Shedding light on the darkness of her genetic fate

Jamie Parish refuses to let HD prevent her from pursuing her goals and helping others

By Christina Colletta
UI HDSA COE Public Relations Assistant

As 29-year-old Jamie Parish sat front and center in a steely glass-walled auditorium on the top floor of the University of Iowa Hospitals and Clinics with a crowd of complete strangers dissecting her family history and questioning her like a doctor questions a patient, her confidence never wavered.

She didn’t waver as she detailed her grandfather’s initial misdiagnosis and eventual death from Huntington disease, nor as she recounted how her father committed suicide before it was known whether or not he had HD. Not even as she revealed she later tested gene positive and, after experiencing intense depression and loneliness, is finally moving forward.

Calling Parish strong is an understatement.

But why would she volunteer to participate in what many would consider to be an unnerving exploration of her most painful and private past experiences?

“I want to help,” said Parish.

Sharing her struggle so others don’t have to

The strangers at the educational seminar Parish took part in were neurologists, psychiatrists, genetic counselors, researchers and students looking to refine their understanding of Huntington disease and the genetic testing process from a patient’s perspective.

“I hope they realize the emotional process of HD. How it changes people’s lives. How there are so many components of the disease to consider,” said Parish.

When Parish was 16 years old, her grandfather was diagnosed with HD after years of misdiagnosis. After learning she may have a 50-50 chance of inheriting the disease, Parish immediately decided she would eventually get tested.

“I am one of those people that need to know everything,” said Parish of Des Moines. “I just wish I talked to somebody who had gone through testing before I made that decision so I would have a better understanding of what I would feel after finding out my results.”

At the facility she went to for testing in Alabama, Parish said she often felt like she was teaching her doctor about HD instead of the other way around. Without the ongoing support of informed professionals, Parish felt aimless and alone after receiving her HD gene-positive results.

“It was really informative for me, being around medical professionals that actually knew what they were talking about,” said Parish. “I could finally ask questions and get the answers I needed.”

It was at the UI HDSA COE where Parish was relieved to learn the depression she was experiencing was a result of receiving the devastating gene-positive test results rather than a symptom of her HD.

“Dr. Jeffrey Long Education day speaker

Huntington disease family members in Iowa have the chance to hear straight from HD experts at the UI HDSA COE on everything from current treatment options to the latest research findings and more at the HDSA Iowa Chapter 2015 HD Education Day on Saturday, May 2 in Des Moines.

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More than 400 people sat in the UI's Pappajohn Business Building auditorium, many in awed silence. Some were still wiping away tears. Others had a look on their face that indicated they had just experienced something impactful, something powerful and meaningful.

Following the UI HDSA COE’s Jan. 29 screening of “The Lion's Mouth Opens,” more than 400 people left that auditorium having learned a lot about HD and knowing your medical fate through the courage of actress and filmmaker Marianna Palka, whose story of finding out her genetic testing results for the genetic mutation that causes HD is told in the documentary.

Though hopeful for a large turnout, UI HDSA COE Public Relations Coordinator Sean Thompson was pleasantly surprised by the size of the audience.

“So much HD awareness was raised through the showing of this film,” Thompson said.

After the film, a panel of UI HDSA COE clinicians, researchers, family members and genetic counselors took insightful questions from the audience. The event concluded with a presentation on advocating for the HD Parity Act from UI HDSA COE Research Assistant Jolene Luther.
Enroll-HD a study for the HD family
Most HD family members eligible for worldwide observational study

By Jolene Luther
UI HDSA COE Enroll-HD Coordinator

In the Enroll-HD study, there are currently 112 sites in 11 countries and over 4,000 participants—and you can be one of them at the University of Iowa HDSA Center of Excellence! The goal of this worldwide observational study is for one-third of the population affected by Huntington disease in each study region to participate, and we need you to help us meet that goal.

Why should you consider participating? While you won’t receive any direct health benefits from participating, the study is so large that it allows us to get a very clear picture of exactly how HD affects families worldwide. This will help build our understanding of HD and help inform researchers when they’re developing future clinical trials. Additionally, when future clinical trials involving drugs to help treat or cure HD begin enrolling participants, all those participating in Enroll-HD can be easily and efficiently notified of their eligibility as a potential participant.

