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At Risk for Huntington's Disease

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5-16-2009

## HD: hurtling towards death

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Serbin, Kenneth P., "HD: hurtling towards death" (2009). *At Risk for Huntington's Disease*. 40.  
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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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## HD Links

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

SATURDAY, MAY 16, 2009

## HD: hurtling towards death

Knowing that the first, subtle, and practically imperceptible symptoms of Huntington's disease are most likely already at work in my brain and body, I have become hyper-conscious about the brevity of life.

We are all in a race to death, but people at risk for life-shortening diseases know that their time to the finish line is painfully fast and troubled. In my case these feelings erupted to the surface of my being as I saw my mother in the devastating final stages of Huntington's disease in 2005 and early 2006 (click [here](#) to read more). They intensified as I dealt with deep grief about her death and my future as an at-risk individual after attending her funeral in February 2006.

Since then I have increasingly thought of the acronym "HD" in a very different light. For me it stands not only for "Huntington's disease," but also for the fact that I am "hurtling towards death."

I've been a workaholic and a perfectionist since childhood. I feel a fanatical urge to "get everything done" before I start having perceptible, debilitating symptoms. And lately the need to build a prominent legacy has consumed me.

### Striving for efficiency

On the professional front, it's not been enough for me to publish several respected books in my field. I strive for ways to liberate my creative activities in the same way that led Isaac Asimov to write hundreds of books.

At home and on the computer I am constantly responding to and/or saving the many e-mails I receive each day from four different accounts, and I am organizing our family papers into files and file boxes.

On the family front, I've been pushing my eight-year-old daughter to practice her piano as we prepare for our second annual piano-guitar duet next month. I pick her up from school three days a week and am in charge of the home for many hours, as my wife also works full time. I regularly have to stop myself from turning our relationship into yet another opportunity to value efficiency above all in my life.

My relationship with my wife has increasingly revolved around raising our daughter, as neither of us has relatives nearby to help with her care or to nurture family ties. As she finishes the third grade, planning for a possible transfer to private school – with her college education in mind – has taken on greater urgency.

We've also been spending lots of time and money remodeling our home, and, as I wrote recently (click [here](#) to read the entry), we've now taken on the building of a swimming pool. The pool will be an antidote to the hectic pace of our lives, but for now its construction is a new source of stress as

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we negotiate with contractors, watch our back yard turn into a massive hole, and put up with the din of machinery.

### A decade of activism

Last month I completed eleven years as an activist for the local chapter of the Huntington's Disease Society of America (HDSA). For seven of those years I wrote, edited, and published the chapter newsletter and participated in a plethora of other activities, from taking notes at board meetings and folding the newsletters to raising money and organizing meetings of HD advocates with California's stem-cell oversight board in the quest for funding HD research.

My latest project was to oversee the overhaul of the chapter web site that I inaugurated in 2002. With limited funds and time, it was a time-consuming but rewarding task. This blog will now be published on the site too, and I will manage and edit the site and produce articles for it (click [here](#) to visit the site).

All of this frenetic activity has come to a head as I worry about the health of my father, a Huntington's disease warrior who cared for my mother for 15 years and who has declined rapidly in the past few months (click [here](#) to read that entry).

### HD people: like anybody else

Two weekends ago someone blind-sided my car, sending me to the hospital briefly and causing \$3,000 in damage to my vehicle. I escaped with just a sore neck, but it was the first time I was involved in an accident. The shock left me emotionally paralyzed for the better part of a week, and the hassle of dealing with insurance companies, getting a rental car, and finding a repair shop threw off my focus.

"This can't happen to me!" I angrily told myself. "I have HD to worry about! I have an agenda to meet and a mission to fulfill!" I was deeply upset at being knocked off balance and losing precious time. As a result, I couldn't work on this blog for a couple weeks.

I had a hard time understanding that people at risk for HD are just like anybody else. Then I remembered an at-risk friend who got breast cancer just before she started having HD symptoms. Being at risk for HD does not make me immune from the rest of life's challenges.

### Unable to dream of the future

With the help of a psychotherapist I struggle to keep juggling the many balls of my life as I face the inevitability of my symptoms. The pace grows ever faster, and I am frustrated that I don't have another six hours each day.

I sometimes fantasize about how calm things would be if I were not hurtling ahead into Huntington's disease. I could perhaps follow the natural rhythm of life, slowing down as I proceed into my fifties and look forward to retirement, my daughter's college, and her wedding in my sixties.

