To D.C. for HD advocacy

UI HDSA COE’s Jolene Luther joins other youth on Capitol Hill to advocate for the HD Parity Act

By Christina Colletta
UI HDSA COE Public Relations Assistant

After losing her grandfather to Huntington disease in 2011, Jolene Luther decided she would do everything in her power to help those affected by HD. Now, the 22-year-old Belgium, Wis. native is commemorating her grandfather’s legacy while living out her mission through her career path, and, as of recently, advocacy.

Luther, a research assistant at the UI HDSA COE, travelled to Washington D.C. twice in three months with members of the HDSA National Youth Alliance (NYA) to advocate for the passing of H.R. 1015/S. 723, the Huntington’s Disease Parity Act.

The journey that defined her purpose

After Luther’s grandfather was diagnosed with HD, her mother and aunt decided to be tested to see if they inherited the HD gene. It came as a huge relief to learn both tested negative.

“My family’s outcome was a very fortunate one, so I very passionately want to continue to fight back against HD for all of the inspiring people that I have met who didn’t have the same luck that I had,” said Luther.

“HD is like a coin toss, and if my mom’s coin toss had gone the other way, it would be me in that situation right now— with one parent suffering from HD and the prospect of having to face it myself on the horizon.”

Since Luther’s grandfather was in his 60s when he started experiencing symptoms, he qualified for Medicare. Her family’s financial situation also allowed them to care for him from their home with the assistance of a home health aide.

Luther realizes most families affected by HD do not have these benefits, which she says can have a profound negative effect on the family structure.

“Often, cognitive and behavioral symptoms early on in the disease will lead families to bankruptcy, divorce, and other devastating outcomes long before they are ever qualified to receive Medicare because of disability,” said Luther.

The Social Security Administration’s outdated criteria (written nearly 30 years ago) for considering whether or not an individual with HD qualifies for Social Security Disability benefits only takes into account HD’s physical impairments, ignoring the debilitating cognitive and behavioral symptoms that can occur long before the motor symptoms.

Because of these inaccurate guidelines, individuals with HD who are not yet displaying motor symptoms are routinely denied or delayed receiving Social Security Disability benefits, and even if

Powers to screen “Twitch” at UI on Oct. 2

The nine-stop international screening tour for the emotionally gripping “Twitch” documentary film is coming to the University of Iowa on Oct. 2 at 7 p.m.

The film’s creator and star Kristen Powers, a 2012 TEDxTeen speaker and student at Stanford University, will be on campus for the screening to talk about the issues surrounding genetic testing and Huntington disease, and answer questions about her incredible journey.

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UI HDSA COE Research Assistant Jolene Luther advocates in Washington, D.C. for HD families less fortunate than her own.

“Twitch” screening
When: Oct. 2, 7 p.m.
Where: 1505 Seamans Center (first-floor auditorium), University of Iowa campus
Admission: Free
Speaker: “Twitch” creator and star Kristen Powers will follow the film with a discussion/Q&A
More info: Visit the UI HDSA COE website (see p. 2 for web address)

Photo courtesy Kristen Powers

Kristen Powers created and stars in “Twitch,” a documentary about facing her HD fate.
“Twitch” follows Powers as she goes through genetic testing for HD. The film highlights the pressures people, especially young adults, face when given the chance to be handed their medical fate.

The film will chronicle the emotional, political, economic, social and medical journey through this important test, as well as the impact on the individual’s future and day-to-day life after receiving the test results. Powers hopes that the momentum from this film will lead to a national conversation about genetic testing and the continued search for a cure for HD and other genetic diseases.

Powers and “Twitch” have received significant media attention, having been featured on “CBS Sunday Morning Show” and in USA Today, Teen Vogue, and The Stanford Daily. Powers was also given the 2013 HDSA “Giving a Voice to HD” award.

HD first entered Powers’ life in 2003, when her mother was diagnosed with the illness after first showing symptoms in 1999. Powers says she does not remember her mother before HD, but does have memories of discrimination her mother and her family experienced because of her mother’s drastic mood swings.

When Powers turned 18, the age at which an individual can be tested for the HD gene expansion, she decided to do so and record the testing and everything surrounding it for this documentary.

“It gave me a lot of control over my genetic testing experience,” Powers said in a February 24, 2014 article in The Stanford Daily. “It was my way of controlling the uncontrollable. I couldn’t control what test result I was going to get, but I could control and manage my film crew.”

After receiving her results, Kristen began the process of taking the footage she had and making it into an actual movie. She financed the project largely through web crowdfunding, receiving modest donations from a large number of people.

The screening is cosponsored by the UI HDSA COE and the HDSA Iowa Chapter.
The Juvenile HD Natural History Study began in 2005, when the European Huntington Disease Network started to support “working groups” for special topics in HD. We were fortunate to be at the first meetings of the EHDN and met with other interested professionals about JHD. We brainstormed what we needed to do to better understand the juvenile form of HD, and a worldwide study was launched. The motor exam was modified. We decided to interview JHD families and collect research data to better understand their situation with the intention of making a difference for the kids and the families. This information was gathered via telephone, family journals, meeting with kids at the HDSA National Convention, and even traveling to HD retreats in Arizona. We made home visits and we had many families who traveled to the UI HDSA COE to be evaluated.

