Love of science, people guides Feely

New clinic coordinator brings prior HD experience to new job

By Sean Thompson
HIND-Sight Editor

Shawna Feely knew early on in her career that she really liked neuroscience and working with issues that involve the brain.

But she didn’t want to be stuck in a lab all the time. She enjoys working and interacting with people, which she says feeds her as an individual.

In her new role as UI HDSA COE Clinic Coordinator, Feely has the opportunity to interact with people and be involved in neuroscience, all while helping coordinate specialized clinical care for HD patients and working with families affected by HD as a genetic counselor.

“You get to go to work and do something you really love all day, and that’s something I would never take for granted,” Feely said.

Feely, MS, CGC, came to the UI in January to help set up a clinic for Charcot-Marie-Tooth (CMT) disease (an inherited neurological disorder). She had previously worked as a genetic counselor and clinic coordinator in Detroit at Wayne State University, counseling and coordinating care for many HD patients and families. She knew she wanted to work with HD families here as well, and took over as clinic coordinator in July.

“I knew the history of the UI and HD and the level of research and involvement they’d had in HD, so I thought it would be great to be a part of that and bring my knowledge base from my work with patients in Michigan,” Feely said.

Feely’s work for HD families doesn’t end when the biweekly HD Clinic winds down at the end of the day. She’s also facilitating the monthly HD Support Group, working on HD education and outreach with other medical facilities and the general public, helping with long-term-care placement and coordinating access to physical and speech therapists. Furthermore, she also fields general questions about HD that come in via email or phone, continuing the UI HDSA COE’s tradition of being a source for HD information in the state and beyond.

Though her duties are varied, Feely says it all boils down to building relationships with HD families. Once that’s accomplished, she says, it becomes easier to help people.

“I’ve really enjoyed working with HD families [in Michigan] and I hope I can build that kind of strong relationship with the families here,” Feely said. “It’s all about knowing the people and what they need.”

For those who are at risk for HD that are interested in genetic counseling and testing, Feely provides that service as a certified genetic counselor. She also counsels any family that requests general HD counseling. Previously, genetic counseling was provided by a different UI Health Care department. Feely said having a genetic counselor internally will make this important service even more integrated into the overall scope of care available at the UI HDSA COE.

Feely emphasizes that genetic counseling is an important component of the genetic testing process, and values the opportunity to help people work through what may be devastating news.

“It’s hard sometimes,” Feely said. “You’re there with people when it’s the worst time in their life, and these are things you can’t solve. But I see that as a gift, to be with them in that time, and I learn and become a better person from those experiences.”

Though it may seem simple (one gene determines if you’ll have the disease), Feely says HD is very complex because of the way it affects each person differently, whether they be at risk, diagnosed or a family member. There’s a lot for care and support providers to learn, and the HD families she gets to work with are Feely’s best educators and motivators.

“I find I learn a lot from the families,” Feely said, “and they keep me going and doing what I’m doing, because they’re amazing.”
A UI student’s journey with HD

Excerpted from “Inside PREDICT-HD: The view of a young person” by UI HDSA COE Student Public Relations Assistant Jolene Luther, a junior Spanish/pre-med major, on the Huntington’s Disease Youth Organization website (www.hdyo.org)

My journey with Huntington disease started when I was 11 years old. I went with my mom and grandpa to a genetic counseling and testing center, where we found out that my grandpa was gene positive, but, most fortunately, my mom wasn’t. My grandpa was then moved from his home in Wyoming to our home in Wisconsin. Slowly, the mountain climbing, long-distance biking, bread making, swim coaching man that everyone loved changed in front of our eyes and there was nothing we could do about it. His battle with HD ended in the fall of 2011, in our home where he had been lovingly cared for by his family for nine years.

I was just entering college at the UI in my grandpa’s last few years, and after he passed away I felt so empty. Taking care of my grandpa had been a part of my life for as long as I could remember and I really wanted to do something to keep his memory alive.

My mom had been coming to the UI HDSA COE to participate in the PREDICT-HD study. I was her companion for one of her study visits and was fascinated by all the fun tests she got to do — and secretly wished I could participate as well! So, as I was finishing up my sophomore year, I decided to reach out to the staff at the center and convince them to give me a job. Thankfully, it worked! I worked this summer doing a lot of writing projects, including summarizing PREDICT-HD articles published in medical journals, in order to make them more accessible to the public.

This job was more rewarding than I’d ever hoped! I’ve learned so much about research studies and learned how extremely important they are. I hope that by summarizing the medical journal articles, those who participated can really see how much they are contributing to the knowledge of HD.

After my summer at the UI HDSA COE came to a close, I headed to Spain to study abroad for the year! I’m so excited for the experiences that lie ahead this

FDA may seek patient input on HD

The Food and Drug Administration has named Huntington disease as one of the conditions that may be included in a new patient-focused initiative.

HD was included on the preliminary list of 20 diseases released in a September federal notice. With input from the public, the FDA will decide which diseases will be explored further in the next five years.

If chosen, the notice says the FDA would then seek public comment from HD families to better understand the severity of HD, the impact of the disease on patients and the adequacy of existing treatment options. The notice says people in HD families are in a unique position to contribute this patient-focused information, which would be used to help weigh benefit-risk considerations in regulatory decision making for potential treatments.

