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Seven years of striving for a realistic and unapologetic view of Huntington's disease

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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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SUNDAY, JANUARY 08, 2012

Seven years of striving for a realistic and unapologetic view of Huntington's disease

This week marks the seventh anniversary of this blog.

On January 10, 2005, I inaugurated the blog with this sentence: "My name is Gene Veritas and I am at risk for Huntington's disease." The article was titled "[Huntington's disease: an early date with mortality.](#)" I adopted a pseudonym – the "truth in my genes" – to protect my family's privacy, avoid genetic discrimination, and express myself freely.

I wasn't sure where the blog would go, but since then I have written a total of 118 articles, exploring in depth the many facets of HD.

Baring my soul

I have bared my soul about HD. I have chronicled my mother's downfall and my devastation after her death, my father's dedication as her "HD warrior" caregiver, and my conversations with my daughter about HD as she moved from early childhood into the pre-teen years. I inherited the HD gene from my mother but, as my wife and I thank God, did not pass it on to our "miracle baby."

I also have tried to document the completely new, little-known, and harrowing human experience of living in the gray zone between a genetic test result and disease onset. Along those lines, *At Risk for Huntington's Disease* has served as both a coping mechanism and method of advocacy. I have written frequently about my fears – and of my frenetic activity in the effort to defeat HD. For me it provides catharsis – and a stimulus to my brain in the hopes of staving off HD's inevitable symptoms.


For a community desperate for good news, I have strived to make *At Risk* a beacon of hope. I have reported from the frontiers of science in articles about [research conferences](#) and potential treatments such as the effort by [Alnylam Pharmaceuticals](#) to devise a [drug to stop HD](#) at its genetic roots.

And the blog has helped me to exit the terrible and lonely "HD closet," where I long hid because of fear of genetic discrimination. In February 2011, I gave the keynote address at the "Super Bowl" of HD research, the sixth annual HD Therapeutics Conference of the CHDI Foundation, Inc. (CHDI, backed by wealthy, anonymous donors, is the so-called "cure HD initiative.") I posted [a video of the speech](#) in the blog. Since then I have written about other public speeches and posted videos from them.

Valuable lessons

I also have explored the many lessons gained from my fight. I have learned to put life in a broader perspective, to pay greater attention to my family, and to value the preciousness of time. Like [Michael J. Fox](#), I consider myself a "lucky man" because of the richer life I have lived.

About Me

 [GENE VERITAS](#)

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HD Links

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

[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](#)

[HDSA Orange County \(CA\)](#)

[Affiliate](#)

[HD Free with PGD!](#)

[Stanford HOPES](#)

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HD Blogs and Individuals

[Chris Furbee: Huntingtons](#)

[Dance](#)

[Angela F.: Surviving](#)

[Huntington's?](#)

[Heather's Huntington's](#)

[Disease Page](#)

In *At Risk*, I have confronted the deep challenge to my Catholic faith posed by the threat of HD. That threat led me to explore the spiritual dimensions of my struggle, and it has strengthened my faith and expanded my understanding of life's purpose. I embrace [a new kind of faith](#) – not one of passive acceptance of one's condition but of active transformation of the world.

The threat of HD and my role as blogger have given me an important mission: to stop the suffering caused by brain diseases.

Difficult truths

The more I have enmeshed myself in the far-flung HD community, the more I feel the urgency of my mission.

When I write, I feel raw anxiety as I am forced to contemplate my gene-positive predicament. I share that anxiety with many in our community as they struggle with symptoms or worry about onset. The lack of an effective treatment, much less a cure, further deepens our collective fear, pushing many people into the closet and away from the research studies and clinical trials necessary for finding solutions.

Indeed, because of the harrowing nature of this existence, I often feel as if the articles somehow write themselves – as if a mysterious, hidden hand were assigning me each topic and guiding my fingers across my computer keyboard.

At Risk has stirred emotions and shed light on difficult truths in a community where silence and stigma are too often the rule.

This past year was especially intense. I wrote 33 articles, and my audience grew as I expanded my blog e-mail list and increased my number of Facebook friends to more than 2,000. In June the Huntington's Disease Society of America named me its [2011 HDSA Person of the Year](#) for my advocacy and blogging efforts.

In 2011, I focused on such difficult topics as HD and dating, conflict and competition within and among the various HD organizations, and the need to combat complacency to generate enough volunteers for the upcoming clinical trials.

My article about the media and the [astronomical rate of suicide in the HD community](#) prompted one activist to request that I stop posting links to my blog on a Facebook page for young people and HD.

