9-21-2011

Waiting for symptoms: How long can I hang on?

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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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WEDNESDAY, SEPTEMBER 21, 2011

Waiting for symptoms: How long can I hang on?

As someone who is gene-positive for Huntington's disease, I live in an uncharted gray zone as I await the onset of the same kind of devastating symptoms that took my mother's life in 2006.

My gray zone had a precise beginning: on June 7, 1999, I received the results of my genetic test, which showed that I had inherited the abnormal HD gene from my mother.

However, I don't know the point where the gray zone ends and a much darker fate awaits. Although the onset of this 100% genetic condition is inevitable, its exact timing and manner are not precisely predictable.

So I play the terrible "waiting game," wondering and worrying about onset and the impact it will have on my job, my family, and my health.

Increasingly, I ask myself the question: "How long can I hang on?"

So far, no classic symptoms

My mother's initial, psychiatric symptoms, such as emotional upset, probably started in her late forties. By the age of 55, and most likely earlier, she had chorea, the shaking and trembling movements typical of this brain disorder, in her case first evident in her legs while lying in bed at night, then affecting her hands and head. Ultimately, HD destroyed her ability to walk, talk, and think.

At the end of this year I will turn 52. All of the research on HD suggests that by now, based on the averages, I should be having symptoms.

Scientists have demonstrated that "premanifest" HD people like me suffer harmful changes in the brain ten or even more years before the start of the classic, easily observable symptoms. HD is likely attacking my brain cells already, perhaps causing subtle changes in my sense of smell or eyesight.

However, as of my last HD checkup in December 2010, I displayed none of the classic effects. As far as I can tell, I continue to live like any "normal," healthy person.

Strategies for health

Over the years, I've been asked the question of how I have avoided onset. I've referred to a number of strategies in this past posts (for example, click here).

In brief, I exercise at least 30 minutes per day, eat a proper diet, cultivate my mind through my work as a college professor and activist for the Huntington's Disease Society of America, consult a psychotherapist, and take medications that combat depression and anxiety and protect my brain.

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
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I take the basic supplements – though their efficacy is still under study – recommended by the Huntington's Disease Drug Works program: creatine, coenzyme Q-10, trehalose (a sugar), blueberry extract pills, and omega-3 fish oil pills.

I also keep in touch with a network of friends and supporters and dedicate myself to my wife and 11-year-old, HD-free daughter. I strive to deal with stress positively, and to deepen my spirituality.

Writing for this blog provides an outlet for my deepest fears and connects me to my brothers and sisters in the HD community.

A lucky man

I can't prove that any of these strategies has actually prevented onset. It's possible that other factors such as an undiscovered modifier gene (a gene influencing the time and manner of onset) might also be keeping me symptom-free.

But I know that none of my strategies is causing harm. For example, I undergo periodic blood tests to verify that the large amount of creatine I ingest is not harming my liver or kidneys.

A lot of what I do (or don't do, such as heavy drinking) belongs to many healthy people's recipe for a happy and stable life.

Whatever the reason for my delayed onset, I consider myself EXTREMELY LUCKY.

That feeling is particularly acute when I'm reminded of people my age or even younger who already have full-blown symptoms.

A 'mild' case?

I've received several messages of encouragement from readers of this blog, basically along the following lines.

You won't get HD until you're in your sixties.

You'll only get a mild case of HD.

You'll have the disease, but be able to function almost normally.

You'll live with the disease until you're 80 (unlike my mother, who died at 68).

I often think of my HD friend Julie, in her sixties, who's lived with HD symptoms for a number of years but can still write eloquently and speak to me on the phone.

"You need to be like Julie," my wife tells me with hope and conviction.

But I also know that HD could attack forcefully, turning me into a mere shadow of myself and leaving me completely dependent on my wife, daughter, and others for the most basic of necessities.

As my wife pointed out not long ago, a man's fifties seem to carry the greatest risks for his health. (My father, for instance, suffered a heart attack at the age of 54.) I feel that if I can get to sixty with few or no symptoms, I might indeed get only a mild case of HD. And, by then, treatments should be available.

A precious gift

Each moment without HD symptoms is a precious gift.

A gift that allows me to help coach my daughter's soccer team.

A gift that lets me to enjoy a movie or a good book.

A gift that allows me to invite my wife out to dinner and afterwards take her on a relaxing drive.

