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At Risk for Huntington's Disease

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## Ten years after the test

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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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## HD Links

[Huntington's Disease Society of America](#)  
[International Huntington Association](#)

SUNDAY, AUGUST 02, 2009

## Ten years after the test

Life goes in cycles, and so do our memories. Lately I've been thinking a lot about the tenth anniversary of when I tested positive for the genetic cause of Huntington's disease.

Yesterday I felt the urgent need to write about what's happened since that day in June 1999 when I learned the terrible news. Two days ago, on July 31, I received a private comment on my blog from a mother who just revealed her HD status to her nine-year-old daughter.

The girl, who has been watching her grandmother succumb to HD, asked if she too would fall ill. Her mom replied, "I don't know." Usually children are not tested for HD, so the daughter won't be able to know her own status until she turns 18. The daughter also wanted to know if her mother would die. "I hope not any time soon," she replied.

The mother's cognitive symptoms – which are causing depression and affecting her temper – have already begun. This reminded me of another friend, in her forties, who had to quit her job and stop driving because of early HD symptoms.

This year I turn 50. By that age my mother, who died of HD in 2006 at the age of 68, was having the odd mood swings that frequently signal the full onset of the disease.

But I have yet to suffer its overt symptoms.

## A crash in the dark

A deep sadness gripped me upon reading the mother's comments and exchanging e-mail messages with her. I told her that my own daughter – who is also nine – had tested negative for HD in the womb. The time is fast approaching when she will start to learn about my status. In January 2000 my wife and I broke into tears of joy when we learned she was negative. We will need to explain all of this to her and reassure her that she will not get HD like her grandmother.

Lately all of this is on my mind.

From time to time I lose my balance and have fallen to the ground on several occasions.

During the early morning hours of yesterday, after getting up to go to the bathroom, I suddenly became disoriented and couldn't find my way back to bed. I seemed to have blacked out or gone sleep-walking.

I usually put my hand on the wall to guide me in the dark, but this time I could not find it. I instead hit the mirror of the sliding door of a long closet and went flailing and crashing down to floor, knocking a picture off another wall, hitting a night stand with my arm, and breaking the frame of

[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](#)

another picture.

Luckily, except for a scraped arm, I am okay. My wife, who had fallen asleep in another room watching TV, awoke thinking that a burglar had entered the home.

Could I, too, be experiencing the first overt symptoms? My mother fell a lot during her battle with HD, especially in the last few years of her life. Once she broke a wrist. Another time she needed staples to close a head wound. In the final months she was confined to a wheelchair.

Or am I just getting older and need to install a night light in the bedroom?

Or – as I think most likely – was my bedroom accident a psychological response to the woman's plight and the future discussions I will have with my daughter?

### Avoiding onset

I cannot foretell tomorrow. But, despite this incident, my current lack of overt symptoms might indicate that the genetic defect is affecting me differently than it did my mother. Maybe, I fervently hope, my onset will occur much later.

I count every day of good health as a blessing and an opportunity.

I have the same degree of mutation in my gene as my mother, and it is the degree that generally determines the age of onset. That's why HD strikes people ranging in age from young children to the elderly, with the most common age of onset ranging from 35 to 55.

Thus, according to standard research on HD, I am likely to develop symptoms soon.

But other factors, as yet undiscovered, could affect onset. Scientists believe that a so-called modifier gene, or genes, could influence the way the defective gene huntingtin operates. Researchers have been searching for the modifier for several years. If discovered, a modifier could become another predictor of age of onset, with a genetic test similar to the one I underwent.

### Different levels of preparation

My mother was the first known person with HD in our family. It came as a complete surprise, and she therefore had no way to prepare for it. I was almost 36 when I received the news of her illness and have tried to care for my health conscientiously. A good diet, regular exercise, avoidance of stress, and psychotherapy all became part of my medical kit against Huntington's. I have also participated frequently in the local Huntington's disease support group, a major source of comfort and solidarity for our community.

I take the [Huntington's Disease Drug Works](#)-recommended cocktail of supplements (the sugar trehalose, coenzyme Q-10, omega-3 fish oil pills, blueberry concentrate, and creatine). Scientists are examining these substances as possible treatments to alleviate symptoms or stave them off.

