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Living in limbo

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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.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▼ 2010 (26)
 - ▶ December (4)
 - ▶ November (1)
 - ▶ October (2)
 - ▼ September (3)
 - [Out of the closet and on to the cure](#)
 - ['More to lose than ever'](#)
 - [Living in limbo](#)
- ▶ August (2)
- ▶ June (2)
- ▶ May (3)
- ▶ April (2)
- ▶ March (2)
- ▶ February (2)
- ▶ January (3)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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HD Links

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

MONDAY, SEPTEMBER 13, 2010

Living in limbo

People who've tested positive for genetic diseases but still don't have symptoms find themselves playing a terrible waiting game.

I tested positive for Huntington's disease in June 1999 at the age of 39. HD usually strikes people in their 30s, 40s, or 50s. My own mother, who died of HD at age 68 in 2006, started showing the psychiatric effects of HD around age 48.

So my symptoms could start any time.

Difficult to predict

With HD, the more severe the genetic defect, the earlier the disease starts. But doctors and scientists cannot predict the exact moment when a person will display symptoms. What makes this fatal brain disease even trickier is its variety and complexity of symptoms. Researchers are finding that the disease affects many functions, from those as subtle as the sense of smell to as basic as the ability to walk.

The disease also causes decline variably in different people. The normal course usually runs 15 to 20 years. But some people live a long time until the worst symptoms kick in, while others become helpless early on.

HD is caused by a single genetic defect, but researchers are searching for so-called modifier genes that might trigger onset. Environmental factors and lifestyle also may affect onset and the severity of the disease.

My own waiting game

So I have played the waiting game for eleven years.

Not long after I was tested, my wife and I noticed that my legs twitched at night as I would fall asleep. We panicked, because the first physical manifestation of my mother's HD was uncontrollable trembling in her legs while in bed.

A physician with detailed knowledge of HD informed me, however, that many people have nocturnal twitching and that mine was probably not related to HD.

We were relieved, but, because the genetic defect eventually strikes *all* carriers, we know it's only a matter of time before something begins to go wrong.

Subtle versus classic symptoms

Over the past decade I've noticed a decline in several areas such as short-term memory and reaction time behind the wheel. This could be HD – or simply the aging process. (I turned 50 last year.)

[Huntington's Disease Drug Works](#)
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[Thomas Cellini Huntington's Foundation](#)
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HD Blogs and Individuals

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

I did well at my last annual check-up with an HD specialist. I am still apparently free of classic HD symptoms.

But I'm also aware that the more subtle symptoms could be at work. And I know that the latest research demonstrates that changes in the HD-affected brain start occurring years before noticeable symptoms arise.

Feeling "cheated"

Recently I've been feeling angry about being in this state of limbo.

Don't get me wrong. I'm very happy to be healthy. When I see other HD-affected people in my age group (40s and 50s), I feel blessed in being able to work, write, travel, and enjoy my family. I'm exercising, eating nutritious food, taking supplements, and keeping an active mind so I can try to stave off the symptoms as long as possible.

I'll admit that sometimes I experience that little bit of death wish that we all do from time to time. During an HD check-up a couple years ago, I expressed amazement to the doctor that I had no apparent symptoms. "Be thankful," he said.

In a weird way, I felt cheated. I had been preparing myself all these years for onset, and it didn't happen!

It's as if I'm preparing for a great battle, but the battle never comes.

I think what I really wanted was *definition* in my life about HD. I wanted to know how it would start and when. (I know that's a narrow focus; onset will bring huge burdens to my wife and daughter.)

Powerful feelings

These visits to the HD doctor always unleash powerful feelings. I see individuals with severe symptoms. I know some of them and have seen them decline over the years.

I feel deeply relieved not to be in their situation.

And I feel sad and guilty watching them struggle with walking, talking, and the other basics of life that HD takes away.

A cruel joke?

Other times my imagination wanders into the territory of conspiracy theory. It goes something like this: the geneticist who gave me my test results made a terrible mistake and mixed up my results with somebody else's. I am not really gene-positive! That's why I don't have symptoms!

A similar version gets paranoid: that geneticist *wanted* me to suffer and *lied* about the results!

"It's a hoax!" I tell myself.

"Is this some kind of cruel joke?" I angrily ask myself. "I'm told I'm going to get a disease, and yet no symptoms have come. I keep wondering about it."

Wanting to "resign" from HD

A few weeks ago, I daydreamed about writing a "resignation letter" from my volunteer position with the local chapter of the [Huntington's Disease Society of America](#) (HDSA). "I'm tired," the letter stated.

I felt especially resentful because I had just returned from a very enjoyable 32-day, 8,300-mile [cross-country car trip](#) with my family. I didn't answer any HDSA e-mail during that time, and I put thoughts of the disease and our cause to the back of my mind.

After the vacation, however, the hard reality of HD worked its way back to the forefront. It's time for my annual check-up, and also for the tenth annual [HDSA-San Diego Celebration of Hope Gala](#), our biggest fundraiser of the year.

Commiserating with Michael Douglas

In late August I watched actor Michael Douglas reveal on national TV that he had stage-four throat cancer. My heart went out to him. But, as he put it with the characteristic Douglas family determination, he had an 80 percent chance of beating the cancer.

"At least there's a treatment!" I thought. Good for him!

But then I immediately thought how there is a *zero* percent chance of beating HD – because there is still no treatment and even less a cure.

So, just as I think about HD practically every morning, so must I daily rededicate myself to the fight against it.