A gift that gives me the time to prepare for the future and be thankful for all that I have.

And then I worry: what will the doctor say in a couple months after my next HD annual checkup?

I am hanging on. For how long, I don't know. But while I am, I intend to make every moment count.

That's when I recognize another facet of the gift: the opportunity to help other HD families in need and join with them and researchers in the search for treatments and a cure.

(For the latest on HD research in the wake of the 2011 World Congress on Huntington's disease, please visit www.HDBuzz.net.)

Posted by Gene Veritas at 9:15 PM

Labels: brain , chorea , cure , father , gene-positive , genetic test , Huntington's disease , modifier gene , research , spirituality , symptoms , treatment

11 comments:

Anonymous said...
Where do you think these gifts come from?

7:34 AM, September 22, 2011

Anonymous said...
Thank you for this post! My husband is in the same situation. Thank you!

4:37 PM, September 22, 2011

Anonymous said...
Thank you for this encouraging post. I needed to read this today after a rough patch in our family. I will look into supplements you are taking as I await test results.

4:56 AM, September 23, 2011

Anonymous said...
Thanks for this, my husband, gene positive is considered "premotor" and everyday is a waiting game for me. when will my life change dramatically? I try to stay in the day but it is hard. Thank you for your hope filled post. It always helps me...

10:13 AM, September 23, 2011

mindy said...
I found your blog today as I was searching for someone to relate to as my mother is in her last stage of HD. She turned 51 this year. I had always thought that no one would live past 55

with this disease, but reading your story has proven me wrong. I have not been tested yet, I am only 19 now.. so it will wait for now. However, she started having symptoms not too long after my sister was born who is 3 years younger than me. It's a terrible disease.

6:53 PM, September 23, 2011

Anonymous said...

I am Happy to hear that your are still symptom free. My sister was in her early 20's when diagnosed. she is now in her mid 30's and totally dependent on our parents for care. I do believe that staying physical, keeping your brain active and eating properly is keeping time on your side. My sister did none of the above. You mentioned that your 11 yr old daughter is HD-Free. Has she been tested? According to the information I have read, children could not be tested unless showing symptoms.

4:11 PM, September 24, 2011

Anonymous said...

Thanks for this post. I was diagnosed for with the HD gene two weeks ago. I have two very young children who I love so much and want to be there for as long as possible. I would do anything to delay the symptoms. Is there anyway I can find out exactly how much of the supplements you take everyday? What does your diet consist of? Please get back to me. I really want to give myself a chance by doing the things you spoke of.

7:28 AM, October 04, 2011

Gene Veritas said...

Information on supplements is at www.hddrugworks.org. You can find me on Facebook.

10:08 PM, October 06, 2011

Anonymous said...

Hello Gene..thank you so much for your HD Activism and this Blog. Would it be possible for you to post more detailed info about the diatary suppliments that you are taking? Specifically the names of suppliment brands that you use for Bluberry Extracts, Omega-3 and Trehalose. There are so many different suppliment brands online, that it would greatly help if you could share the ones that have worked for you. Thank you.

2:13 PM, November 29, 2011

Unknown said...

My husband got diagnosed at the age of 20. He's 27 now, and he doesn't have very many of the symptoms except the chorea. They look like seizures, but they are not. Some people would describe it as an "episode" but he prefers to call his moments of chorea an "attack". Lasts anywhere from 10 minutes to an hour. It's unfortunate, because as his wife I want to help, but there's

is nothing I can do. I try to just comfort him as much as possible and talk him through his attacks. Sometimes it calms him down and the attack will stop, but only sometimes. We have two children now, and we are hopeful that a cure will happen in the next 20-30 years so our kids won't suffer the worst effects of the disease. Taking care of yourself is the best thing you can do to try to prevent, or su stain, the dreadful disease.

9:05 PM, June 25, 2017

Marihipotenusa said...

Hallo,

Really thanks for sharing your experience with us! I´m writing from Spain I´m a 41 years old woman without symptoms and I have a brother and a sister starting now with them. We are really afraid!!!! We are going to take all the complement that you are trying.. but, what about the dose? Do you think that we could start with all them togueter or maybe we should start step by step?? and about the "trehalosa" Do you buy pils directly or do you eat it in wild honey, for instance?

Waiting for an answer

Huggs

Sofia

10:56 AM, February 12, 2018

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