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Huntington's disease: an early date with mortality

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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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MONDAY, JANUARY 10, 2005

Huntington's disease: an early date with mortality

My name is Gene Veritas and I am at risk for Huntington's disease.

I have been thinking of starting this blog for some time. Something happened last Friday evening, January 7, 2005, that helped me put things in perspective and finally pushed me into sharing my story with the world.

I was having a beer with an old friend who happened to be attending the same professional convention as I. We go back twenty-five years and hadn't seen each other in more than a year. We talked about writing and publishing, our passions. We had only thirty minutes to talk, because I had to catch a plane back home so that I could get in some volunteer work in the campaign to stop Huntington's disease.

Our conversation quickly turned to HD. My friend wanted to know how my health was. I explained that I had just started taking a dietary supplement that is part of a new "treatment now" HD program that aims to cut through the bureaucracy and lethargy of other HD organizations. I told my friend that I would be taking additional supplements, all over-the-counter or FDA-approved, in the coming months, including creatine, for which I will have to get blood tests to make sure it doesn't damage my liver or kidneys. Just thinking about this scares me, but I feel I have no choice.

My friend wanted to know what my psychological reactions to living at risk for HD. He especially wanted to know if I was angry.

No, I am not angry, I told him. It's been nine years this December 26 that I learned of my mother's diagnosis with HD. I have come to accept HD as part of my life.

I think a lot about death, I continued. I don't know exactly when HD will strike. It could be as early as in the next five years, or it could take twenty years. I'm trying to squeeze as much life into my days as possible before I starting living life as a "vegetable," I said.

"I envy you," my friend said. "I feel immortal. I don't believe I'm going to die. But you know you're going to die, and so you can live your life more fully."

The conversation shifted to God. My friend is a non-believer. Recently my wife, my daughter, and I resumed attending church. It is one of the supports we feel we need to get through our daily struggle with the impending onset of HD in our lives.

I rarely have the kind of conversation that I had with my friend, not even at HD support group. It hit me how fast the nine years living at risk for HD have gone by and how profoundly it has affected my life and the life of my family. I've thought a lot about death in the last nine years – so much, in fact, that I am now almost calm about it.

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My finger twitched the other day and I showed my wife. Was it HD? We don't know. I was only happy that it was not painful. If this is HD, I can take it, I told myself.

But will I be able to take the cognitive loss that afflicts all HD people? I have an accepting attitude now, while I'm healthy, but how will it feel when I can't write or publish or stand at the bar with a friend and have a beer anymore?

Posted by [Gene Veritas](#) at [10:01 PM](#)



12 comments:



Ian said...

It's interesting that I found my way to this blog. Only a few short weeks ago I had thought about starting my own HD blog. I'm 21, and I found out I had the HD gene about 2 years ago, just before my mother died of HD.

Hopefully that gives you some background on me. The most important thing for me and my young wife is that we have God in our lives. Living with any disability or tragedy in this life is so much easier when you know that this life is not the end.

Hopefully this post will be the start to some open dialogue about this Disease. For me it will force me out of my comfort zones and into a community that I have not had much contact with.

I don't have any answers to many of the questions; I'm smiling as I think about trying to answer the questions that arise knowing I have HD. The one thing I do know is that even if you can't stand at the bar and have a drink with a friend, you can always sit and have a drink with a friend.

[7:49 AM, January 11, 2005](#)



Sharon said...

Hi Gene and Ian

My mum is currently in the late stages of Huntington's Disease, she has been in a nursing home for 6 six years.

My mum was officially diagnosed in 1993 after several years of mis-diagnosis due to no family history of HD and the predictive testing not then available. She was 43 when she started showing symptoms and is now 59.

I am the eldest of three children, myself and my sister underwent testing within 6 months of mums diagnosis. We had five children between us, my youngest was 4 weeks old when we learnt of HD.

Both my sister tested negative however our brother has refused to undergo testing. His daughter, who is due her first child in March, underwent the testing and also tested negative. My

nephew has not been tested.

It is hard to put into words how I feel about how HD has affected our family, every time I think or talk about it I feel an overwhelming sadness.

I try not to think about HD as it brings with it an incredible sadness. My sadness is not for mum any more but for my dad who cared for her at home as long as he could and visits her daily. It is also for her grandchildren (she has 9) 4 of whom have never known her well.

