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One Man's Story: Entering the Light

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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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HD Links

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

FRIDAY, SEPTEMBER 02, 2011

One Man's Story: Entering the Light

(At the invitation of the Huntington's Disease Society of America [HDSA], I wrote this article for the September 2011 issue of the HDSA support group newsletter [We Are HDSA!](#))

By Gene Veritas, author of *At Risk for Huntington's Disease* and recipient of the 2011 HDSA Person of the Year award

As a severely disabling and fatal brain disorder, Huntington's disease carries a deep stigma that often leads individuals and even entire families to hide the truth about their situation.

In learning of my mother's diagnosis of HD on the day after Christmas of 1995, I wanted to get tested immediately. However, my mother's geneticist and the president of the local HDSA chapter warned me against rushing into a test. They pointed out that gene-positive individuals sometimes faced discrimination from employers and insurance companies. So I postponed testing, and I kept my at-risk status private.

I thus entered the "HD closet," a terrible and lonely place where I struggled with the wrenching fears of HD as I watched my mother decline.

In June 1999, I tested positive for HD. That life-jolting event caused me to retreat even deeper into the closet.

I lived in the grips of a massive contradiction: activism for HDSA and the need to shield myself from discrimination.

Enthusiastically, but anonymously, I served on the board of the San Diego Chapter of HDSA from April 1998 to October 2010.

In 2005 I started the blog *At Risk for Huntington's Disease*. To protect my identity, I adopted the pseudonym "Gene Veritas," the "truth in my genes." Since then I have written regularly about the many challenges of HD – including the deeply frustrating experience of the HD closet.

But I knew that, if I wanted to truly defeat stigma, I someday would have to exit the closet.

Thanks to a combination of factors, in 2010 I began giving public speeches about my situation, using my real name.

Now in my fifties, I feel I have sufficient gravitas to negotiate the inevitable complications, including discrimination. Crucially, two pieces of federal legislation have given me and other gene-positive people support: the Genetic Information Nondiscrimination Act (GINA) of 2008, which bars certain kinds of discrimination, and the 2010 health-care reform law (the Patient Protection and Affordable Care Act), which, in 2014, will prohibit denial of coverage to people with pre-existing conditions.

[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](#)
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[Earth Source CoQ10, Inc.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

Most importantly, HD researchers are making great progress, giving me the confidence that an eventual treatment or cure would end the HD closet forever.

From the scientists, I have begun learning that the closet poses a huge obstacle to their work. Without the active participation of our community in clinical trials and other experiments, the researchers cannot test potential treatments for safety and efficacy.

In my new role as a public advocate and as the 2011 "HDSA Person of the Year," I urge everybody in our community to get involved, summoning up the courage *we know we possess* to exit the terrible and lonely HD closet.

You can make a difference in many ways: by attending the local HD support group, volunteering for your local chapter or affiliate, and joining in HDSA's advocacy and fundraising efforts. I also sincerely believe that if you are at risk, you should seriously consider the possibility of genetic testing.

You can also contact your local [HDSA chapter](#) or [Center of Excellence](#) to learn more about observational and clinical trials.

Above all, as we exit the HD closet hand in hand, it's time to tell a friend or relative about Huntington's disease and how it affects your family's life. Your personal testimony provides the most effective way to fight stigma, inspire others to join the cause, and build awareness about the need to defeat HD.

Posted by [Gene Veritas](#) at [11:05 PM](#)      

Labels: [at-risk](#) , [brain](#) , [clinical trial](#) , [closet](#) , [cure](#) , [diagnosis](#) , [discrimination](#) , [fatal](#) , [gene-positive](#) , [genetic](#) , [genetic testing](#) , [Huntington's](#) , [mother](#) , [stigma](#) , [tested](#) , [testing](#) , [treatment](#)

1 comment:



hdatrisk said...

My mother was diagnosed last sept. Thinking of getting tested. I am in my 40's. Scared & in the closet banging on the door but afraid to open it

[6:23 PM, September 20, 2011](#)

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