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A cascade of emotions about Huntington's disease

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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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About Me

 GENE VERITAS

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MONDAY, MARCH 14, 2011

A cascade of emotions about Huntington's disease

The world will remember Friday, March 11, 2011, as the day that a devastating earthquake and tsunami overwhelmed Japan and triggered a potential nuclear disaster in a land already scarred by the bombs of Hiroshima and Nagasaki.

I also will remember that day for some very personal reasons: a cascade of difficult feelings about Huntington's disease nearly overwhelmed *me*.

My heart goes out to the people of Japan. More than ever, the world needs to show solidarity with the victims of natural and manmade disasters.

I'm also reminded of the need for solidarity with people affected by HD and so many other similar diseases – like an acquaintance, the mother of three, struck down in her prime by multiple sclerosis.

Memories of testing

My own series of difficult feelings began the evening of Sunday, March 6, when I checked one of the HD groups on Facebook and read about a young man in the armed forces who was getting tested for the disease. The young man's father has HD, and his mother was seeking advice from the group.

The military doctor knew nothing about HD. The clinic drew the serviceman's blood and sent it to a commercial testing service. The serviceman received none of the pre-test genetic counseling that is mandatory at clinics that follow accepted standards for genetic testing.

The young man's situation triggered a flood of memories of my own genetic test for HD in 1999. My wife and I received counseling prior to obtaining my result, and, as my support person, my wife was required to be at my side at the moment the doctor revealed the result. The counselor was also present on that day.

I tested positive. My wife and I left the medical office in a daze. As I backed our car out of the space in the parking garage, I swung too far to the right and scraped the right front fender on a column ([click here](#) to read more).

I felt deep anger, frustration, and resignation. Now I knew that I would share the HD fate of my mother, who already had full-blown HD and had lost most of her ability to speak and care for herself. She ultimately died of HD in 2006.

Desperately wanting to help

I desperately wanted to help the young serviceman obtain support.

I wrote to the Facebook HD group:

“He should NOT just test instantly like that! There is a protocol that

HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
[HDSA Orange County \(CA\) Affiliate](#)
[HD Free with PGD!](#)
[Stanford HOPES](#)
[Earth Source CoQ10, Inc.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

requires counseling from a genetic counselor and a psychologist. ... Testing is a huge event in a person's life – whether the result is negative or positive. A counselor or psychological support person should be there when he gets the results, and also a friend, spouse, or other family member.... Also, it's important to remember: a positive test result for HD is NOT a diagnosis for HD. The person can live years or even decades without symptoms.”

I frantically began to work my contacts in the local community to see if we could arrange for a genetic counselor or other professional support person to assist him on the day of his test results.

Driving home our message

Before I got too far, though, his mother notified the group: he tested negative!

What a relief! I thought.

But, also, what a close call! I wondered: how would he have reacted had he tested positive?

This young man's story once again underscored the message that I and other HD activists must drive home.

Sadly, HD remains a largely unknown disease, even within the medical community. As a society we need to build greater awareness about orphan diseases, provide up-to-date information on the procedures and implications of genetic testing, and be on the lookout for potential genetic discrimination.

Sharing my story (again)

As other HD community members and I attempted to assist the serviceman and his family, I braced myself for another stage in my transition to a public advocate for HD.

On February 7, I gave a public speech to some 250 people at the annual “Super Bowl” of Huntington's research, the 6th Annual HD Therapeutics Conference, held in Palm Springs, California, and sponsored by the CHDI Foundation, Inc., informally known as the “cure Huntington's disease initiative.” And on February 28 I came out about my gene-positive status in a talk to the local support group in San Diego.

A couple days later, I read that a former college classmate, now a prominent philanthropist and documentary filmmaker, would be in town on March 8 to give a presentation.

We hadn't seen each other since graduation from Yale in May 1982, but I decided to attend her event as a show of support for her work in social justice and women's rights.

Before the event, I wrote her a personal letter thanking her for her social commitment.

“I wanted to share with you my own odyssey of the past 16 years advocating against genetic discrimination and raising awareness about the need to find treatments for Huntington's disease (HD) and other orphan diseases and neurological disorders,” I wrote. “I believe all areas of social justice are interconnected.... So I believe we share common ground.”

Before she gave her speech, my classmate greeted me warmly. We hugged, and she asked me about what I had been up to since graduation. I told her of my deep involvement with Brazil as a professor of history.

Afterwards, I went to congratulate her. I gave her an envelope with my letter – and a copy of my CHDI speech, “*Blog Entry No. 85 ... Unmasking the World of Gene Veritas: An Activist Copes with the Threat of Huntington’s Disease.*”

Struggling with doubts

My old classmate is extremely busy, so I don’t know yet whether she read the letter or watched my speech.