Anecdotal evidence suggests that HD people with poor habits such as heavy drinking get sick earlier. Some in the HD community have also commented that traumas such as car accidents and operations can cause onset or lead patients into a sudden, deep decline. In late 2007 and early 2008 I faced a decision about an operation. I had an extremely painful anal fissure and, wanting to avoid the possible trauma of surgery, first tried another treatment for a couple of months before finally opting for the operation ([click here](#) to read more).

### A positive attitude

I believe that a positive attitude has also kept me stable. Since 1998 I have worked as a volunteer activist for the [Huntington's Disease Society of America](#), and for almost five years I have blogged on living at risk.

My wife has given her love and unconditional support. Although she does not yet know my status, my daughter is aware of HD and my activism. My devotion to them helps me keep a healthy balance among work, activism, and family life, and their love provides an incalculable emotional boost.

This blog is a catharsis that helps keep me focused and sane. I'm producing a record of my struggle with HD and the larger movement to care for HD families and find treatments and a cure. I can vent my feelings and share them with a wider community.

I am also very fortunate that a journalist friend – who inspired me to start this blog – reads every entry, assists with editing, and, most important, helps to deepen and clarify my message. I have come to depend on his selfless dedication. Familiar with the disease long before I ever heard of it, he has become my Huntington's alter ego.

Knowing that he and others are reading about my thoughts and feelings provides another enormous boost to my morale.

I stay informed about potential treatments, sign up for experiments ([click here](#) to read more), and strive to understand the many scientific discoveries about the disease. One old pharmacist friend from the local support group – who became symptomatic only in her early 60s and who still remains lucid – is convinced that understanding the disease is a factor in delaying onset.

### My life's calling

My dedication to the campaign against Huntington's connects me to the "big picture" of the human struggle for a better life for all. I am exercising leadership in ways I never imagined. To speak out at support group, to respond to an e-mail from someone in distress about Huntington's, to help jump-start stem-cell advocacy in California, to report on the scientists who are working hard on treatments – all of these kinds of activities bring me deep satisfaction.

I feel that I have found my life's calling. If I follow in my mother's footsteps and become disabled by HD, I will have fought to the best of my ability to care for myself and to make others aware of the urgent need to end HD's devastation.

Yesterday morning, upon remembering my crash in the night, I wanted to forget HD. But when I thought of the HD-stricken mother and her daughter – and then my own daughter – I knew that I needed to write down my feelings and prepare for another day in the fight. Whatever the reason for my current lack of overt symptoms, I have the opportunity to play a part in the historic effort to eliminate one of the world's cruelest diseases.


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Posted by [Gene Veritas](#) at [11:49 AM](#)



6 comments:



 **Unknown said...**

Hi Gene,

Nice entry. I read them all. I am a neurologist who see patients


with HD and I do HD research. I cannot prove it to you in a court of law, but my firm belief daily mental and physical activity is helpful in delaying onset and slowing progression. I tell my pts to shoot for the equivalent of 30 min walking daily, more if they can handle it. I thank you for your efforts. They help keep clinicians and researchers like me motivated.

Best,

Jang-Ho Cha

Boston, MA


7:49 AM, August 03, 2009

 **Anonymous said...**

Thank you for all your entries. You are so inspiring to my family and I. I appreciate everything you do!

9:01 AM, August 03, 2009



 **Gene Veritas said...**


Dear Dr. Jang-Ho Cha,

Thank you for your untiring support of the HD community and this blog, and for your research efforts. Together we will find a way to stop this disease. Seeing you at work in search of treatments is a big boost to our families.

Yours,


Gene

5:10 PM, August 03, 2009

 **Medical Call Center said...**

You are a very strong and upright personality...keep up the strength of your mind and all the best for ill health that you have to cope with.

12:55 AM, September 16, 2009

 **Medical Billing Software said...**

Goos article.Sometimes I feel my pain is the most and why me.Then when I read of others pains I feel there are braver ones than me.keep up your bright spirits.

12:16 PM, September 22, 2009

 **Anonymous said...**

I was reaching out to find recent information about Huntington's Disease. I tested gene positive in 1996, learned everything about HD and then just moved on with my life.

I just had my 40th birthday which has been a real whopper of a birthday. It has brought up a whole rats nest of worries, and I'm headed to the Neurologist for a check up.

How comforting to find your blog, and Dr. Cha as a commenter. Thank you for your help.

Do you know how many people have now tested positive for HD and are living in limbo like this?

4:59 PM, [September 25, 2009](#)

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