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Unmasking Gene Veritas: a Huntington's disease activist goes public

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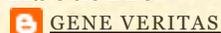
At Risk for Huntington's Disease

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.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▼ 2011 (33)
 - ▶ December (2)
 - ▶ November (4)
 - ▶ October (4)
 - ▶ September (2)
 - ▶ August (1)
 - ▶ July (2)
 - ▶ June (2)
 - ▶ May (4)
 - ▶ April (4)
 - ▶ March (3)
 - ▼ February (3)
 - ▶ [Coming down from coming out: recharging the activi...](#)
 - ▶ ['Drug hunters' bring hope to Huntington's families](#)
 - ▶ [Unmasking Gene Veritas: a Huntington's disease act...](#)
 - ▶ January (2)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me



SUNDAY, FEBRUARY 13, 2011

Unmasking Gene Veritas: a Huntington's disease activist goes public

After 15 long and often painful years, I have taken off the mask that led me to use the name "Gene Veritas."

I have left the darkness surrounding Huntington's disease.

At 5 p.m. on February 7, 2011, I gave the keynote address at the Sixth Annual HD Therapeutics Conference, sponsored by the [CHDI Foundation, Inc.](#), informally known as the "cure Huntington's disease initiative."

About 250 prominent scientists, physicians, drug company representatives, and others listened to my speech, which was titled "[Blog Entry 85 ... Unmasking the World of Gene Veritas: An Activist Copes with the Threat of Huntington's Disease.](#)"

I was introduced by Robi Blumenstein, the president of CHDI Management, Inc., the organization that implements the foundation's goal of finding treatments and a cure for HD. The meeting took place at the Parker Palm Springs hotel in Palm Springs, CA, from February 7-10.

Vanquishing disease

I revealed my real name. I described my family's struggles with HD, my personal challenge to live a healthy, balanced life under severe pressure, and how, while maintaining a career and family, I have dedicated my life to ending the threat of this cruel disease.

And I saluted the scientists in the room and around the world working hard to find treatments and a cure. I urged them to redouble their efforts.

"You and I – the HD-positive man and the community of HD researchers – you and I stand on the cutting edge of science and of history," I declared. "Because, in conquering HD, *you* are going to hold out the hope of a world in which disease is vanquished."

At the end of this article I have posted a home video of my speech. (A professionally edited version of the video will become available in the near future.)

A liberating feeling

I have stepped decisively out of the HD closet.

But "Gene Veritas" will still live on in cyberspace. That powerful name – the "truth in the genes" – has become my trademark. Through its anonymity and universality, it symbolizes the common struggles of families threatened by HD and numerous other neurological and genetic diseases.

[View my complete profile](#)

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 \(CA\)](#)

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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)

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[Huntington's?](#)

[Heather's Huntington's Disease Page](#)

In my speech, I spoke of the need for HD activists to liberate the entire community from the darkness and stigma surrounding HD. Before my speech, I wrote that I felt like an “alien” because of that stigma ([click here](#) to read more).

Now, however, I feel liberated.

Not time to rest yet

To say the least, it was a momentous week for me.

For now, I just wanted to share with you the speech.

Soon I will post another article exploring the impact of the speech and its implications for my future. I will post other articles and videos about the CHDI meeting, the “Super Bowl” of Huntington’s disease research.

The speech was a milestone. But the task of treating and curing HD still remains.

Scientists have made great progress, but we cannot rest until we reach our goal. For so many of us, time is short.



Unmasking Gene Veritas: a Huntington's disease activist goes public

from [Gene Veritas](#)

1:00:09



[Unmasking Gene Veritas: a Huntington's disease activist goes public](#) from [Gene Veritas](#) on [Vimeo](#).

Posted by [Gene Veritas](#) at [1:43 PM](#)



Labels: [activist](#) , [CHDI](#) , [closet](#) , [cope](#) , [cure](#) , [genetic](#) , [Huntington's](#) , [mask](#) , [Robi Blumenstein](#) , [stigma](#) , [treatment](#)

6 comments:

Dawn said...

Thanks you Gene (can I use your real name yet?) for all you have done. Yours is one of the most sensible usable blogs I have found - and watching your speech makes me want to find a way to become an HD activist. I just found out I inherited the gene (42/18) in October 2010. I'm 40 years (happily childless) old and am trying to figure out how I should spend my future days. My grandfather died of HD at age 83, my father is 61 and

doesn't seem to have signs, but I don't yet know what their CAG count was.

I'm trying to tell my father's 4 other siblings and children about family about my diagnosis and that there is hope that effective treatments and a cure are coming, but we need them to get tested and to get involved in clinical studies.

I also just want to have a good life and not only see myself as an HD activist. Although I do see via your example - and others - that activism can enrich as life as well.

I've been following reports from the latest CHDI conference with interest on the HDBuzz.com site.

I hope we can meet some day.

10:31 AM, February 14, 2011

🌀 **Anonymous said...**

I was at the CHDI meeting last week and wanted to tell you what a wonderful and moving speech you delivered. I am a Neuroscientist studying HD and found great inspiration in your words. On a day to day basis it can be hard to see the forest from the trees. The closest I typically come to the disease is handling my transgenic mice! But meeting HD affected families and hearing about your struggles always puts things in perspective and reignites the passion I have for finding a cure! Thank you for sharing your story.

8:00 AM, February 15, 2011

🌀 **Anonymous said...**

What a amazing speech, to say the least! I have been following your blog for over a year now. You really bring hope to a lot of us that sometimes feel hopeless. Thank you for EVERYTHING you do to contribute for the fight against HD.

It was a pleasure to meet you! :)

1:59 PM, February 15, 2011

🌀 **Anonymous said...**

Ken, you are definitely one of my heroes in our war again Huntington's Disease. I know your pain, and I also know your determination to lead in our fight. I'm committed to do the same, and I'll stand should-to-shoulder with you, the scientists and HD families until we conquer this devastating disease through a treatment or a cure. May God give us the strength to endure everything that we must, and may God bring us together as one big family for the cause.

With deep admiration and appreciation for all that you do,
Frances Saldana

7:24 PM, February 15, 2011

⌘ **Anonymous said...**

When I was a child I was often told how beautiful my mother was. Her beauty was not restricted to her appearance. She had a powerful intellect and a gift for developing strong ties with family and friends.

We all know the HD story: my mother contributed to this tome. The physical and intellectual degradations were tough to deal with. Her psychological state(s) became unpredictable. I watched many of her lifetime friendships disappear in a puff of argument.

In the end, I watched my mother wrestle wildly into her death. She pounded the bedsheets with her translucent, blue veined body until she drew her last breath. To this day, I see it as a gross marathon of sorts.

Now, my gross marathon has begun. Everyone is trying to help me plan for the big winding down - when all I want to do is fight.

My stories tend to be long things. So I'll end this here.

8:34 PM, February 18, 2011

⌘ **Anonymous said...**

A few more things. I'll be celebrating my 50th birthday by jogging 50 miles.

My diet is about %90 organic. I don't consume any alcoholic beverages whatsoever. I do not consume any dairy products either. I take a fish oil supplement. I eat mostly fruits and vegetables. I jog 25 miles per week.

8:51 PM, February 18, 2011

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