Editor’s Note: To find out more about the HDSA National Youth Alliance, we asked Elizabeth Speth of Van Horne, IA to write about her experiences as an NYA member)

My dad was diagnosed with Huntington disease when I was 12 years old. It was one of the hardest things I have ever had to deal with in my life. I felt as if I had no one to turn to that was my age or could understand the difficulties that come with having an ill parent. I truly felt lost and alone.

I attended my first HDSA National Convention my sophomore year of high school. This is where I found out about the HDSA National Youth Alliance (NYA). The NYA is a group of young people ages nine through 29 who are affected by this devastating disease and want to make a difference. Our motto is “Making this the Last Generation Affected by HD.”

It was here where I got to meet young people just like me from across the country. The NYA is very supportive of the HD community. We usually host a silent auction and talent show during the national convention. The money raised supports not only research but also scholarships that help youth members attend the convention. Without such scholarships, those members may not be able to afford to attend.

During the convention, there is also a day dedicated to the NYA. A local company will sponsor this event and the NYA members get to have a day to themselves. It’s an opportunity to meet up and just have fun. During the rest of the year we will meet up on our online board where we have a place just to chat.

I cannot tell you how many wonderful people I have meet who are affected by HD. I now feel like I have unlimited support when it comes to dealing with HD. I now understand that I can make a difference in someone’s life just by being that “someone to talk to.” I have daily contact with many of the people I have met through the NYA, and it has done amazing things for me. I could never put into words exactly how much that means to me.

On the Web
If you are interested in finding out more about the NYA or becoming a member, visit www.hdsa.org/nya

HDSA Research Forum: hindsight and foresight

By Anne Leserman
Social Worker and UI HDSA COE Coordinator

During the research forum at the 25th Annual HDSA National Convention June 26 in Raleigh, NC, Marcy McDonald, Ph.D., professor at Harvard Medical School, reviewed the progress made over the last 25 years. She covered the formation of the HD gene in 1993. She closed covering the various partnerships, study beginnings and study completions that bring us to today. With 150-200 laboratories around the world working on HD, this completes an impressive 25 years.

Looking forward, Rick Morimoto, Ph.D., professor at Northwestern University, talked about gaining a better understanding of the huntingtin protein. He uses nematodes (simple-celled worms) to try to restore balance in the protein. The idea is to use protein “chaperones” and other defense mechanisms to prevent protein aggregation, which is a major disruption causing problems in HD.

Steve Finkbeiner, M.D., Ph.D., director of the Taube-Koret Center for Huntington’s Disease Research, at the University of California, San Francisco, talked about applications of induced pluripotent stem cells, another exciting topic. These adult cells can be converted to become stem cells again. Cell replacement may be the most difficult method of treatment given issues of how to transplant cells, safety and making the right connections. But Dr. Finkbeiner thought these stem cells may be better used for drug screening for potential treatments and to assist researchers in better understanding the disease mechanism.

Several of the researchers presented the analogy of a key in the door. It is critical to find both the right door and the right key to prevent the devastation of HD. But we also need to understand how to insert the key in the door.

We wish these researchers all the best in their search for treatments and a cure.
Nursing homes giving more freedom to residents

"It’s not for us to give them freedom. They should have it."

Julie Boggess
CEO of Bethesda Home

when to bathe, eat and sleep; allowing them to organize their own activities; and redesigning nursing units into small “households.”

Such homes are in the minority – but not for long, advocates say. They claim residents in such homes are happier and healthier; the employees have more job satisfaction; and giving care this way even costs less.

Julie Boggess, chief executive officer at the Bethesda Home, doesn’t even like to speak of “allowing” residents to sleep late. “It’s not for us to give them that freedom,” she said. “They should have it.”

Even those wanting to make the changes find it hard. Janet Meyer, the home’s director of nursing, had proposed a single change: letting residents sleep late.

But “that’s a bigger deal at a nursing home than you might think,” she said.

Mealtime practices had to be changed to accommodate late risers. Housekeeping had to be done more flexibly to avoid waking residents for vacuuming.

Most challenging, the morning medication system had to be changed. Nurses struggled to adjust, and residents worried that if they didn’t get their morning medications at the precise time they always had, their health would be harmed.

Removing nursing stations is another common element of culture change; the stations are reminiscent of hospitals.

“We are open to and support the concept of changing nursing homes to be more homelike environments,” said Melaney Arnold, spokeswoman for the Illinois Department of Public Health.

Giving out medications individually can be more time-consuming, a nurse at Bethesda admitted, but “you’re relating to people on a little different level. You’re actually consulting with the resident.”