A team approach to testing
Presymptomatic testing now offered directly through UI HDSA COE

By Shawna Feely, MS, CGC
UI HDSA COE Clinic Coordinator

Since the advent of presymptomatic genetic testing for HD, many people have struggled with the question of whether or not to test.

Because of the impact testing can have on a person's life and the complexity of the decision, forward thinkers at the HDSA published “Guidelines for Predictive Testing for Huntington Disease” in 1989 with a revision published in 1994. Since the ramifications of presymptomatic genetic testing for HD were substantial, HDSA sought to create a platform where each individual considering whether or not to test could make a fully-informed decision.

The University of Iowa Hospitals and Clinics has provided testing for many years following HDSA guidelines. Only recently, however, has presymptomatic genetic testing been offered directly by the UI HDSA COE itself. The newly established testing protocol allows people who are at risk for HD and considering testing to work directly with the HD specialists in the UI HDSA COE. These specialists' direct knowledge about HD treatment options, disease management and current research can be valuable not only for people who have HD, but also those living at risk.

Like most HD testing centers, the new UI protocol involves several steps. Each individual will meet with a neurologist, psychiatrist and genetic counselor, allowing them to reach out to any of these individuals for any needed assistance. This is the strength behind this process, as it allows each individual to have a multidisciplinary care team in their corner to not only help them through the process of testing, but also provide support after testing.

Under the new protocol, the first visit is scheduled after an individual has made contact with our center. This visit includes both a neurological exam performed by a neurologist and genetic counseling by a Certified Genetic Counselor (CGC) who works with the UI HDSA COE. The neurological exam can help to reassure people who are going through the testing process simply because they think they are showing symptoms of HD. The genetic counseling portion of this visit provides an overview of the testing process and an opportunity to discuss issues such as genetic discrimination, family planning, long-term goals and financial planning. The genetic counselor will be the same throughout the process and will attend each visit.

The second visit is to help focus on the needs of the individual and their family, along with the emotional ramifications of making this decision. The genetic counselor will attend each visit.

New HD at-risk support group available

A new HD support group aims to cater to those dealing with the unique issues surrounding being at-risk for HD or presymptomatic, and let them know they are not alone.

When he was younger growing up with a mother who had HD, UI Psychiatric Nursing Assistant Brandon Rogers said he often felt isolated, not knowing anyone else from an HD family.

“I felt like I was on my own little island and I didn't feel like there was anyone out there dealing with what I was dealing with,” Rogers said.

A year after Rogers’ mother Jayne passed away from HD in 2012, he attended his first HD Support Group meeting at the UI HDSA COE. It felt good to talk openly about his mom, what it had been like to be a caretaker for her and having to explain HD to others or feel embarrassed by it. He was comforted by people who knew firsthand exactly what he was talking about.

“As I’ve gotten older, I’ve realized there are people out there [who understand], but there are also people like I was that don’t know where to turn.”

That’s why with the help of UI HDSA COE Clinic Coordinator Shawna

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Shawna Feely
Genetic counselor

(From L to R) UI HDSA COE Research Associate Courtney Shadrick, HDSA IA Chapter President Lori Wesack and daughter Amelia (front) at the 2013 Cedar Rapids Hoop-A-Thon, where over $3,500 was raised for HD research and care. Thank you to the HDSA IA Chapter for all its efforts during the 2013 Iowa Hoop Tour!

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Paulsen named Carver Chair

Given current economic and budgetary realities, UI HDSA COE Co-director Dr. Jane Paulsen says researchers will have to maximize their capabilities to keep up with the increasingly faster pace of HD research.

One source of inspiration when facing this challenge for Paulsen is Roy J. Carver, the Muscatine entrepreneur and namesake of the Roy J. Carver Chair in Neuroscience, an honor which Paulsen recently received.

Paulsen explained during an investiture ceremony on March 8 that as a young industrialist, Carver was at one time insolvent. But he continued to innovate and invent, and less than a decade later, he was one of the most successful businessmen in Iowa. Researchers are going to have to show some of Carver’s resilience in the coming years, she said.

“To succeed and move science forward in this economic climate, we’re going to have to be risk takers,” said Paulsen, a professor of psychiatry, neurology, psychology and neurosciences.

The $2 million fund endowing the chair is a gift from the Roy J. Carver Charitable Trust, made through the University of Iowa Foundation in order to establish the chair. A faculty chair is the highest honor given by the university to an outstanding member of the faculty.

An internationally renowned expert in HD for more than 25 years, Paulsen and her collaborators’ findings on HD represent the greatest growth in knowledge about HD since study of the disease began.

UI President Sally Mason thanked Paulsen acknowledged those who have worked with her at the UI HDSA COE and across multiple disciplines for their dedication and collaborative efforts toward helping those with HD and other neurodegenerative diseases.

A place to share, learn with those who understand

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Feely, he started the new support group in April for those who are at-risk for HD or those who have tested and aren’t yet diagnosed with HD.

Rogers, who is at-risk for HD but untested, said he started the group as a spin off from the regular HD support group in part because the new group caters to those who often feel out of place at a regular HD support group.

Feely says the new group’s target audience is dealing with unique issues, such as genetic testing, when and how symptoms might arise, future planning, insurance questions and how to plan a life around the uncertainty of being at risk for HD.

“Because of these distinct differences, having a group that can help to meet each of these needs is essential to providing support,” Feely said.

Much like Rogers, those who find support groups to be beneficial often cite the companionship and support from people who understand where each other are coming from.

