



UI Associate Professor of Psychiatry Leigh Beglinger, Ph.D. and UI Junior Luke Prest examine HD patient data. They found a correlation between declining cognitive scores and driving recommendations that could serve as a standard to help clinicians make driving recommendations.

Study looks at driving and HD

By Sean Thompson
HIND-Sight Editor

For many people, driving a motor vehicle gives them a strong sense of independence.

The symptoms of Huntington disease can impair a person's ability to drive safely to the point where, unfortunately, they shouldn't be driving anymore.

"It's not something as a clinician I take lightly in terms of making recommendations about driving or not driving," said UI HDSA COE Neuropsychologist Leigh Beglinger, Ph.D., "because you realize how important it is to people."

HD impacts people younger than other neurological diseases that can impair driving like Parkinson's and Alzheimer's diseases, but there has been little research into HD and driving. That's why Beglinger and UI junior Luke Prest decided to look into the correlation between clinicians' driving recommendations and cognitive, psychiatric, motor and functioning assessment results. If they could show that a decline in certain assessments coincided with a clinician's recommendation to stop driving, clinicians could use those assessments to help guide or reinforce their driving recommendations.

"We're going on the assumption that a clinician's decision is possibly one of the best ways to decide whether a patient should be driving or not," Prest said. "This would be a way to help verify a clinician's decision or tell them which tests they should look at first when trying to decide."

When Prest and Beglinger reviewed patients' charts, they found the strongest indicator of when a clinician would make a recommendation to stop driving was a declining score in cognitive (thinking ability) testing, especially tests measuring short-term memory, psychomotor speed and attention. Beglinger said those are key areas that are known to be affected by HD.

Prest, who received a grant from the Iowa Center for Research by Undergraduates for the project, is hoping to continue the research after the current results are published in a scientific journal. He wants to talk to HD families about when people actually decide to stop driving and what caused them to stop.



Luke Prest
UI Junior

Protection for HD families against health ins. discrimination

Legislative action taken in Iowa this year prohibits insurance companies from discriminating against persons with HD based on genetic testing results.

Gov. Chet Culver signed Senate File 2215 into law in April, which is meant to prevent genetic information, such as a positive HD test, from being used to deny someone health insurance, according to Sheldon

Kurtz, UI Percy Bordwell Professor of Law. The bill also says insurance companies cannot set rates based on genetic information.



Sheldon Kurtz
UI Professor of Law

"We don't want health insurance companies, based on these genetic tests, to exclude people from coverage," Kurtz said. "I think it's an overall positive statute for people who might have a genetic marker."

The bill's importance could ultimately be determined by the enactment of the federal health care reform bill, Kurtz said. If the federal bill holds up as it's currently signed into law, all insurance discrimination based on pre-existing conditions will be prohibited in 2014. But for now, the bill provides needed protection for Iowa HD families.

According to the *Des Moines Register*, the bill was prompted by several women in Dubuque who wanted to know if they had genetic markers related to breast cancer, and were afraid their genetic test results would be used against them by insurers.

On the Web

For more on the bill and more from Prof. Kurtz, visit www.uihealthcare.com/depts/huntingtonsdisease for a web-exclusive extended article.

2011 HDSA Iowa City Hoop-A-Thon set for March 27

The 2011 HDSA Iowa City Hoop-A-Thon will take place March 27.

More details about the second-annual fundraiser will be announced soon, says event co-chair Kelly Herwig.

The Hoop-A-Thon is centered on a free-throw shooting contest and also includes a silent auction, raffle, cake walk and concessions. Proceeds will go toward HD research and care. This year, about \$5,500 were raised, Herwig said.

“We’re looking forward to an even bigger and better event in 2011,” Herwig said.

For more information or to donate items or volunteer at the event, contact Herwig at kelly-herwig@uiowa.edu.

Medical equipment exchange available through HDSA

Medical equipment can be expensive, especially the kind of specialized equipment that some HD patients need. The HDSA aims to give families a no-cost option for obtaining used equipment with a new online tool.

The HDSA Medical Equipment Exchange Board offers a venue to post information about durable

medical equipment for people with HD. If you have equipment to donate or are looking for something, the resource is available on HDSA’s home page, www.hdsa.org.

