Bringing HD advocacy to Washington

UI Neuropsychologist Megan Smith represents the UI HDSA Center of Excellence at HDSA’s Advocacy Day

By Megan Smith
UI HDSA COE Neuropsychologist

On March 18, I was one of nearly 100 Huntington disease (HD) advocates who converged on the Capitol Building in Washington, D.C., for the Huntington’s Disease Society of America’s first Advocacy Day.

Our diverse group of health care workers and HD family members from 25 states began the day with presentations from representatives of Strategic Health Care, an advocacy firm working with the HDSA. We also heard from HDSA CEO Louise Vetter, who focused us on our goal for the day: persuading our representatives to support HR 678, the HD Parity Act (see sidebar).

We learned that sharing our expertise on HD, as well as personal stories of how this legislation would make positive changes for patients and families, were the most effective methods of communicating with our elected officials. We also welcomed visits from US Reps. Brian Bilbray, R-California, and Bob Filner, D-California, who were the original sponsors of the bill. The representatives joked that our raucous cheering was the first positive reception they had received in a long time, since our visit occurred in the midst of the health care reform vote. They both emphasized that they never would have known about the necessity of updating Social Security definitions of HD or reducing the waiting period for Medicare for individuals with HD if it hadn't been for the efforts of their constituents. This was just the inspiration we needed to head into our meetings.

Though it was easy to feel intimidated when walking past metal detectors and guards in the beautiful yet imposing Senate office buildings, the legislators I met with were gracious, welcoming, and interested in the opinions of their constituents. Senator Tom Harkin, D-Iowa, was, understandably, in meetings about the upcoming health care vote, and I met with one of his aides on the Health, Education, Labor, and Pensions committee, one of the most powerful committees in the Senate. I shared my experiences working as a neuropsychologist in both PREDICT-HD and our UI HDSA Center of Excellence. I emphasized that because The UI has been a leader in HD research and clinical care, our representatives should be leaders in HD advocacy.

Later in the day, I met with Rep. Dave Loebsack, D-Iowa, who represents Iowa's 2nd district and was already a co-sponsor of HR 678. I thanked him for his support and urged him to speak with colleagues who had not yet signed on.

Lastly, I met with Sen. Chuck Grassley, R-Iowa, the ranking member of the Senate Finance committee, and two of his advisors on health policy and social security. I was tired from my day of lobbying, but invigorated by sharing the HDSA's message about the HD Parity Act and the opportunity to take my knowledge of HD beyond the clinic and research.

I strongly encourage HD advocates to make their voices heard and contact their representatives directly on this issue. This bill is still waiting for the House to move it to a vote and still needs a sponsor to introduce it in the Senate. Personal phone calls (or visits if you can make the trip) are the most effective. You can learn more about the status of the bill and whether your representatives are co-sponsors here: http://thomas.loc.gov/.
Iowa Hoop Tour hits the road for HD

By Sean Thompson
HIND-Sight Editor

As public relations coordinator for the UI HDSA COE, I traversed the Hawkeye State in March and April during the HDSDA Iowa Chapter’s 2010 Iowa Hoop Tour.

Thanks to many generous contributions by individuals and businesses, the chapter raised $36,392 for Huntington disease research and care.

I attended all five Hoop-A-Thon fundraisers in Storm Lake, Bedford, Audubon and Des Moines before coming home to help run the first ever Hoop-A-Thon in Iowa City. By the end of the tour, I had accumulated several lovely Iowa Hoop Tour T-shirts, a sore shooting arm

At the Iowa City Hoop-A-Thon, UI HDSA COE Director Jane Paulsen is interviewed by KGAN CBS-2. The report aired on the evening news.

and a great admiration for the way each of the five communities came out to support a great cause.

Joining me at all the tour stops were HDSA Iowa Chapter President Karen Brown and other members of the chapter board.

“The Iowa Hoop Tour was a great success again this year,” Brown said. “We continue to have new people come out to help and enjoy the events, and we appreciate all that everyone does to help the events succeed year after year.”

Storm Lake kicked off the tour in style on March 20 with its biggest Hoop-A-Thon yet, with 67 shooters stepping to the free-throw line to see how many shots they could make in five minutes. I was impressed with the attendance and level of organization thanks to Chair Amanda Danwood and her fellow organizers.

Bedford and Audubon followed on March 27 and 28. The Bedford event thrived on a close-knit feel established by Brown over many years. Audubon organizer and teacher Carrie Tibben’s standing with the community’s school-aged kids was evident at an event that buzzed with youthful enthusiasm.

On the final weekend of the tour, April 10-11, the AIB College Activities Center in Des Moines was an impressive

facility, and organizer Sarah O’Neil had shooters going throughout the afternoon.

Finally, our inaugural Hoop-A-Thon event in Iowa City was a success! We had a nice mix of UI HDSA COE staff, local HD families, volunteers from West High School and members of the Iowa Hawkeyes women’s basketball team provided rebounding and encouragement for our shooters. We are already looking forward to having an even better event next year!

I’ll defer to Karen to sum up the 2010 Iowa Hoop Tour:

“We have raised much-needed money to help find a cure for this devastating disease,” she said. “Thank you!”

Stem cell treatment for HD progressing

Researchers at the University of California, Davis are hoping to conduct a new clinical trial involving stem-cell treatment for Huntington disease, says the director of the stem cell program there.

Dr. Jan Nolta, Director of the UC Davis Stem Cell Program, shared an exciting research update with attendees at the HDSDA Northern California Chapter Convention on May 1 in Sacramento, CA. Members of the UI HDSA COE attended the convention to answer questions about the PREDICT-HD study.

