Iowa Education Day coming May 21

By Emmy Szymanski
UI HDSA COE Editorial Assistant

Nationally-renowned Huntington disease speaker Jimmy Pollard headlines HDSA Iowa Chapter’s Huntington’s Disease Education Day on May 21 in Des Moines.

A 15-year veteran of providing care for those affected by HD, Pollard will discuss gaining a new perspective on the thought processes of those with HD and also how to care for caregivers. Originally a special education teacher, Pollard was introduced to HD while managing a nursing home and has been looking into providing proper care for HD families ever since.

Longtime HDSA National Youth Alliance (NYA) member Vanna Lowes from St. Louis will talk about advocating for the HD Parity Act. Additionally, various speakers from the UI HDSA COE will discuss the basics of HD, psychiatric issues associated with HD, family planning options, how to talk to kids about HD, participation in research and more.

“I am looking forward to another year of educating people and raising awareness about HD,” HDSA Iowa Chapter Vice President Jamie Parish said.

With new guest speakers and participation from Des Moines law enforcement, this year’s education day promises to be full of new insight.

Walking for hope in Coralville

Supporters took the Team Hope Walk indoors for the first time on Nov. 7, 2015 at the Coral Ridge Mall in Coralville. Around $10,000 was raised for the HDSA Iowa Chapter thanks to fundraising efforts of about 50 walkers, money raised through a silent auction and sponsor contributions. Thank you to Ingrid Wensel for all her hard work organizing the walk!

Gene silencing drug passes early tests as clinical trial continues

The first drug treatment designed to target the cause of HD is preliminarily complication-free in humans and effective in animal models, study officials say.

The antisense drug, IONIS-HTTRx, was given to four participants in England and Canada via an injection at the base of the spine. The drug is then carried to the brain through cerebral spinal fluid.

According to a post from blogger Ken Serbin, study investigators announced at the HD Therapeutics Conference in California in February that this early phase, which started in October 2015 and involved four doses per participant, was completed without any safety incidents.

Also in February, study officials announced a 50 percent reduction in levels of the huntingtin protein in parts of the brain and throughout the central nervous system in monkey models of HD treated with the drug. Researchers also observed an improvement in motor skills in mice models of HD.

If further safety tests of the drug with small numbers of people go without incident over the next 9–12 months, the study will expand to more participants. The focus then would be both safety and seeing if the drug is effective at silencing the gene expansion that causes the harmful huntingtin protein.

“It is very exciting to have the possibility of a treatment that could alter the course of this devastating disease,” said Dr. Blair R. Leavitt, a study principal investigator and interim director of the Centre for Molecular Medicine and Therapeutics at the University of British Columbia in Vancouver.

“These results are first steps in a long process. If the clinical trials meant to prove the drug is effective run as researchers hope they do, Leavitt said, it would still be years before the drug was used in clinical practice.
Gaining control of her future

Emmy Szymanski and her twin sister are at risk for HD, the same disease their father has and their grandfather died from. Emmy is determined to keep a positive outlook as she plans to pursue presymptomatic genetic testing soon to find out her medical fate. For an expanded version of this article, visit our website.

photo by Owen Wade

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UI HDSA COE Editorial Assistant

It was a cool summer night after a long day of thunderstorms. My older brother (the Boy Scout) had stashed away several chunks of wood earlier that morning, so my family and I had dry seats to sit around the campfire one last time before the end of our vacation.

For my twin sister and me, our freshman year of high school would soon be starting. My parents always insisted on taking these family camping trips throughout the summer, and even though more often than not it tended to rain, we always managed to have fun.

This time, though, was different.

Now, gathered around the fire, we sat in stunned silence. I remember trying to process the verbal punch that my parents had just delivered. The flames danced as I stared straight ahead.

“Your dad is sick,” my mother had told us.

It was such a simple sentence, but it immediately changed our lives.