According to the HDSA, the donated

equipment may be new or used and must be clean. Users are reminded to only post durable medical equipment, such as Broda chairs and beds, wheelchairs, walkers, hospital bed accessories, and assistive

mobility devices. The exchange board is designed to promote direct collaboration between individuals seeking medical

equipment and those who no longer need it, according to the HDSA. The HDSA and the UI HDSA COE do not endorse, guarantee, or recommend any equipment, not do they participate in any equipment transaction.

On the Web

If you are looking for HD-related medical equipment or have something to donate, visit www.hdsa.org and follow the shortcut for “Equipment Board”

“Our fairy godmother” — Midge Toole (1925–2010)

By Kristine Bjork
UI Editorial Associate

This September, we lost Midge Toole, an influential and dear friend of The University of Iowa’s Huntington Disease Society of America Center of Excellence.

Her \$50,000 contribution is the largest private donation the center has ever received. Midge’s donation started the Shield Family Endowment, and donations from various supporters continue to be added to the fund.

In 2007, Midge approached the University of Iowa Foundation to set up a fund specifically for care of Huntington Disease patients and their families.



Midge Toole
Courtesy photo

Midge had an uncle with HD, so she saw firsthand the suffering and stigma associated with the disease. She wanted to help improve the quality of life of individuals and families with HD.

This fund has allowed individuals who do not have insurance to get genetic tests and attend comprehensive clinic



(from left to right) UI HDSA COE Coordinator Anne Leserman, Midge Toole and former UI HDSA COE Co-Director Hank Paulson in 2007.

appointments that include cognitive testing and visits with a neurologist and a psychiatrist.

“Money is no longer an issue for people coming to the clinic,” said Anne Leserman, UI HDSA COE coordinator. “She allowed us to do things that were just the right things to do. It’s really been a pleasure to pass that along. She leaves a nice legacy to us.

“Midge was a real spunky lady. She was our fairy godmother.”

Reminder: Support Group Holiday Party December 12

The UI HDSA COE Support Group is hoping you join us for our Holiday Party on Dec. 12 from Noon to 2 p.m.

Lunch will be provided, and members of the UI HDSA COE research and care team will be on hand to celebrate the holidays with the group.

The party will be held in the Della Ruppert Conference Room at UI Hospitals and Clinics. **You may RSVP by contacting Anne Leserman at (319) 353-4307 or anne-leserman@uiowa.edu.**

We hope to see you there!

From the editor

We are saddened by the passing of Midge Toole (see left), but her legacy lives on in the HD patients helped by her generous contribution. If you’d like to contribute to the Shield Family Endowment, please contact the UI Foundation at (800) 648-6973.

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

Find friends, information at support group

By Sean Thompson

HIND-Sight Editor

When Mary Woods' daughter Erin was diagnosed with Huntington disease several years ago, Mary didn't know what to expect as the disease progressed.

Woods, of Mount Vernon, wanted a "non-medical, non-technical" overview of what was to come. So she attended the UI HDSA COE HD support group for the first time.

"I wanted to go to a support group where I knew people were knowledgeable," Woods said. "And people who know about HD are the ones that live with HD."

The support group has provided her with lots of knowledge about HD, and equally important, Woods says it has provided her with numerous friendships. She says the UI support group is like a close knit family.

At an HD support group in Des Moines, caregivers, friends, family members and persons with HD all attend the meetings, said group coordinator and social worker Mark Hillenbrand. At a typical meeting, members set the topics of discussion based on what's going on in their lives.

"Support group is a place where those affected by HD can come and spend

time with others facing similar challenges," he said. "Where they can feel understood, and gain support or strength from others who have faced this disease."

At the UI support group, guest speakers are often scheduled to discuss things like nutrition or palliative care, Woods said. She likes the variety of learning from experts coupled with group discussion with other caregivers, where she might learn a coping strategy she hadn't thought of or just have an opportunity to vent.

"Then you go home and you don't think about it all the time," Woods said.

Support groups are particularly beneficial for families facing a relatively uncommon and unknown disease like HD, Hillenbrand said. The group provides a place where members don't feel the need to keep discussion of HD relegated to a whisper.

"Often times, HD is not talked about," Hillenbrand said. "The support



Mark Hillenbrand
Social Worker

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

group offers a safe place to begin learning the skills of talking about it."