While my training as a journalist and a historian might have prompted a response emphasizing free speech – why should someone else deny others information? – HD has a way of challenging any belief in absolutes. I agreed to let the activist serve as a gatekeeper for that Facebook page and to decide whether to post my articles.

Challenging absolutes: HD and abortion

Just last month, the issue of absolutes was tested in a way many readers found personal, and painful.

I tackled – as fairly as I could – the issue of HD and abortion, examining the cases of two families, one opting for [genetic testing and termination](#), the other forgoing testing and deciding to [carry the pregnancy to term](#).

Interviewing the families and writing the articles presented one of my most difficult challenges in nearly 14 years as an HD advocate. Hearing their stories stirred up sad memories of the horrible weeks of worrying and wondering as my wife and I awaited the results of our daughter's HD test in early 2000.

I received a record number of comments on the blog as well as numerous comments on Facebook.

Some commentators described the first family as “murderers.”

“I think that posting this article glorifying the killing of a baby is irresponsible of you,” wrote one commentator who opposes abortion and hadn’t slept for two nights after reading the first article. “You are a powerful voice in our community, and I am disappointed in your blog, especially around the holiday season.... It is sad that a family who kills their baby because it has the gene for HD is glorified.”

Others warned against passing judgment, urging compassion for families facing such terrible choices.

“I really absolutely admire your bravery in exposing this disease in a realistic and unapologetic way,” wrote Stella, another gene-positive blogger, in response to the same article. “As for this family, I wish I could just hug them all.”

Combating stigma (again)

My articles led Dr. LaVonne Goodman, the founder of Huntington’s Disease Drug Works and physician to several dozen HD patients, to write a scientifically informed article on “choice and reproductive decision-making in HD.”

In this balanced piece, Dr. Goodman referred to the deep controversy raised by my articles and once again raised the crucial question of stigma and its stifling impact on HD families.

“Those who are affected by identifiable genetic disease like HD suffer not just from societal and intra-family stigma – but also from internalized stigma that we have ‘learned’ from others, and incorporated into self,” Dr. Goodman wrote. “Often internalized stigma has great negative impact on HD individuals and families.... How many decisions are made because we hate aspects of ourselves – not just the disease?”

“The goal is to make life worth living: No one should answer for another whether life was, is, or will be worth living [just] because HD gets bad for a long time at the end. Instead all of us, our HD institutions, our organization, and our families should put more energy into improving treatment and care for those with HD, so that lives become more worth living. And we should work to identify, describe, and decrease HD stigma – which adds so much burden for all in HD families. And in regard to helping with reproductive decisions we should work to provide non-discriminatory support and easier voluntary access to PGD [pre-implantation genetic diagnosis] with attention to supporting the emotional and financial costs involved in this procedure.”

No need to apologize

I often wonder: how many tragic stories do we never hear because of people’s inability or unwillingness to exit the HD closet?

Indeed, because of understandable but unfortunate feelings of stigma, our community often seems timid and even apologetic – precisely the attitude that we can and should combat. Everyone can contribute to this effort – by participating in a support group, joining the local HDSA chapter or affiliate, or volunteering at fundraising events.

No one should apologize for having HD, living at risk, caring for an HD person, questioning the scientific and organizational status quo, or raising awareness!

We all rely on denial to get over the daily fear of HD, but ultimately we must compartmentalize denial and confront the truth of our existence.

No one need hide the hard reality of HD. It is a fact of our lives – and [a crucial event in the quest to control neurological disorders](#) and improve the overall health of the brain.

The next seven-year cycle

In popular wisdom, life proceeds in seven-year cycles.

Seven years ago, I fully expected that by now – age 52 and the time of onset of my mother – to have symptoms and be unable to write. I have been extremely lucky in remaining asymptomatic.

I fervently hope to proceed through my next seven-year cycle without symptoms. Until a treatment is found, this can only mean an even deeper commitment to the cause – but also to enjoying the healthy moments, the blessing of each symptom-free day.





During this new cycle, my daughter will grow into a young woman and prepare to head off to college.

Will I stave off HD in order to help her reach her goal and watch her enjoy her own life?

Or, in a darker scenario, will she become my caregiver and perhaps even shoulder the task of writing occasional updates to this blog?

These kinds of questions will haunt my days as I await news of a treatment.

No matter what the outcome, I will proceed as unapologetically as ever.

Posted by [Gene Veritas](#) at [9:16 PM](#)    

Labels: [abortion](#) , [advocacy](#) , [Alylam](#) , [denial](#) , [faith](#) , [gene-positive](#) , [genetic discrimination](#) , [genetic test](#) , [genetic testing](#) , [HD closet](#) , [Huntington's](#) , [stigma](#) , [suicide](#) , [symptoms](#)

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