Finally I think about her death constantly and feel guilty of my mixed feelings about this. She has no quality of life, she recognises no one, she cannot talk, toilet or feed herself, she looks like a skeleton and is slowing curling into a ball.

Unfortunately she still opens her mouth for food, her heart beats strongly and despite given no preventative medication or antibiotics she overcomes all colds and flu as well as pneumonia.

My comments will undoubtedly upset those that are at risk and for this I am truly sorry.

Gene I am glad you are not yet symptomatic and I have faith in the medical research taking place that something will soon be available to slow the onset or even cure HD. It will be too late for mum but not for thousands of others.

I have also decided today that I will not be making a donation to the Tsunami appeal but will make my donation to HD instead, many charities will miss out on much needed donations and I think Australians have raised an enormous amount of money for Tsunami and I am sure wont begrudge mine going to HD.

Sharon

[4:09 PM, January 11, 2005](#)



fran said...

Have you been tested at all?

[2:22 PM, January 20, 2005](#)



margb said...

well, we have had a 4 year rest from HD. My mother died of it 4 years ago and left 7 children. She lived to be 79. My siblings now range in age from 45 to 58.

I knew when she died that the relief would be temporary....my oldest brother is now in the process of being diagnosed.

It is all i have been able to think about since hearing from my brother..

I began again to read all the web pages on living with HD and only get more frightened and saddened.

The thing is that these pages are much scarier than what i witnessed with my mother and my aunts. They lived long lives with the later years filled with odd neuroses but certainly not devastating. Of coarse the final 5 years or so were hard...but isn't it true that lots of people have difficult final years.

Maybe, with late onset HD, which my mothers family had, things are not as bad as when it strikes earlier.

9:43 PM, May 20, 2005

⊗ **Anonymous said...**

I found this website and read every comment. My mom has H.D. She is in her final stages ...and my dad can't get no help of any kind ... so I stay at home so he can work ... he isn't a rich person as a matter of fact we are barley keeping our heads above water. But things got so bad that I quit school to help and I have mixed emotions on the situation that my family is in. I want to go get tested but finding the time and a place to do that is a struggle. My brother and sister act like nothing is wrong (mostly my sister) My mom can't feed herself so me and my dad have to feed her and she choke's all the time and I get so scared. She can't walk even though she try's ... she ALWAYS falls. She tries to talk. She can't go to the bathroom. And sometime's when she and my dad are asleep I slowly open there door and just stare at her ... she sleeps curled up in a ball. Sometime's I run back in my room before I start crying I feel so bad for her and I can't help but to think that my brother or my sister or I will have H.D. I think about it alot probably more then I should. I can't help it. And she is so mean ... it's so hard to help her when she makes things so difficult. We can't yell at her, you know its not her fault. When my dad gets upset I tell him to leave and when I get upset I ask my brother to watch her. I try not to ask him I don't want to admit that I can't handle it but sometime's I just can't. I am just glad I have my brother.

12:47 AM, May 22, 2008

⊗ **Anonymous said...**

Hi all,

My older Brother was diagnosed with HD 4yrs ago. It was the most terrifying news and a big blow to our family, or to any family who shares this emotional rollercoaster of a journey.

Since then our Mum has been tested for the gene and the result was negative, so was my sister's and so was Dad's! We are all full brothers and sisters from the same parents. This is extremely rare. The professors have said it was a genetic mishap when he as created in the womb... although no websites

EVER mention that this is possible.

4yrs on since his diagnosis and unfortunately his balance is becoming a danger to himself and others around him, so on that basis we have just invested in a wheelchair. This had made days out so much easier! Due to him being prone to falling (on average once or twice a day) he tends to speed up whilst walking to avoid stopping and losing his balance, so therefore he's like a steam train trying to keep up the momento. Although the downside to having a wheelchair is that his leg muscles have weakened.

One of the reasons why I posting this blog is because there is a major issue which is baffling us, and i'd be interested to hear any similar stories...

My Brother, Carl, has now got an extremely sensitive sense of smell! He has now got an OCD (obesessive compulsive disorder) over smells and cleanliness. HD Professors at Cambridge (UK) have never come across this before and in fact have said that the condition normally lessens your sense of smell?!! My brother is so bad with his OCD that he cleans seats before he sits on them, at home, outside or even in a car and he won't even be pushed past a cafe or fast food restuarant because of the smell. It makes meal times difficult and it also makes caring from him very hard as the carer has to pretty much starve whilst in his company, through fear of him having a tantrum or attempting to run off.