So you think you want to participate? Great! Anyone from an HD family can participate in Enroll-HD. At the UI HDSA COE, you are eligible if you are 18 years or older and have tested positive or negative for the disease, or if you are untested and at risk (if you have a parent or grandparent with HD). You may also participate if you are under the age of 18 but have clinically diagnosed features of HD and have had a positive genetic test. Spouses, partners, and caregivers may also participate.

Each annual visit consists of a blood draw (mandatory for the first visit, but optional for the rest), questionnaires and surveys about your current health, cognitive tests, and behavioral and motor examinations. We want to know what your health is like, what you think of your health, how you think, how you feel, and how you move.

We make it as easy as possible for you to participate! You will have only one visit each year, and each visit takes just two hours or less. You will be compensated with a prepaid debit card to help offset the cost of traveling to the University of Iowa to participate. If you are a patient in our HD clinic, you can include participating in Enroll-HD as part of your regular clinic visit so you don’t have to travel here multiple times a year. We can also set up visits so that you and multiple family members can travel here together and complete your visits at the same time.

If you’re interested in participating, please contact me at jolene-luther@uiowa.edu or 319-384-1008.

Thank you to those participating or considering participating in this important study! Your involvement is crucial to learning more about the effects of HD.

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Parish, with the support of her mother, also decided to follow her therapist’s recommendation to attend an HD support group meeting.

“Finding a good doctor and talking to other people going through the same thing as me really helped with the loneliness and depression.”

Remapping her life to reach new goals

With the added support of others from the HD community, Parish says she is turning her life around to make a difference.

“I’m volunteering, and I’m the vice president for the HDSA Iowa Chapter,” Parish said. “Now I’m turning it into a good thing rather than the bad thing it has been for so long.”

Parish also sees the importance of participating in research. She was a PREDICT-HD participant and is also an HDSA clinical trial diplomat for Iowa.

“Everybody together can make a difference, which is why we need people to connect and talk about it instead of keeping it a secret, for their own sake, too.”

Parish admits coming to terms with the fact that she will one day develop the disease is an ongoing part of her life, but her positivity and determination to support others is helping immensely.

“I don’t know when I am going to get sick. It’s just not something I can think about every day,” said Parish. “Nothing could have prepared me. I am a completely different person now and my hopes and dreams have changed.”

“I am working to help others because I can,” said Parish. “I want to help with going forward.”

Pigeons and children may learn alike, study says


The more scientists study pigeons, the more they learn how their brains—no bigger than the tip of an index finger—operate in ways not so different from our own.

In a new study from the University of Iowa, researchers found that pigeons can categorize and name both natural and manmade objects.

Ed Wasserman, UI professor of psychology and corresponding author of the study, says the finding suggests a similarity between how pigeons learn the equivalent of words and the way children do.

“Unlike prior attempts to teach words to primates, dogs, and parrots, we used neither elaborate shaping methods nor social cues,” Wasserman says of the study, published online in the journal Cognition. “And our pigeons were trained on all 16 categories simultaneously, a much closer analog of how children learn words and categories.”

For researchers like Wasserman, who has been studying animal intelligence for decades, this latest experiment is further proof that animals—whether primates, birds, or dogs—are smarter than once presumed and have more to teach scientists.

“Differences between humans and animals must indeed exist: many are already known,” Wasserman said. “But, they may be outnumbered by similarities.”

The UI researchers used a computerized version of the “name game” in which three pigeons were shown 128 black-and-white photos of objects from 16 basic categories: baby, bottle, cake, car, cracker, dog, duck, fish, flower, hat, key, pen, phone, plan, shoe, tree. They then had to peck on one of two different symbols: the correct one for that photo and an incorrect one that was randomly chosen from one of the remaining 15 categories. The pigeons not only succeeded in learning the task, but they reliably transferred the learning to four new photos from each of the 16 categories.

Wasserman acknowledges the recent pigeon study is not a direct analogue of word learning in children and more work needs to be done. Nonetheless, the model used in the study could lead to a better understanding of the associative principles involved in children’s word learning.