“Sick” was their way of telling us that my dad had Huntington disease, which had rendered my grandfather bedridden for the majority of my childhood. That night I was forced to realize the truth: my dad, a healthy man in his mid-forties, had a rocky slope stretched out before him.

Every day since that night around the campfire, I have been continually confronted by the various ways this disease impacts my family and me. My father, who had been the main income earner in our family, can no longer work, and now my mother must take on that role in addition to being a caregiver and a mother.

However, while HD is a serious disease that unfortunately results in an untimely death, diagnosis does not have to mean the end of the world. My dad, for example, continues to find new hobbies – he has taken up intensive bike riding (50 miles per day), guitar playing, and working on model trains. It goes without saying that not every day is perfect; my dad has his ups and downs. But overall, we are grateful that we can continue to make fun memories together as a family.

Working for the UI HDSA Center of Excellence, I get to combine my professional goal of becoming a copy editor with my personal desire to help cure HD. There are so many stories to tell within the HD community, and I look forward to celebrating the lives of those affected by the disease.

HD and my future: Where does this leave me?

Now as a senior in college with “real life” awaiting me after graduation in May, I find that I’m suddenly confronting HD from a whole new perspective. In the near future, my sister and I will undergo presymptomatic genetic testing for HD. With a 50-50 chance of being gene positive or gene negative, we are spending our last year in college trying to sort out life insurance while most of our peers are focusing on jobs or graduate school.

For some people, the possibility of developing HD means having to live a lifetime in as short a time as 35 years, since the average age of onset is around 40. My test results will most certainly influence my future goals, such as traveling the world, becoming a mother and where I will end up living.

Although I am anxious about the results, I am looking forward to having closure to this phase of uncertainty in my life. I’ve encountered far too many sleepless nights wondering what my next steps will be.

For me, though, knowing the genetic testing results will not determine my fate, but will instead help me shape my future. Testing positive wouldn’t be the end of the world, and that is the most important thing for me to remember. Being at risk for HD has changed my perspective on life – it has taught me to find the best in every situation because now I see that life is so short, with or without the threat of a genetic neurodegenerative disease.

I am determined to keep a positive outlook regardless of my genetic testing results, because there are so many great things in life, and I won’t let a disease take that appreciation away from me.

Editor’s note: Emmy Szymanski came to the UI HDSA COE last fall after seeing a student job posting involving Huntington disease. Given the impact the disease has had on her and her family, she knew she would apply. Here is her story, in her own words.

Gaining control of her future

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HD Support Groups

Des Moines
Valley View Village Conference Room
2571 Guthrie Avenue
Third Sunday at 1:30 p.m.
Mark Hillenbrand
(515) 277-0814

Omaha, Nebraska
Valentino’s Italian Buffet
5022 S. 108th Street
Second Thursday at 6 p.m.
Tiffany Smith
(402) 880-7694

North Liberty (Iowa City)
North Liberty Recreation Center
520 W. Cherry Street
Fourth Sunday at 1 p.m.
Amanda Miller
(319) 335-6640
Hayes empowered by participants, colleagues

By Sean Thompson  
HIND-Sight Editor

Usually, a broken leg leads to a cast, probably some crutches, rehabilitation, and eventually, a healed leg. For Terry Hayes, breaking his leg led him to becoming a research assistant at the UI HDSA Center of Excellence.

One day during his freshman year in high school, Hayes was playing basketball and fractured his lower leg in three places. This led to time spent with an orthopedic surgery team. He was impressed by both the science of health care and the way the medical professionals worked as a team to help him recover. The experience inspired Hayes to pursue a career in the health sciences, providing direction he had been lacking.

“From that point, it dawned on me that I wanted to help people in that capacity,” Hayes said. “I had the people skills and there’s something rewarding about helping people in that way, promoting health and well-being.”

Hayes went on to attend Iowa State University in Ames for a change of pace from St. Louis and Cedar Rapids where he grew up. Hayes gravitated toward kinesiology, which he describes as the study of motion as it pertains to health and human physiology. He got involved in conducting research at the undergraduate level, looking at physical therapy methods for improving mobility in older individuals.