Meanwhile, the FDA is accepting feedback and comments on the choice of the 20 diseases on the preliminary list. Written comments can be submitted to www.regulations.gov or mailed to Division of Dockets Management (HFA-305), Food and Drug Administration, 5630 Fishers Lane, Rm. 1061, Rockville, MD 20852. Comments should refer to Docket Number FDA–2012–N–0967. Comments are due Nov. 1.
JHD “changed all of our lives”

By Sean Thompson
HIND-Sight Editor

Aidan Smith is a lively seven-year-old boy who likes SpongeBob SquarePants and loves the Iowa Hawkeyes. He enjoys watching his brother play baseball in the summer and is pretty interested in cars, much like many of his first-grade companions.

Aidan also falls frequently and his legs can get stiff and painful. He experiences petit mal seizures, which are best described as staring spells. And when his handwriting began to decline, his mom, Denise Hudgell, took him to see a neurologist.

Aidan was diagnosed with Juvenile Huntington disease (JHD) in July. The disease doesn’t define Hudgell’s “sweet little boy,” as she calls him, but it has changed his life drastically in a short amount of time.

“It’s changed all of our lives,” Hudgell said. “So many people are affected by his diagnosis. So many people that love and care for him are hurting watching him fight this disease.”

According to the Huntington’s Outreach Project for Education, at Stanford University (HOPES), JHD is a rare, more rapidly-progressive form of HD that is often fatal within 10 years of onset. In an article that appeared in PLOS Currents Huntington Disease, researchers estimate only about five percent of all HD cases are JHD.

Some symptoms of JHD are different than adult HD, including stiffness and rigidity instead of chorea. About one-third of children with JHD have recurrent seizures. Other symptoms include decline in school performance, behavior and personality changes, speech difficulty and a loss of certain mental functions.

It’s a devastating disease that impacts the youngest and most vulnerable, a truth Hudgell knows all too well. She sees the changes in her son and has heard stories from other parents about how JHD has affected their children. Hudgell also knows there’s a lot more that scientists need to learn about the disease before they can hopefully find a cure. She and Aidan are not waiting around for research to happen, rather, they are participating in it, for themselves and for the whole JHD community.

“All of the children with JHD deserve a chance to have a long, happy, pain and worry-free life,” Hudgell said. “If my family can be a part of that and if being involved helps even one child with JHD, we will have made a difference.”

Aidan is a participant in the JHD Natural History Study and Kids-HD, both of which are accepting new participants at the UI HDSA COE. The goal of the JHD Natural History Study is to better understand the disease and to improve the currently available tools to follow the course of the disease. Kids-HD looks at brain structure and brain function in kids from HD families (not exclusive to JHD) to determine how the brain develops in those at risk for HD from childhood throughout the course of their lives. See the info box above for eligibility information.

Aidan recently completed the testing for both studies at the UI HDSA COE and had what Hudgell called an “exceptional” experience.

“It was clear to me during our visit how much compassion and passion the clinicians and researchers have for finding a cure for JHD,” Hudgell said. “We always felt welcome, valued and cared about.”

In addition to participating in research, Hudgell and her son are also active in their hometown of Council Bluffs and online in raising JHD awareness and raising money for the JHD Initiative (www.jhdkids.com). She said she has found some solace in connecting with people who share her goal of finding a cure for JHD, and who care about her sweet little boy.

“This journey through JHD is going to be a long, tough road,” Hudgell said. “I know that Aidan and our family have a huge support system.”

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

www.medicine.uiowa.edu/psychiatry/huntingtons disease

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Chocolate cravings may be tied to certain brain region


Scientists have discovered a brain area that helps control your desire to eat sweet, hyper-palatable foods like chocolate.

The area, part of a larger brain region called the striatum, had previously been primarily linked to the control of physical movement.

The new research, published in the journal *Current Biology*, adds the piece of neuronal turf to a growing list of areas whose function can best be described as, “Oooh, I want some of that!”

The scientists, from the University of Michigan, decided to see what would happen if they infused the area with a synthetic version of the endorphin enkephalin, which acts naturally in the region, while letting rats eat as much as they wanted of an experimental substance you might have heard of: M&M chocolates.

It turned out that when the researchers infused that specific area with enkephalin, the rats suddenly upped their intake of chocolate by more than double. And when they took another group of rats and measured the levels of naturally-occurring enkephalin in the area, they found that M&M consumption led to an immediate increase in enkephalin.

Was the area involved in making the rats want the chocolate more, or did adding enkephalin suddenly make the chocolate taste better? To answer that question, the researchers studied the rats’ faces while they ate. If the rats did things like lick their lips more when there was more enkephalin in the area, that would suggest the chocolate actually tasted better. But instead, their facial expressions were the same, meaning the change could probably be chalked up to increased motivation.

The finding fits with some compelling previous research showing that restoring function to the area could get a mutant mouse with no appetite to feed again. But it’s worth noting that the area — like all parts of the brain — does not act alone. Instead, it exists within a circuit, receiving input from other parts of the brain.

These multiple pathways to consumption are the product of necessity. Our brains, evolved in times of scarcity, when fatty, highly-palatable foods were hard to find and should be shoved into one’s face with wild abandon.

In this context, it should come as no surprise that our brains are triple, maybe even quadruple booby-trapped to want that last M&M really, really badly.