Nolta and colleagues have been looking at the use of mesenchymal stem cells (MSC) harvested from a healthy donor’s bone marrow to protect and heal neurons in the brain that are damaged in individuals with HD. The method has worked in animal models, but, htt, the mutant protein that causes the neuron damage, still remains.

In order to cure the disease, htt must be continually reduced, Nolta said. Nolta and colleagues believe the same stem cells that heal neurons can also be used as delivery vehicles to transport small interfering RNA (siRNA), which have been shown to decrease the damage-causing mutant protein in mouse models.

“We really have shown that it’s safe and not going to cause any harm,” Nolta said.

The next step is a clinical trial to examine the outcomes of MSC stem cell treatment in people with HD. Nolta said initial paperwork to begin such a trial has been filed with the Food and Drug Administration.

From the Editor

We here at the UI HDSA COE are looking forward to the upcoming HDSDA National Convention in Raleigh on June 25-27. For more info, visit www.hdsa.org. If you can make it, be sure to stop by the PREDICT-HD info booth!

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
Drug trial enrolling at UI

Researchers are hoping to determine if a drug that has shown to pose minimal risk to Huntington disease patients has any positive effect on thinking ability for people with HD.

The HORIZON trial is currently enrolling participants at about 50 sites across the world, including the UI. HORIZON is a trial of the research medication Dimebon in persons who have been diagnosed with HD. The goal is to determine whether the drug has an effect on cognition or thinking ability such as memory or problem-solving skills, said HORIZON UI Coordinator Elijah Waterman. “The investigators think the drug might improve people’s memory or see less of a decline in memory over time,” Waterman said.

During a previous study, the same investigators did see an improvement in learning and memory skills for those taking Dimebon when compared to those taking a placebo. Those preliminary results from the Phase 2 trial were published in February in Archives of Neurology.

HORIZON Principal Investigator Dr. Karl Kieburitz of the University of Rochester said the current Phase 3 trial is being conducted to see whether the initial published findings can be confirmed in a bigger sample of participants.

In order to qualify for the HORIZON trial, you must be at least 30 years old, have clinical features of HD and have tested positive for the HD gene. You must also have a companion or caregiver who spends at least five days a week with you at least three hours a day. The companion plays an important role in providing feedback on whether or not the participant’s thinking ability is improving, Waterman said.

During the trial, participants will be assigned randomly to receive either daily doses of Dimebon or a pill that looks like Dimebon but has no active ingredients, also known as a placebo. The trial includes 26 weeks of taking the drug or placebo. During that time, there are eight visits and one telephone call scheduled to evaluate general health, thinking ability, memory, mood, overall functioning and movement.

Waterman says it’s important to have some of the participants taking the placebo, because the act of simply taking a pill or participating in a study can make one feel better. If everyone in the study starts is taking a pill that may or may not be the study drug, then researchers can determine if the drug is truly effective.

Participants who complete the trial, including those who received the placebo, will have the option to receive Dimebon at the end of their 30th week in the trial. This is known as an “open label” trial. They can continue to take Dimebon at no cost until it is approved for sale.

Those who complete the study will receive a total of $600 for their time and any expenses. If a participant does not finish the study, he or she will still be paid for the visits you completed. Travel reimbursement is considered on a case-by-case basis.

At the UI, Waterman is joined by HORIZON Investigators Dr. Leigh Beglinger, Dr. Eric Epping and Dr. Megan Smith.

HORIZON is sponsored by Medivation, Inc., in collaboration with Pfizer, Inc., and is an official Huntington Study Group trial.

On the Web
For a listing of study sites and more information, visit www.huntington-study-group.org.

Other studies currently enrolling at the UI
- PREDICT-HD: Contact Anne Leserman, (319) 353-4307, anne-leserman@uiowa.edu
- COHORT: Contact Anne Leserman (see above)
- 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
- HART: Contact Nancy Hale (see above)
- PREQUEL: Contact Nancy Hale (see above)
Working overtime may harm your heart


If you've been saying for years that long hours at work are killing you, send this article to your boss — it might literally be true. According to a new study, people who work more than 10 hours a day are about 60 percent more likely to develop heart disease or have a heart attack than people who clock just seven hours a day.

It's not clear why this is, but the researchers suggest that all that time on the job means less free time to unwind and take care of yourself. Stress may also play a role — but not as much as you might think. Working long hours appears to hurt your heart even if you don't feel particularly stressed out, the study found.

“Balance between work and leisure time is important,” says the lead author of the study, Dr. Marianna Virtanen, M.D. “If you work long hours, the fact is that you may be exposed to higher stress levels and you do not have enough time to take care of your health.”

The study followed more than 6,000 British civil servants with no history of heart disease for an average of 11 years. During the study, a total of 369 people had heart attacks (some of them fatal) or were diagnosed with heart disease after seeking medical attention for chest pain.

Compared to people who worked seven hours a day, those who worked 10 to 12 hours a day had a 56 percent increased risk of heart disease, heart attack or death. Those who worked for 8 to 10 hours a day were not at increased risk.

To try to pinpoint the effect of work time, Dr. Virtanen and her colleagues took a range of health factors into account in their analysis, including blood pressure, cholesterol levels, diet and exercise and whether or not the participants smoked. They also factored in the workers’ rank and salary, since socioeconomic status has been linked to heart health.

The people who worked overtime were also more likely to exhibit “Type A” personality traits, which includes aggressiveness, irritability and a “chronic, incessant struggle to achieve more and more in less and less time.”

But the workers who burned the candle at both ends were still at greater risk of heart disease even when all of these factors were accounted for, which suggests that something besides stress, personality and behaviors may be responsible.