The response from the JHD community was amazing, and went beyond participating in the study! We quickly had responses from all over the United States. Some of the families pulled together to produce educational materials, and others took it upon themselves to raise money to conduct the pilot research. Many families found support from one another. We learned a great deal about JHD and were honored to have the experience of getting to know so many courageous people. Without a doubt, the JHD community changed who I am as a person, as a mom, as a friend, and as a researcher.

As many of you know, recently there have been great complexities about how to structure JHD at Iowa. As with all complex situations, they must be worked out collaboratively. Recently, we have been evaluating the best way to move forward. Sometimes the best way to start a new chapter is to conclude the old one. It is with some reluctance and sadness that we will close out the JHD Natural History Study at the UI HDSA COE. Analysis of the data we have already gathered continues. The international community has requested to use the data to write a collaborative medical journal article detailing our findings, and our participants will forever be a major and critical partner in the first worldwide research collaboration for Juvenile HD! We are forever grateful to the participants and families who participated in this research. You are pioneers in the fight and you deserve to be applauded.

We encourage you to participate in the new Kids-JHD study at the University of Iowa. As you know, we all need to work together to learn about JHD so we can develop new treatments and find ways to provide better care to the patients and families suffering. We believe in a research partnership among all health care professionals, patients, families, friends, businesses, institutions, support groups, and researchers, where every voice is heard.

Today, the JHD families are in my heart, on the walls of my office and even photographically on the outside of my cup of tea! Those of you who have contacted me regarding this study have touched me and renewed my passion for all of you. Please know I’m not going anywhere. I will be right here and I will forever be an advocate for JHD.

**HD studies currently enrolling at the UI**

- **Enroll-HD**: An observational study for anyone in the HD community. Contact Jane Kerr, jane-kerr@uiowa.edu, 319-353-4955.
- **PREDICT-HD**: An observational study of pre-symptomatic individuals, currently enrolling gene-negative individuals. Contact Bella De Soriano, predict-hd@uiowa.edu, 319-353-4212.
- **CREST-E**: Clinical drug trial for symptomatic, diagnosed individuals. Contact Jacky Walker, jacky-walker@uiowa.edu, 319-353-4537.

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**“The Lion’s Mouth Opens” at UNI**

On Sept. 22 in Cedar Falls, two-time Academy Award nominated director Lucy Walker (left) screened her film “The Lion’s Mouth Opens,” a gripping and powerful documentary telling the story of director/actress Marianna Palka as her HD genetic testing results are revealed.

HDSA Iowa Chapter Board Member Jamie Parish (middle) and UI HDSA COE Public Relations Coordinator Sean Thompson (right) joined Walker to answer questions about the film and HD following the screening.

Walker was the featured director for the University of Northern Iowa’s Clohesy Documentary Film Series.

*Photo courtesy UNI/Chris Martin*
Fruit, veggies may affect physical, mental health

Excerpted from “Eating five portions of fruit and veg a day is also good for brain and helps prevent depression” by Madeline Davies in Mail Online on Sept. 25, 2014

Five daily portions of fruit and vegetables won’t just help stave off disease — they could also keep the blues away.

A new study has found a person’s mental wellbeing may be closely linked to how much fresh produce they eat.

Mental wellbeing was defined as a state in which people feel good and function well, the researchers said.

Optimism, happiness, self-esteem, resilience and good relationships with others are all part of this state, they added.

More than a third of people with good mental wellbeing ate five or more portions of fruit and vegetables a day, compared with only 6.8 percent who ate less than one portion.

A further 31 percent of those with high mental wellbeing ate three to four portions and 28 percent ate one to two.

Previous research has shown that eating plenty of fresh fruit and vegetables helps prevent people from developing more than one chronic disease.

Chronic diseases include high blood pressure, very high cholesterol, diabetes, arthritis, hepatitis, heart disease, asthma, stroke and cancer.

The study — carried out by Warwick University’s medical school — used figures from the Health Survey for England.

It found the effect on mental wellbeing from eating more fruit and vegetables was found in men and women.

Dr. Saverio Stranges, who led the study, said: “Along with smoking, fruit and vegetable consumption was the health-related behavior most consistently associated with both low and high mental wellbeing.”

Researchers said mental wellbeing is strongly linked to mental illness and mental health problems like depression and anxiety.

It is important not just to protect people from mental illness but because it protects people against both common and more serious physical diseases, they added.

Co-author Professor Sarah Stewart-Brown said: “Mental illness is hugely costly to both the individual and society ... It has become very important that we begin to research the factors that enable people to maintain a sense of wellbeing.”

The study was published in the BMJ Open medical journal.