Carl is getting harder to care for now and needs 24hr supervision, mainly because of falling and his swallowing.

I have searched websites looking for new medicataions, trials or different treatments to consider, and there's one that we're intrigued about after reading positive reviews:

A drug called: Tetrabenazine.

Apparently it lessens the jerky movements and has proved to give a better quality of life for suffers. It has proved to aid with better quality of sleep and for them to be able to feed themselves.

We have asked for this drug to be prescribed, although Carl's Professor refused to prescribe it on his last asesment. Her reason being that a side effect to this drug is that it tightens muscles (stiffens the suffer so they're more ridged), although the positives in my opinion look to out-weigh the negatives.

Perhaps it's a postcode lottery and if certain regions can afford

it on their budgets??? Has anyone in the UK managed to get this drug prescribed? Again, i'd be interested to hear if so.

Anyway i hope that some of this has been useful to Carers or for HD carriers.

Jo (UK)

[4:34 AM, August 28, 2008](#)

🌀 **Anonymous said...**

... forgot to mention that my Brother is noww 33yrs old.

Jo

[4:39 AM, August 28, 2008](#)

🌀 **Anonymous said...**

hello everybody i am 16 and my dad has HD he is now 39 he started to suffer from it when he was 33 and it has got worse over the years. i dont see him any more as we fell out my mum has always said to me that girls arnt affected by it but after reading this there is women who suffer from HD. i feel upset because i feel my mum has lied to me. i would rather die than have HD

COULD SOMEONE TELL ME IF I CAN HAVE THE TEST BEFORE I AM 18. thanks x

[1:56 AM, August 30, 2008](#)

🌀 **Anonymous said...**

my step father had HD but he is also the real father of my 2 olderst brothers anyways both my brothers have 6 kids between them if my brothers refusing testing can his kids still get tested? I have been told not not until my brothers pass? i find this selfish on behalf of my brothers as they both just assume they do

[5:25 AM, December 21, 2009](#)

🌀 **Lin said...**

My story is not unlike a lot of others above. My mother was diagnosed 5 years ago and sadly passed away last November. both me and my sister are at risk and as there is a choice to know if we also have this awful disease we choose not to find out.

Knowing that there is HD in our family has changed my outlook on life completely !! im scared to become close or start a serious relationship with anyone as i dont ever want them to go through what my Farther did (he was her carer right to the end - which he did willingly and with unconditional love) those of you who have placed a blog will know how it changes a person both body and mind and i would not like any man to

have to go through that. I also find myself realising that a family is no longer possible (unless i take a test and get the all clear) how could i pass HD knowingly onto an infant !!!

So my life has changed, im starting be become stronger and like many of you make sure i live my life to the full doing all the things that i would probably have thought of but never actioned before. I never think of the future only maybe a year or maximum two ahead. This way i know i will be healthy for my plans.

Its good to know that my thoughts are shared in some with many others. I only wish i could do more to help. I have offered my services to HDA as a volunteer but there is nothing they need me for. If you are involved in any association or group and you need or could use support please ask im here to help anyone who needs it.

7:05 AM, March 01, 2010



beth said...

i am 15 and my mom has huntingtons disease. the only reason i found this blog is because of facebook. HD has been really hard on my family and ever since my moms symptions started to come out when i was about 10 i became very sad and angry. when i found out that my 3 brothers, my sister, and i were at risk for it... well i became very unstable. my mom got worse and i felt as if i were being punished.

now i realize that its apart of life and all of those emotional downfalls have made me and my family stronger. and i didnt realize it till about a year ago that out of all my family my mom was the strongest one. she copes with it and lives with it and i found that her faith has grown stronger with HD. so if she could live with it i can. even now know where she could hardly walk and moves uncontrollably she is still very happy so i am happy.

so i know its hard knowing your at risk for HD but i think that in some weird way that it will make you stronger... that it will make me stronger. i just wanted to write this because i felt the need to.=)

7:59 PM, September 21, 2010



Unknown said...

You are not living to the fullest, fall in love, have a family. If you pass through life without either you have missed so much.

6:07 PM, December 17, 2016

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