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Losing control, seeking connections

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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GENE VERITAS

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HD Links

Huntington's Disease Society of America

International Huntington Association

MONDAY, OCTOBER 11, 2010

Losing control, seeking connections

As a person who is gene-positive for Huntington's disease, I have steadily stepped up my involvement in the cause to stop it. My commitment began a couple years after learning of my mother's diagnosis in late 1995 and intensified after I tested positive in 1999.

Lately, as I take on ever more tasks in the movement, I should feel great satisfaction. And I do.

But, ironically, I've also felt that I'm losing control over my life. I feel overwhelmed by what I call my three jobs: family, work, and the HD cause. And my decision to gradually go public about my status will forever change how people see me.

Big goals

On September 24 I made my first speech in the United States about my family's struggle against HD.

After blogging on that presentation, I delved into an overdue writing project for my work. A lot is riding on it, because, if successful, it could lift my profile in the world of writing and help me raise awareness about the need to fight HD and other genetic diseases.

I had been working on this project for six months, and when I turned it in last Thursday, October 7, I felt an enormous relief.

But I immediately had to prepare for something even more important: the next day, October 8, I would pay my annual visit to Isis Pharmaceuticals, Inc., for an update on the company's historic attempt to stop HD.

Genetic guerrillas

My professional writing project is about former South American guerrillas accused of terrorism. Suddenly, I had to shift to thinking about oligonucleotides, or oligos, which are a bit like genetic guerrillas. If all goes as planned, these guerrillas will bind to messenger RNA in the brain cells of HD patients and block the process that kills the cells.

Known as antisense technology, the Isis approach is a rare attempt to stop HD at its genetic roots. So it might lead to a "cure," although Dr. Frank Bennett of Isis cautions against the use of that word. The more likely outcome is a treatment that becomes one in an array of medicines.

I spent several hours reviewing my past articles on Isis, posters on oligos presented at scientific meetings, and the notes from my conversation with Dr. Doug Macdonald, the director of pharmacology at CHDI Management, Inc., informally known as the "Cure Huntington's Disease Initiative," a collaborator with Isis in the oligo project.

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My life in their hands

At Isis I was overwhelmed to see Dr. Bennett, the senior vice president for research, and Dr. Gene Hung, the scientist in charge of the HD research project. In my imagination these two men, along with others on the Isis team, hold my life – and the lives of tens of thousands of HD patients and at-risk individuals – in their hands.

Before we even began the interview, I warmly thanked Drs. Bennett and Hung for their dedication to assisting the HD community.

I desperately wanted to hear from them that Isis had found the treatment and was ready to begin testing in humans. In a nutshell, the project is taking longer than anticipated, but the progress is remarkable. (Later I'll blog in greater detail on what I learned.)

Driving home from Isis, I felt a strange mix of euphoria and angst. I had just received encouraging news, and I had successfully carried out an interview on a difficult and complex subject.

But there are no guarantees the project will ultimately arrive at an effective treatment.

And, I wondered, what if it comes too late? My mother died of HD in 2006 at the age of 68, and, at 50, I am already past the age at which her symptoms began.

I wanted to both celebrate and hunker down.

The grapevine

Several months ago I told a good friend and professional colleague about my situation. This was the first time I revealed HD to anybody in my field. He showed great compassion and even made a donation to the Huntington's Disease Society of America.

Last night I got a surprise call from a mutual friend and colleague who had heard that I was facing "health issues." He was concerned that I might have something like multiple sclerosis or prostate cancer.

The inevitable grapevine has gone into action, I thought to myself. I have known this person for well over a decade and have trusted him on many professional questions. I decided to tell him about Huntington's disease – and about how it was important for me to keep it hidden for so many years.

HIV-positive and HD-positive

The first friend had no inkling whatsoever about HD, but the second knew a family affected by HD and had learned in great detail about its medical and social impact.

He immediately got the picture.

This man is openly gay, and so I knew that he could identify with someone who was gene-positive for a deadly disease. In fact, I had previously imagined coming out to him because of his background as a gay rights activist.

We spent a while discussing the similarities between the situations of HIV-positive and HD-positive people.

Both groups have suffered a horrible stigma, leading to problems of discrimination in the workplace and other areas of life. Success in our shared professional field depends a lot on perceptions, and the slightest

hint of an inadequacy of any kind can sour a person's plans to advance.

And the victims of both HIV and HD face a terribly agonizing waiting game of wondering when and how symptoms will develop.

The end of control?

My friend expressed unconditional support, including future advice on how to come out.

I am sure I'll be calling on him in the coming months. As I've written before, our society has developed a ritual for coming out about HIV and other well-known maladies, but still lacks one for genetic diseases, especially orphan conditions such as Huntington's.

Although my two friends have promised to protect my identity, I know that as I speak out more about HD, the grapevine effect will grow. There is no such thing as a secret once it's been shared. I will need to prepare myself for more phone calls, e-mails, and personal questions.

The lack of control over people's perceptions of my HD status is something that I'll have to live with the rest of my life.

I become especially distressed when I remember how my own mother lost control of her mind and body as HD ravaged her brain. HD people lose control over their movements and basic abilities such as walking, talking, and thinking.

HD people pass control over their lives to caregivers and, as death nears, to nursing home workers. I vividly remember how my father and later healthcare personnel spoon-fed my mother. It was as if she had returned to childhood.

In the end, nobody controls his or her biological destiny: death. People with devastating diseases have an acute awareness of this fact of life.

New and better bonds

As I approach my own destiny with HD, I will need to build ever stronger ties to people.

Going public will forever eliminate control over my genetic information, but it will also connect me to a growing number of people within the HD community and beyond.

I have long feared going public, but in doing so I can find new allies like the friend who called me yesterday to offer support.

HD could leave me completely dependent on my wife and daughter, so I also need to continue strengthening my bonds with them. If and when they need to care for me, I want that transition to go as smoothly as possible. I don't want to be a burden, but know I could become one. I want to love and care for them while I can.

Posted by Gene Veritas at 6:03 PM

Labels: antisense , brain , CHDI , come out , coming out , cure , daughter , gene-positive , going public , HD-positive , Huntington's , Isis , mother , RNA , stigma , symptoms , tested positive , testing , wife

1 comment:

Unknown said...

Hello I am Jeanie Shugart, and I know how you feel. My mom died in April 2010 from HD and she was 67, 10 years younger

than my grandmother when she died from HD.

We did not know we had HD in the family until after the 5th suicide attempt she ended up finally being tested to find out what was happening. That was in 1994, I attended my 1st HD Convention in 1997, I was tested in 1999 found out I have 43 repeats, I joined the Predict HD study at Emory University 2002 or 2003.

We have attended many different conventions over these years.

This year was Predict HD II and I had to have a diagnosis to determine pre symptom or showing signs, this would determine which study I can participate. I am showing signs of movements, however for many years I have had the mental expressions in OCD, etc...

My visit was about 3 weeks ago to Emory and I have the protocols to see which study I can attend easier. Atlanta GA is a long drive from Jacksonville FL. I actually live in a small town in GA exit 1 actually.

The protocls that have been used to determine actual on set come from me and my statements to Dr. Jane Paulsen early in the process of getting NIH $$.
Like Itold her that when I attended my first HD Conference and heard the way other children of HD Parents had been treated I finally felt wow I am not alone, I was not treated this way becasue she could help it.

I have been getting your Blog fOr years. thanks for just letting everyone that gets this see what you are doing and going through. I wish you many more years of no symptoms.

Jeanie Shugart

6:57 PM, October 13, 2010

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