Hayes is currently coordinating the SIGNAL study, which is testing a treatment that would, if effective, slow the progression of brain inflammation caused by HD. It is enthralling, Hayes says, to work on a trial of a drug that not only targets symptoms, but aims to delay or prevent those symptoms from happening.

“The idea that you can help a patient and their family have a higher quality of life and a longer and more fulfilled life, according to their standards, is something that’s very exciting for me to be a part of,” Hayes said.

Terry Hayes says at the end of each work day, he wants to look back and have improved something within the HD community or even just feel like he accomplished something bigger than himself. He credits his parents for that mindset with the example they set for him. For an expanded version of this article, visit our website.

photo by Owen Wade

Life after college for Shaw means helping others

By Emmy Szymanski  
UI HDSA COE Editorial Assistant

This autumn, for the first time in over 22 years, Emily Shaw sat down at her desk not as a student, but as an employed adult.

A UI graduate this last spring, Shaw began working at the UI Huntington’s Disease Society of America Center of Excellence as a research assistant, specifically as a study coordinator. After spending a short summer at home in the Chicago suburb of Lisle, Ill., Shaw has come back to her alma mater to officially break in her bachelor’s degree in psychology by putting to practical use the knowledge she gained in all that time in the classroom.

“I’ve spent most of my life in school, learning how to be a good student,” Shaw said. “Now that I have graduated and have found a job, I look forward to learning how to be an adult and how to be a good research assistant.”

Shaw was led to this position by her desire to help people, which has always been a part of her. While her various experiences in high school like volunteer club really helped develop this part of her personality, it was the example set by her best friend Macks that inspired her to get more involved. Macks volunteered for Little Friends, an organization serving children with autism and other developmental disabilities.

“Watching him always reminded me of how one person can really make a difference in someone’s life,” Shaw said.

As a research assistant, Shaw welcomes the opportunity to step away from the desk and connect with those participating in research.

After starting at the UI HDSA COE in August 2015, Shaw’s experience working here has already provided her a strong foundation and a sense of her role within the HD community.

“It’s such an impactful disease, both for the patients and their families,” Shaw said. “But I’m looking forward to learning more about HD and to help find a cure.”
Higher education, lower dementia risk, study suggests


The risk of developing dementia is decreasing for people with at least a high school education, according to an important new study that suggests that changes in lifestyle and improvements in physical health can help prevent or delay cognitive decline.

The study, published in The New England Journal of Medicine, provides the strongest evidence to date that a more educated population and better cardiovascular health are contributing to a decline in new dementia cases over time, or at least helping more people stave off dementia for longer.

The findings have implications for health policy and research funding, and they suggest that the long-term cost of dementia care may not be as devastatingly expensive as policy makers had predicted, because more people will be able to live independently longer.

In any event, in the next few decades, the actual number of dementia patients will increase because baby boomers are aging and living longer.

“You don’t want to give the impression that the Alzheimer’s or dementia problem is disappearing — it’s not at all,” said Dallas Anderson, a program director on dementia at the National Institute on Aging, one of two agencies that financed the study. “The numbers are still going up because of the aging population.”

Still, Maria Carrillo, chief science officer for the Alzheimer’s Association, said “this tells me there absolutely is hope for Alzheimer’s.”

There are many theories about why education may help stave off dementia, including that it leads to better economic opportunity, which can propel healthier habits and better access to medical care. Another theory is that learning generates more neural connections, allowing brains to compensate longer when memory and cognitive functions falter.

Marie and Joe Porcello, study participants, are 86-year-old high school graduates with no significant cardiovascular problems or family history of dementia. But Mr. Porcello remains healthy, while his wife, a retired secretary, developed dementia about 10 years ago and is in an assisted-living facility.

Their daughter Cynthia Johnson, 54, who received a bachelor’s degree in computer science, belongs to a generation that researchers would now predict to have less dementia.