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Feeling like an alien: going public about Huntington's

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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](#)

MONDAY, JANUARY 31, 2011

Feeling like an alien: going public about Huntington's

How do you overcome the stigma and fear of discrimination associated with a brain disease that could leave you horribly disabled?

I've struggled with this question constantly since my mother's diagnosis for Huntington's disease in 1995. HD caused her body to move uncontrollably and robbed her of the ability to speak, eat, and think. She died in February 2006.

My fear of HD and discrimination increased exponentially after I tested positive for the disease in 1999.

But in 2010 I started to come out of the HD closet. After turning 50 and putting in twelve years as an activist for the [Huntington's Disease Society of America](#) (HDSA), I believed it was time to speak out. I also felt encouraged by the passage of the Genetic Information Nondiscrimination Act of 2008 and last year's new healthcare legislation, which will ban the exclusion of people with pre-existing conditions from health coverage.

I took two very big steps last year. In June I revealed my gene-positive status in public [for the very first time](#), and in September [I gave a presentation](#) on my family's struggle with HD at Vertex Pharmaceuticals.

Going fully public

Now I am preparing to go fully public. On February 7, I will deliver the keynote address to Huntington's researchers from around the world at [CHDI's 6th Annual HD Therapeutics Conference](#) at the [Parker Palm Springs](#) hotel in Palm Springs, CA.

Starting the day after Super Sunday, this event is the "Super Bowl" of HD research. The CHDI Foundation, Inc., informally known as the "cure Huntington's disease initiative," is the largest private sponsor of HD research.

CHDI is going to record my speech and very likely place it on the web.

For the first time, the greater HD community – and anybody else who watches the video – will know my real identity.

New burdens

So I'm scared!

Living in the closet was comfortable. It allowed me to deny the "truth in my genes" to both myself and my friends and acquaintances.

But after February 7, I'll take on new burdens, including the deep misunderstanding many people will likely have about an unknown,

[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
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[Heather's Huntington's Disease Page](#)

complex, genetic, and deadly disease.

For years I've played through my mind all kinds of scenarios about coming out and people's reactions to it.

Starting next week, I'll be dealing with the *reality* of coming out.

Dual identities

To help me get ready for the CHDI speech, I read the graphic novel *It's a Bird ...*, written by Steven T. Seagle and illustrated by Teddy Kristiansen. The 2010 CHDI keynoter, Seagle is from a family affected by HD.

Seagle's story about a man's fear of HD, which afflicted the main character's grandmother, strikingly resembles parts of my own family's story – and that of so many other families struggling with the stigma of HD.

Steve, the main character and a comic-book writer, is like Clark Kent/Superman: he has two identities, one public and one secret.

But while many people identify with Superman, Steve hates him. The dual identity painfully reminds him of Huntington's disease as he struggles to come to terms with his own at-risk status and his parents' cover-up of the disease. This predicament sometimes leaves Steve downright miserable and unable to share his feelings with his girlfriend or anybody else.

I, too, live with a painful dual identity – my HD world and non-HD world.

HD 'aliens'

Steve narrates the story of the day he visits his aunt, who lies gaunt and twisted in bed as she goes through the final stages of HD (boldface in original):

*You can shield a **child's** eyes from this, but as an **adult**, there is no **looking away**.*

*What you see, immediately... What you know... Is that there's no good thing to hope for a Huntington's patient. If you hope they're fine except for their **body** – you're condemning them to a life sentence lived out inside a useless shell.*

*If you hope they're vegetative and mentally **gone** – then you've damned them to a meaningless living death.*

*And the concerns **compound** when you own up to the fact that in another twenty years ... this could possibly be **you**...*

*With your kids looking down at **your** twisting, writhing body and wondering the same thing about you ...*

*... And **themselves**...*

... Because this is not a condition you could hide like a rash, or a tumor secreted on the inside.

*This disease sets you **apart**, marks you as **different** ...*

*... **Alien**.*

Superman is an alien.

I feel like an alien with my HD-positive status.

How are people going to react? Will people at work question my ability to perform? Will people make discriminatory comments? Will my 10-year-old daughter hear jokes at school?

And how will *I* react to people's reactions?

Seeking support

On January 24 I participated for the first time in several years in the local HD support group's breakout session for at-risk individuals.

My HDSA activism began through support group in the late 1990s, and, last year, I decided to return to my roots in the organization by resigning from the board of directors and dedicating more volunteer time to support.

In the past I gained much from this group. Now I want to give back.

At first I felt strange sitting with the two facilitators and two other at-risk individuals.

But I also opened up about my deep fears about going public.

I was once again struck by the undeniable reality of HD.

As I take the fight against HD public, I'll need more support than ever.

Posted by [Gene Veritas](#) at [12:29 PM](#)      

Labels: [activist](#) , [at-risk](#) , [brain](#) , [CHDI](#) , [closet](#) , [coming out](#) , [diagnosis](#) , [disabled](#) , [discrimination](#) , [gene-positive](#) , [genetic](#) , [Huntington's](#) , [mother](#) , [pre-existing condition](#) , [stigma](#) , [tested positive](#) , [Vertex](#)

7 comments:

Anonymous said...