But that's where my imagination stops, because my mother started showing signs of HD in her late forties and had full-blown HD by her mid-fifties. The last ten years of her life she hardly spoke and eventually ended up in a wheelchair. By age 68, when she died, she was a mere shadow of herself.

She never really got to know her granddaughter. And now, because of my fear of following in my mother's footsteps, I can't even dream about the day my daughter will bring her own child into the world.

So instead of relaxing, I often accelerate my work with HDSA and my other projects. Every day I try to squeeze in as much life as possible.

The fight against HD often feels long and weary. My other passions and manias often help me escape the thought of HD. But they have often left me exhausted.

So, as I write this today, I start to focus on an important question: what should my most important legacy be? But before I even begin to answer this question, I need to catch my breath.

Posted by [Gene Veritas](#) at [8:42 PM](#)      

7 comments:

 **Lou said...**

Hi Gene, as usual you've put into words the real fears of those at risk, suffering from, and love ones dealing with HD (horrid disease). I am so glad you write this blog. I hope you stay well for a long, long, time.

[6:24 PM, May 17, 2009](#)

 **Anonymous said...**

Great commentary. As teh spouse of an HD victim and the brother in law to two others,I struggle with what I shouyld be doing to help. Like you, I am rasing at risk kids and want to make sure that although HD is in our lives, it does not run our lives. Blessings to you and keep up the good work! Jeb

[8:23 AM, May 18, 2009](#)



 **Maine Affiliate for HDSA said...**

Gene I enjoy reading your blog. Thank you as you are inspiring me to write a book as well.

[8:38 AM, May 18, 2009](#)

 **Anonymous said...**

Thank you Gene. I am new to this forum and my connection with HD is an in-law who has begun showing signs. I have wept much since she first confided in me (only 5 people in the world know as she changed her identity and left home long ago to escape the horror). She is the bravest person I have ever met. I do not know how you live with the time bomb, and I pray for her continually to know a measure of peace. I am adding you to my prayer list as well.

[7:55 PM, May 19, 2009](#)

 **Anonymous said...**

Hello Gene, This post even feels frantic as I read it. For your daughter's sake don't let your "hurtling" keep you from spending time with her and just being her dad. When all is said and done, our relationships with those we love are much more important than anything else we do in life or any legacy we may

leave. That's true of all of us whether we carry the HD gene or not.

9:01 AM, May 21, 2009

⌘ **Anonymous said...**

I guess I have chosen to see the "time bomb" that is living HD positive as liberating, rather than incarcerating.

I am thirty. I have a relatively new a thriving profession as an attorney. I have two beautiful boys (1 and 3). I too am gene positive.

However, despite recently learning of my HD status, I consider myself lucky.

For the first time in my life, I am optimistic. For example, I like to think of myself as "barely positive", as I only have 40 repeats, (which I believe is the same for you).

After all, there is research which demonstrates that individuals with 40 repeats have lived well into their 70's without significant or debilitating symptoms. To support this optimism, my mother has 41 repeats, is approaching 60, and is showing very mild symptoms of HD (if you were not looking for them, you would never notice). My grandfather who had 44 repeats died of HD at 70, and despite definite struggles in his disease course, he had a wonderful life through to the end.

I guess the way I see it, we all have a time bomb ticking beneath our feet, and as HD positive individuals, we have the opportunity to be acutely aware of the brevity of life, which for me, transfers into an ability to slow down and appreciate all that life has to offer.

Like you, I have always been a perfectionist. I have also always been consumed with worry. When I discovered I was HD positive, I felt this tremendous weight lifted. Suddenly all of the worries I previously consumed myself with fell to the way side. If I'm in a fatal car accident, so be it, I'm living my life fully today, and that means I won't deal with HD tomorrow.

We're all living on borrowed time. Few appreciate the reality of what that means. For me, testing gave me the gift of realizing that life is now, and tomorrow is never guaranteed.

I think your legacy is best left to your family--one of rich memories and lots of love.

7:24 PM, May 21, 2009

⌘ **kelyna said...**

How generous of you to share your story with us.  
Huntington's disease is in my family and i'm watching my  
younger brother slowly disappear. Each day it breaks our  
hearts a bit more. Thank you.

9:37 AM, August 12, 2009

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