Fighting on a new level

Not coincidentally, I'm gradually and very strategically going public about my gene-positive status. In June I gave a [speech in Brazil](#) in which I came out to an audience of several hundred people.

Later this month I will make a presentation on my life with HD for a local biotech company, [Vertex Pharmaceuticals](#), which researches the disease. It will be the first time I speak in public about HD to an American audience.

I really do wish HD were just a cruel joke or a bad dream. But as I think of my mom and all of my friends and acquaintances living with the disease or at risk, I know all too well that HD is real.

Posted by [Gene Veritas](#) at 8:29 AM



Labels: [brain](#) , [cure](#) , [daughter](#) , [exercise](#) , [gene-positive](#) , [genetic](#) , [genetic defect](#) , [geneticist](#) , [HDSA](#) , [HDSA-San Diego](#) , [Huntington's](#) , [memory](#) , [modifier gene](#) , [mother](#) , [symptoms](#) , [tested positive](#) , [treatment](#) , [Vertex](#) , [wife](#)

7 comments:

Anonymous said...

I can't say I understand how you feel. I do not have HD but my brother does. He just turned 40 and struggles daily with this horrible disease. I wish you the best and keep the faith!

[11:53 AM, September 13, 2010](#)

Anonymous said...

To be honest with you, I didn't say everything in my last comment. When I first read your post all I could think was how you should be happy and blessed that you are not experiencing the uncontrollable body movements, the difficulty in talking and remembering things. Hard time swallowing your food or wearing depends at the age of 40. My brother was robbed of his life in a way. He will never be married or have children

unfortunately. Just be thankful you were able to take that road trip with your family and you are able to do what you can now in your life. Some people with HD never get that opportunity. I can see how the waiting game is overwhelming but the onset is far worse!

12:30 PM, September 13, 2010



Unknown said...

Gene, I'm glad you took a real vacation from being such a brave and relentless HD warrior. Now you're easing your way back into combat mode and preparing for your presentation later this month. No wonder ambivalent feelings about the good fight are emerging. Just remember that you are an inspiring role model for those of us who do a little bit more in our fight against HD because we are indebted to you for all you have done. Thanks! Persevere, and take some well-deserved breaks as often as you need them.

Beverly

7:31 AM, September 14, 2010

Lauren said...

Gene, I thank you for your blogs. I tested positive 4 years ago, 5 years in November with no symptoms yet..I too am playing the "waiting game", so I know the struggle..and no one is saying that that is harder than going through the disease itself-- certainly not. But the waiting is hard. I understand. I just don't think anyone who isn't in that situation can understand. So I'm glad that you do and that you share!

8:20 AM, September 14, 2010

Anonymous said...

me two tested positive 10yrs back am 57 and have youngest in nursing home pam

middle sis is in middle stages and im the oldest doing the best go figure all 3 girl have it and my mom feed my baby sister evryday for 2 yrs in a home its so awful hugs to all gail crisp fla

10:32 AM, September 18, 2010

Susan Elaine said...

Gene,

We have one life to live, and in living we have a Billion chances and then some to make a valiant difference in this world. And if we do... we have a sense of self worth, and if we don't...we can only wonder if we could have made a difference or if we were meant to walk this earth with a "Greater Purpose". Most people fear that opportunity to know and act upon a greater purpose when the call is there. However, we all wait for that "Chance" to truly "BE" who we are. For me, I thought my greater purpose

came when my work life presented challenges in the area of Ethical and Moral determination in the area of balancing work and home life. REALLY? I thought...how many Women need to understand?! More than I could Fathom was the answer. So I would delve into so many difficult positions women take in life with regard to work and home life. i actually thought I was helping. but WHO? i didn't like the answer (like most) So I first felt lost. then, my heart...ent on. Searching for my purpose: Then came the challenge of learning about a whole new spiritual outlook. Wu Wei... Movement without movement...just "BE". OMG I thought, I need to share this with others. Maybe I was supposed to be this person who lived by example. Don't Talk...Just "BE". So I did. I paid so much attention to the "Here and Now". But then, I realized that the Here and Now, was just that! For Everyone. I prayed.. "Lord, What is it that i should watch for, what is it that you want me to do?"

Then, I went for my annual physical with no thought for anyone, or anything. I just casually mentioned that My mother and grandmother were Pos for HD. Without hesitation, my Primary Physician tested me and even she didn't know what HD was. I didn't know I should be counseled. I didn't understand how devastated I would feel "Knowing'. I didn't know or even understand how my life would change forever "Knowing'. I just did what I was told, and gave Blood.

So...Now I know. POSITIVE 41 CAG Repeats.

I'm still me, and I still don't have a clue what my "Purpose" is. I'm just ME...Like YOU.

I don't know a damn thing, except that life is full of challenges, just like it was before my diagnosis. I still live my life asking the same questions, and still never know if my living is making a difference or serving my "Ultimate Purpose'. The truth is... that is the one thing I never have to worry about. It is...what it is, and like the My Father in Heaven...

"I am, what I am".

God Bless! Just be "YOU". It may never be revealed until after this life.

Until then, "Together", we CAN and WILL make a Difference.

~ Susan E Lawrence

4:42 PM, September 18, 2010

⊗ **Unknown said...**



Thank you for sharing. I am also playing the waiting game. My grandfather losing his battle 9 years ago and now I watch my aunt and mother decline fast. People may not realize but waiting for this disease plays games with your mind. You see every time I forget something, I think arr it's starting! Or every time I feel a bit down or I feel restless, it must be it. Sometimes I wish I had never been tested but then again children of a huntingtons parent will always be plagued by what if? and how long?

3:46 PM, May 20, 2017

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