Dear Gene, Know that you go to that podium on Feb. 7th with the prayers and good wishes of all of us who get so much out of reading your blog. To paraphrase a plaque I have got hanging on my bedroom wall--Nothing is going to happen at that conference or in the days and months to come that God and you cannot handle.

We'll all be there with you.

[2:20 PM, January 31, 2011](#)

Anonymous said...

Your honesty takes great courage. I hope that after your butterflies subside, you will feel a wash of freedom that gives you nothing but strength to continue doing your excellent work. Thank you for your posts. They mean the world.

[4:18 PM, January 31, 2011](#)

Julie said...

Hi!

From the 2009 CHDI keynoter to the 2011 CHDI keynoter, I thought I'd give you a little advice on what it's like. And some of the goals as I see it.

1. I'd say 95% of your audience does not work with HD patients. Only animal models. Or cells. Or strands of DNA. Or maybe only theory. They are disconnected and probably don't make a ton of money.

2. The audience is already aware that you or a loved one of yours is affected by HD. So, a surprise reveal will be somewhat silly.

3. I would say the goal is to make them feel that researching HD is the right thing to be researching. Many in the audience may feel that Parkinson's, and Alzheimer's is sexier and will garner them more success. NO WAY! HD IS WAY BETTER! We will have results before the others will. :-)

4. Make them know that there are lots of people who care about what they do and thank them for their time, effort and work. Make the researchers feel good so they care and keep working as hard as possible.

5. Encourage the room to work together. People in the science community hate sharing.

I will be there on Feb 8th to say hello. Take all your nervous energy and throw it into rallying the research troops!

6:03 PM, January 31, 2011

 **Anonymous said...**

It feels like HD day. I'm going for testing on the same day.

I hope that your coming out goes well.

Good luck and don't worry about the nerves :D

M. in the UK

1:37 PM, February 01, 2011

 **Anonymous said...**

My mother is in the final stages of HD and we face the same agonizing decisions you faced in 2006 about feeding tube at present.

It helps to read your blog and know other people have gone through what we're going through. My sister, like you, is positive for the gene and looking at my mum is like looking in the mirror for her. I just hope and pray we can find a cure before it's too late for her - and for you. Thank you to everyone who is carrying out the research - please keep going!

CS in UK

3:48 AM, February 07, 2011

🌀 Anonymous said...

Dear Gene

I wanted to thank you so much for the courage and resolution it took to be the keynote speaker at this year's CHDI HD conference, and to match up both your 'HD indentity' with your true identity. The inspiration you, and the HD affected community give to all of us 'HD researchers' is beyond words. It is true that sometimes we do forget the big picture as we concentrate on the minutia of our individual research. Despite the exhausting deluge of information and meetings that surrounds this conference, I think I speak for many people who always come back invigorated to do better, and try harder. Your words make a difference not only to those who are positive for the HD gene, but to those who are dedicating themselves to help find therapies that work. Each year we see new data, learn more and become more sophisticated in our understanding of the disease, and I can honestly say that I am optimisitic that there will be real progress made in the next couple of years, that will start impacting the lives of those afflicted.

With best wishes, and many thanks. Keep doing what you are doing!

11:29 AM, February 13, 2011

🌀 Anonymous said...

Dear Gene

Thank you for your blog. I am HD positive. My father died from HD in 2005. I am a 52 year old mother of 2 and grandmother of 8. I had some good jobs with the Federal Government where I received awards. I ended up working at a bank. My Supervisors were very critical. I was a Head Teller, trained employees, received awards at previous jobs I was Asst Head Teller at this bank. I started to forget and not be able to learn a new process. My supervisors yelled at me, wrote me up. So many things happened. They fought with me over going to Dr. appointments. They played games with me constantly. We had several tests that we were required to pass that I used to be excellent with. I wasn't able to process what I read, remember what I read, and didn't comprehend questions in the tests. I was telling them that I was having those problems. My co-workers talked about how they don't understand why my supervisors were treating me like a DOG. My Head Teller started taking me to the back where noone could hear her and she threatened me about my Dr. appointments and scheduling. I told her that I was trying to get into a research clinic. She was demanding that I tell her now when and how long, a day, a week, a month or 2-3 days, what was I going to need and she needed to know. The next day was the same thing and she told me that she would just have to replace me! I started going to the doctor because my blood pressure ran very high, where I was passing out. She

insisted that I show up at work that afternoon. I quit my job and my supervisors called me telling me that I needed to come in and count my drawer down. I know as a Head Teller, if someone didn't come back, I would have to do dual controll with another supervisor and balance it out. My supervisors insisted they knew all about my disease and told me what I could do to make things better. When we tell people that I have HD, they don't want anything to do with me. My partner of 7 years left. He said he couldn't handle it. My daughters and sons-in-law have alienated me. One son-in-law is jealous of my daughter and I having a relationship and she can't see that so it causes us to not have any communication. I don't have communication with their children. My other daughter feels like I am exagerating so we only talk when I need to babysit. When I meet up with people and mention HD, they look at me like I am in their way.

6:05 PM, February 14, 2011

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