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At Risk for Huntington's Disease

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In a time of crisis, the best investment of all

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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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SATURDAY, APRIL 04, 2009

In a time of crisis, the best investment of all

The economic crisis threatens to end our leadership of the world's financial system and erode our standard of living. We have borrowed too much on our future, leading other nations to doubt the value of the dollar and sapping resources from investments that could reinvigorate the economy. The export of jobs and factories to China and other countries has weakened our ability to bounce back. The state of California is broke, and the extra taxes of all kinds we're already paying here won't put more than a dent in the deficit.

It's a tough time to raise money to cure a disease – especially a cruel and fatal one such as Huntington's disease, where not a single treatment is available for attacking the root causes.

It's an especially harrowing time for me as I approach the tenth anniversary of my positive test for Huntington's and the age at which my mother, who died of HD in 2006, began to show symptoms. Like most other Americans, my wife and I saw the value of our retirement savings plunge by 30 to 50 percent. For the first time in our careers we will not get a raise.

I worry a lot about what will happen if I become symptomatic and lose my job, forcing my wife to carry the full burden of supporting the household and saving for our eight-year-old daughter's college education.

Taking on debt

So what did we do last month? We responded the American way and took on more debt! With the government pushing mortgage rates to historic lows, we decided to refinance ours at a very attractive 4.375 percent – and took out \$75,000 to build a swimming pool and fix up the house.

We easily qualified for the new loan because we prudently stayed away from extra borrowing during the financial bubble. In fact, we've always played it very conservatively with our money because of my at-risk status.

But I'm scared about this new path we're taking. Sometimes I think we are just as crazy as our financially irresponsible leaders in assuming this new debt at the time that my HD risk grows exponentially. In HD gene-positive status means that a person definitely develops the disease.

My wife denies it, but I believe that she wants a pool to substitute for the second child we did not have. Our daughter tested negative for HD while still in the womb, and the prospects of a second round of prenatal (or pre-implantation) testing, coupled with the stresses of my own at-risk situation, kept us from going through another pregnancy.

My wife sees the pool in the back yard, including a spa, as the new focal point for family relaxation and a place to enjoy with friends. Most of all she thinks it will provide fun, exercise, and unforgettable memories for our

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

[Chris Furbee: Huntingtons Dance](#)
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daughter.

In one of those many episodes of delicate negotiation that make up the everyday reality of marriage, I finally agreed to the pool. (In the deal I am supposed to get some custom bookshelves for my home office to replace the wobbly ones purchased many years ago at a discount outlet.) Like so many of our decisions, we ultimately agreed because we want our daughter to grow up with as many opportunities as possible. She just loves playing in a pool!

As I write these words I can see her laughing and splashing in the water as I stand at the grill preparing dinner and my wife sits in the spa with a glass of wine. It's the kind of picture I use to help me escape reality.

Enjoying the moment

But the daily reminder of my gene-positive status and the memory my mother's death jolt me into the reality of mortality.

Life really *is* short, and every moment that passes is unrecoverable. I do want my wife and daughter to enjoy that pool to the fullest. If we just keep waiting for the "right moment," it could be too late for all of us. My daughter will have grown up, and perhaps I will have become like my mother – speechless and confined to a wheelchair.

I also view the pool as a place for me to unwind. Those living at risk for Huntington's are bolstered when stress is lowered. The opportunity to swim more often will also be therapeutic, as we want to install an "endless pool," an underwater jet spray that creates a current against which to stroke.

Despite Huntington's and the bad economic news, life must go on. I'm at risk for HD, and that means our family inevitably ends up taking more risks in other realms of life.

I am striving to live out one of the grand lessons that being at risk has taught me. There are things more important than career and even more important than taking part in the monumental effort to find treatments and a cure for HD. They are the moments I can love my family and leave my daughter with the warm feeling of togetherness and being cared for.

That's the best investment of all.

Posted by [Gene Veritas](#) at [10:31 PM](#)



4 comments:

Anonymous said...

Glad you took the "plunge"....oh, what an awful pun...but I couldn't resist it! As I thought about your vision of all of you around the pool, I was encouraged to not dwell too much on the future and the security that I think I need to survive when my husband is gone. But rather, to seek out opportunities to live and enjoy life while we can. Quite frankly, how much money is enough to prepare for an uncertain future?? Sometimes you just have to live a little.....so congratulations on taking the opportunity of lower interest rates and living in the present moment! As a mother of a 15 yr. old who is himself at risk, I can tell you, it's mandatory. God's abundant blessings upon you and your family! Kathy Hunn, St. Louis

5:55 AM, April 07, 2009

⊗ **Anonymous said...**

my wife is a 3rd generation huntingtons victim. she is 21. we have a 2 month old girl. we didnt test her as you did yours. its my first child and i never knew love like this before. it feels suffocating to look at her and think she may have the gene. i just die inside to think she may grow without her mother who has very early onset symptoms. we even have special handling and arrangements in place for our daughter as it pertains to her mother carrying her and handling her. my bloodline is clean but my wifes mother and grandfather died of huntingtons. money is tight but after reading your writings, i decided to take her out yesterday and get some things she has wanted recently...including new shoes. she cant work and we have a new child so money is important. when i think of the future, i cant breathe and my mind locks down. today is reeally what we have and the future is unknown. i have to tell myself this multiple times daily or lose sanity. seeing my daughter with her mother is the most beautiful sight i have ever seen. have a nice swim

5:47 AM, April 08, 2009

⊗ **Ian said...**

Hi Gene (or whatever your real name is),

My name is Ian and I live over here in the UK. I've only come across your blog because my father (carer to my mother who has HD) forwarded me your email from the HD newsletter over there.

I just wanted to say that I have found your postings to be most informative, a real "at the coal face" view of what all aspects of HD are like. I've enjoyed your postings, cried a little, laughed a little and agree with almost all of what you have to say – but in particular your decision to build the pool (and get your book shelves in the negotiation). The picture of you and your family is embedded in my mind is something so very special and positive.

I'm very impressed by your spirit and think you are very brave. Keep up the good work in creating those memories and good luck.

Don't burn the burgers!

With much admiration,

Regards,

Ian.

[7:21 AM, April 15, 2009](#)

Anonymous said...

Thank you for your blog. I just found out my father is positive- we have no family history of it and I just discovered what HD is-(I think everyone died so young they were never symptomatic.) I am a wreck and hardly functional as ten years ago I went to a neurologist to find out why my short term memory was rapidly deteriorating. I wish you the best--and thank you for this blog.

[9:15 AM, December 27, 2009](#)

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