Woods says any member of an HD family should attend a meeting if they're at all interested.

"Give it a try," she said. "Feel free to come when you can and ask any question you want."

Creatine trial recruiting participants

The UI HDSA COE is continuing to recruit participants for a clinical trial measuring the effects of creatine-monohydrate on the progression of functional decline in HD over 37 months.

If you or someone you know is 18 years of age or older, has clinical features of HD and have tested positive for the HD gene expansion, you may be eligible for the CREST-E clinical trial. The trial

is being conducted by the Huntington Study Group at several sites around the world, including The University of Iowa. Research Assistant Nancy Hale, R.N., is coordinating the study at the UI.

The trial is also designed to assess if the drug is safe and tolerable for persons with HD and its effect on clinical symptoms and quality of life. Evaluation will also include how a variety of biological processes are affected by the study drug.

Following an initial visit, participants will be randomly assigned either the study drug or a placebo. Participants will continue to take the drug or placebo for 36 months, and a series of regularly-scheduled visits and telephone calls will be held to evaluate general health, movement and mood.

For more information on participating, contact Hale at (319) 353-4537 or nancy-hale@uiowa.edu.

Other clinical trials at the UI HDSA COE

— CIT-HD

What: A 22-week study to evaluate the effect of citalopram compared to a placebo on daily activities such as working, attention, thinking ability and muscle movements.

Who: Individuals 18 to 75 who have tested positive for HD and are not currently taking medication for depression.

More: Compensation is available, and travel reimbursement is provided.

Contact: William H. Adams, (319) 353-4411, william-h-adams@uiowa.edu.

— 2CARE

What: A five-year study to evaluate the effect of Coenzyme Q10 on the progression of functional decline in HD, as well as long-term safety and tolerability.

Who: Individuals 16 or older with early HD.

More: 2CARE will be the largest therapeutic trial to date in HD, with 600-plus participants.

Contact: Nancy Hale, (319) 353-4537, nancy-hale@uiowa.edu.

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

www.uihealthcare.com/depts/huntingtonsdisease/

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Search for:
U. of Iowa Huntington

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Research providing breakthroughs in Alzheimer's

By Kristine Bjork
UI Editorial Associate

Researchers say they are getting close to finding a treatment and slowing the dementia caused by Alzheimer's disease (AD).

The most common cause of dementia, AD is a brain disorder in which those effected first suffer from memory loss, followed by a decline in thinking skills and changes in behavior and personality.

In the last 30 years, scientists have made leaps and bounds in their knowledge of the disease, from knowing almost nothing about the disease to understanding it on a molecular level.

"The understanding we've gained in the last two or three years is phenomenal," said Dr. Dennis J. Selkoe of Harvard Medical School in the HBO video, "How Far We Have Come in Alzheimer's Research."

Until now, the focus has been on decreasing dementia symptoms after they start. Now, researchers are looking at targeting the disease process before

"The understanding we've gained in the last two or three years is phenomenal."

Dr. Dennis J. Selkoe
Harvard Medical School

symptoms develop. Earlier diagnosis, they say, is key to learning more about this disease. It will take time, but these scientists are confident that they will be able to slow the progression of the disease.

Because researchers can search the human genome like never before for any genes believed to affect the onset of AD, three genes linked to the formation of the disease have been identified. This focus on genetics allows researchers to target the disease before it starts and to see who might be genetically predisposed to develop the disease.

Until recently, it has been almost impossible to see Alzheimer's in a brain scan. Large clusters of proteins called amyloid plaques build up in the brain of

an AD sufferer and can short circuit nerve cells. These plaques, along with clusters of dead nerve cells known as "tangles," may be the main cause of the dementia associated with AD. Scientists say they are close to being able to block or partially block this plaque build-up in order to slow the onset and progression of dementia.

Scientists are trying to stimulate the human immune system's natural process of removing these plaques from the brain, and they say results in mice models have been promising. They hope to replicate those results in humans.

"We are at the brink of controlling one of the major diseases affecting world health," added a researcher in the HBO video.

Information gathered from the HBO video series, "The Alzheimer's Project," at www.hbo.com/alzheimers. Videos summarized include "How Far We Have Come in Alzheimer's Research," "Understanding and Attacking Alzheimer's" and "Looking Into the Future of Alzheimer's."