But, as I said in an e-mail to some friends, the reconnection with my classmate was “very emotional.”

Just seeing a classmate for the first time in nearly three decades was enough emotion for one day.

But, on top of that, came my HD activism – my life’s work, my *life* itself, so deeply affected by my mother’s demise and my inheriting the defective gene from her.

I struggled with doubts in the days leading up to her event: should I “bother” her by coming out about something so sad and complex as Huntington’s disease and its terrible impact on families? Isn’t it presumptuous of me to give her a letter and my DVD after so many years of no contact? Will she be interested in the cause in any way?

“Maybe she’ll make a film about HD,” a friend and HD activist suggested hopefully.

“I didn’t ask for anything in the letter,” I replied. “I am doing my job as an advocate: getting the word out about HD. I will just be happy if there is just one more person praying for us.”

Testing the waters in the workplace

On Thursday, March 10, I started exploring a huge and inevitable step: coming out about my HD status in the workplace, potentially the most explosive arena of my life in terms of genetic discrimination.

During lunch with a trusted co-worker, I mentioned that I was living an extremely intense period of my life outside of work.

This was the very first time that I alluded to my activism after erecting an absolute firewall between my HD life and my professional life following my mother’s diagnosis in 1995. I have kept that firewall intact because of fear of genetic discrimination.

The disintegrating firewall

I didn’t mention the word “disease” to my co-worker, but I did explain that I am involved with a cause and a situation that could ultimately impact my situation in the workplace. I revealed to her that I had given a speech and that I would like to give her a copy of it sometime. I asked her to keep my situation confidential for now.

My stomach felt as if it were turning upside down, and my mind wanted to go blank. I was having a difficult time finding the right words.

I felt the firewall between my job and my activism being disintegrated by my words and the violent currents of my fears about a future with Huntington’s disease. As if to act out this huge change in my life, I moved my arms back and forth next to each other along the table. This gesture represented my dual life – my job and my HD activism moving in parallel and never intersecting.

My co-worker sensed my difficulties and reassured me by saying that I should tell my story on my own terms and on my own schedule.

Indeed, as I told her, I still haven't worked out for myself how to proceed on the professional front.

Planning a trip to Alnylam

More than a month has passed since my CHDI speech. I'm living as intensely as ever as I step further and further out of the HD closet.

I turned 51 last December, and as I progress into this decade of my life, I will get closer to the inevitable onset of the HD symptoms that destroyed my mother's mind and her ability to walk and eat.

But there has never been a time of greater hope in the quest of scientists to find treatments and a cure for HD.

In the midst of my personal churn of emotions last week I firmed up plans to visit [Alnylam Pharmaceuticals](#) in May to give a talk on HD and observe the companies' researchers at work on a potentially revolutionary treatment using RNA interference to stop the disease at its genetic roots.

A break from the real battles

Luckily, I began a week's vacation on March 11.

That also happened to be the opening day for the film *Battle: Los Angeles*, about an invasion of aliens seeking to colonize Earth for its water resources.

After school I picked up my daughter – our 10-year-old “miracle baby,” who tested negative in the womb for HD.

As the first act of her weekend and my vacation, we headed for the movie theatre.

Life's major battles continued – in the stark reality of both the Japanese tsunami and the search for treatments and cures for HD and other life-sapping neurological conditions.

And also in the fantasies of Hollywood, where, for at least a couple hours, I could find a bit of escape and catharsis.

Posted by [Gene Veritas](#) at 9:17 PM



Labels: [Alnylam](#) , [CHDI](#) , [closet](#) , [cure](#) , [diagnosis](#) , [discrimination](#) , [gene-positive](#) , [genetic testing](#) , [Huntington's](#) , [orphan disease](#) , [research](#) , [RNA interference](#) , [social justice](#) , [symptoms](#) , [tested negative](#) , [testing](#) , [Yale](#)

2 comments:



Nancy J. Hess said...

Thank you Gene for posting your thoughts. So often we find ourselves helping others comfort us when talking about HD. This can bring on an unexpected loneliness but then, as one might say to one's self from time to time, "Get over yourself!" The truth is, there are only going to be a few in our lives who get it, and can stick with us through the dark passages. Thank you for noting that both positive and negative gene tests can significantly impact us. I tested negative but not a day passes that I am not living presently with this disease in my life and

thinking about a cure. But pearls of joy and happiness still appear, and that is the real miracle of life we can celebrate.

6:21 AM, March 16, 2011



Unknown said...

Gene: Thanks for all you are doing for our HD community. I'm glad your exit from the closet didn't do away with Gene Veritas, a writer and activist I admire. The other fellow you've begun to introduce to us--the one who spoke at Palm Springs--is interesting, too, and I hope to learn more about his career and interests as time goes by.

Beverly

6:43 PM, March 17, 2011

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