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Squeezing in the life

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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](#)

THURSDAY, JANUARY 14, 2010

Squeezing in the life

Because I am gene-positive for Huntington's disease, I know my time could be extremely limited. As a result, I'm squeezing as much as I can into my life before the symptoms start.

This feeling especially impacts me during the holidays. For me the end of the year brings celebration, but also reflection, in large part because my birthday falls on December 31.

This time I turned 50, so I became especially contemplative.

Ups and downs of 2009

I had much to be thankful for. During 2009 I achieved great progress as an activist for the [San Diego chapter of the Huntington's Disease Society of America](#) (HDSA). Among many other activities, I inaugurated a new website, [reported on the project at Isis Pharmaceuticals, Inc., to stop HD in its genetic tracks](#), and completed my fifth year of writing in this blog.

And I remained free of overt symptoms.

When I tested positive for HD in June 1999, I thought that by 50 I would surely have developed the disease in the same way as my mother, whose psychiatric symptoms probably began in her late forties.

I cannot predict tomorrow. But it felt especially good knowing that I had beat HD in 2009.

This month marks the tenth anniversary of the news that our daughter had tested negative for HD in the womb. Our "miracle baby" is now nine and a half. Knowing that she is HD-free and can develop to the fullest of her potential once again brought a great sense of relief. Even though HD might strike me down, a part of me will live on in her.

But 2009 also brought enormous stress and sadness. My father, [the Huntington's disease warrior who cared for my mother for 15 years](#), declined rapidly and died on September 25.

By December, 2009 became one of those years that I just wanted to end.

A Huntington's manifesto

The last few weeks of the year I delved into writing a long article I've titled "God, Huntington's disease, and the meaning of life," which I hope to post here in the near future and perhaps publish in a magazine or journal. The article, which I have dedicated to the physicians and scientists seeking treatments and a cure for HD, represents the culmination of several years of reading and reflection in an attempt to make sense of the extraordinary predicament faced by gene-positive and HD-affected individuals.

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

HD Blogs and Individuals

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

As I wrote, I oscillated between almost unbearable anxiety about the likelihood of a shortened life and almost manic exhilaration about finally having discovered a way to fit my gene-positive status and HDSA activism into the big picture of life, science, and history.

Like so much in my HD-ready life, I felt a deep urgency to finish the article. Indeed, as my wife and daughter made the final preparations for our annual combination birthday/New Year's Eve celebration, I sat at the computer frantically tapping out the final paragraphs of the piece.

Finishing the article just before I turned 50 was profoundly symbolic. I described it as a "manifesto of faith and HD." It was like a rite of passage that I needed to complete before entering a new stage of life.

Although I often feel that I have already lived life with the greatest intensity possible, turning 50 and producing that manifesto have galvanized me to seek a new, higher, and even more intense stage of activism, writing, and living life.

A new urgency

So 2010 started with a new burst of activity and a new urgency about squeezing in as much life as possible into the symptom-free time I have left.

I began by sharing my manifesto with several people and initiating an intense conversation with them about how to share it with the HD community. One doctor friend already wrote back with helpful comments on New Year's Day.

On January 4, I started an extra, temporary job to earn money for a planned cross-country family road trip this summer. I have good memories about such trips with my parents when I was a child. I want to bond with my wife and daughter by exploring with them the beauty and fascinating history of our country.

The trip will be especially poignant for me, because I often wonder whether my gene-positive status will prevent me from seeing my daughter graduate from college and start her own career and family.

Meeting a renowned activist

On January 7, I came out about my real identity to one of the leaders of the HD movement over the past several decades, Alice Wexler, the author of *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* and *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*, which I reviewed in 2008.

I have long admired Alice, as well as her sister and renowned scientist Nancy, who helped discover the HD gene. After their mother developed HD in the 1960s, their father, the late psychoanalyst Milton Wexler, founded the [Hereditary Disease Foundation](#), a leader in the search for treatments and a cure.

Now I was sitting across from Alice and telling her about how my family learned about my mother's illness and my subsequent struggles with living at risk.

Should I go public? If so, when and how? What impact could I have in the HD community and beyond with my activism and writing? How had my gene-positive status enriched my life? How had genetic discrimination impacted our lives and the lives of other at-risk people we knew?

A special bond

For two-and-a-half hours we discussed these questions, as well as my manifesto on faith and HD, which she agreed to read.

It was a singular moment for me. Alice has spent most of her adult life living at risk and researching and writing about the social aspects of Huntington's disease. I felt privileged to meet someone so important in the HD community. I also felt that she had instantly become a new friend – even a sister – in arms against HD. Few people could understand me in the way that Alice could.

Bonding in this way means a lot, because my own biological sister has lived in deep denial about HD and disowned me and my family.

As Alice and I said goodbye, we hugged for a long time.

Leaving the plateau

On January 12 the HDSA-San Diego board held its first meeting of the year. There, too, I felt a sense of urgency.

For several years now our chapter has been a leader in fundraising, advocacy, and other areas. But at the meeting people seemed to be saying that we were standing on a plateau still looking at the mountainous challenge of stopping HD and assisting affected families. For the first time we began to challenge ourselves to start moving off that plateau and up the mountain.

I left feeling the meeting feeling once again the enormous burden of HD on my shoulders – a burden that I carry for myself, for my family, and, along with so many other activists, for the entire HD community.

In 2010, I thought, I will need to become better on all fronts: more efficient at my two jobs – my “real” job and my HD work; more dedicated to eating, sleeping, and exercising properly; and more thoughtful, focused, and loving with my family. At the same time, I will have to become better at relaxing and enjoying the moment.

That's a lot to squeeze into life. I just need to make sure that I don't squeeze too hard.

Posted by [Gene Veritas](#) at [5:45 PM](#)



2 comments:



Ernst said...

High Gene

sounds very impressive on your blog. Actually could once take up on a complementary approach which can contribute to better quality of life.

Have gained some experience with Chinese Medicine in HD so we could have a chat around that.

see you

Ernst

[12:49 PM, January 16, 2010](#)

Anonymous said...

I for one am waiting eagerly to read your manifesto. I have written before about my relative who stays hidden, isolated, who left her entire life in another country behind to come here

and hide this horrific reality. Though she came out to me in a weak moment once, we have never been able to talk about it since. The door cracked open and then slammed shut. Each time I read your blog I consider sharing it with her, but I fear the consequences. So perhaps your manifesto would be something to open that door. I say go for it and get it to us as soon as you feel you can.

Your life has touched so many already and though you feel an urgency, I hope you can relish the joy of having been a vessel for hope to so many.

9:18 AM, January 19, 2010

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