“Whether it’s through laughter or pain, when people with similar challenges have the opportunity to reach out to each other, they can sometimes find a source of support that surpasses what current medical treatment can provide,” Feely said.

For those who are unsure if participating in a support group is for them, Feely hopes they are willing to push through the initial anxiety and try it out.

“If this can help even one person feel better about a decision to test or not to test, if it can make one person feel less alone while living at risk, then it is worth it,” Feely said.

Through education and an open exchange of thoughts and ideas, Rogers hopes support group attendees will be better equipped to deal with the disease.

“I’m hoping attendees feel more comfortable with Huntington disease, and they’ll be educated about it as opposed to being afraid of it,” Rogers said. “And I hope they get a sense of well-being, knowing that you’re not the only person who’s dealing with it and there is strength in numbers.”

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.
Shawna Feely
(319) 353-4307

Psychiatry Department Head Dr. James Potash (Paul W. Penningroth Chair) as those appointed to named chairs.

“We can’t do all we hope to do without the most talented people,” Mason said. “[These appointees] exemplify all that is best about the University of Iowa.”

Pauulsen wishes attendees will be educated about Huntington disease, and they’ll be educated about it as opposed to being afraid of it.”

Rogers said. “And I hope they get a sense of well-being, knowing that you’re not the only person who’s dealing with it and there is strength in numbers.”
Through social work, Miller aims to help those in need

By Sean Thompson
HIND-Sight Editor

Amanda Miller has always had a bit of a soft spot for the underdog; as she puts it, those who could use a boost somewhere along the way in their lives.

That desire to advocate for people and empower them is in part what led the Eagle Grove native to where she is today, as the UI HDSA COE’s new social worker.

“I feel like there’s a responsibility within our society to help take care of each other, and I’m comfortable doing that and enjoy doing that,” Miller said. “I’m lucky I get to spend every day doing something that I’m passionate about.”

On the job since December 2012, Miller provides social work services for patients in the HD Clinic as well as for research participants. She’s also directly involved in research as the coordinator for the Juvenile Huntington disease Natural History Study. While she’s taken on a number of different duties, Miller says her top priority will always be as a helpful resource for people living with HD, caregivers and other HD family members.

“Whether it’s emotional support, connecting them with services or helping them understand what the next step should be,” Miller said. “I’m here to provide that for them.”

Before working at the UI HDSA COE, Miller had a personal connection to HD through her good friend Brittney Robinson, who is the HDSA Iowa Chapter’s Vice President and whose father Michael died from HD.

“She really helped me understand the disease,” Miller said, “and while the disease is rare, it’s so massive in the lives of the people who are affected by it.”

Miller, who holds a bachelor’s from the UI and master’s from the University of Northern Iowa in social work, previously worked as a program manager for the Alzheimer’s Association East Central Iowa Chapter. She notes similarities between the two neurodegenerative diseases, such as the hope displayed by those in HD families for future advances in treatment and, someday, hope for a cure.

“I find myself almost surprised at the positive outlook that people living with the disease have,” Miller said. “I’ll meet someone in the early-to-mid stages of the disease and the attitude they carry and the general spirit they have is powerful.”

After practicing health care social work as an undergraduate at the UI, Miller

Protocol allows an informed testing decision

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...social worker to help bring it all together for the HD patient.

“The UI HDSA COE is made up of incredibly passionate, incredibly knowledgeable people, who without question er was eager to get back into the health care field. She has an appreciation for the team mindset among the neurologists, psychiatrists, neuropsychologists, genetic counselors and researchers and the role of the social worker to help bring it all together for the HD patient.”

Find us on Twitter, Facebook and the web at www.medicine.uiowa.edu/psychiatry/huntingtons-disease/
**BRAIN Initiative holds promise for understanding**

*Excerpted from “UI officials express interest in Obama BRAIN initiative proposal” by Brianna Jett in The Daily Iowan April 10, 2013.*

Science is turning inward and approaching the next frontier — the human brain.

On April 2, President Obama announced a new project, called the BRAIN Initiative, or Brain Research through Advancing Innovative Neurotechnologies. This project is a targeted investment of money aimed at mapping and understanding the brain. From that understanding, many scientists hope to find better treatments and cures for diseases like Parkinson’s and Alzheimer’s.

Scientists across the country are excited about the focus on the human brain — and scientists at the University of Iowa are no exception.

“As a scientist who has advocated for increased funding in research, I can’t do anything but applaud the president,” said William Talman, a UI professor of neurology and neuroscience.

The initiative will invest $100 million in research. About $40 million of that will come from the National Institutes of Health.

Talman believes that the project is very promising, but should only be the beginning of research.

“Trying to unravel the complexity of the brain is such a huge task, $100 million could just be the start of things,” he said.

Timothy Pedley, the president of the American Academy of Neurology, said the BRAIN Initiative will focus on understanding the normal behavior of the brain. From there, scientists will be able to better understand abnormal behavior, like diseases or trauma effects, and treat or cure those.

“I think it’s a terrific challenge,” Pedley said. “The brain really is the last frontier.”

Talman emphasized that the general public will not see results immediately. He estimated that what scientists learn, it will take about ten years for it to directly touch the average man or woman.

“It must be recognized that money spent today won’t lead to a new candy bar tomorrow,” he said.

Pedley believes that a side effect of this initiative will be a greater understanding among the public of how the brain works.

“I think it is going to be incredibly important for all humans, not just scientists, to understand how the brain works,” he said.