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At Risk for Huntington's Disease

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## Huntington's support group: seeking solidarity, fighting denial

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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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## About Me

 [GENE VERITAS](#)

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THURSDAY, MARCH 03, 2011

## Huntington's support group: seeking solidarity, fighting denial

As I live at risk for Huntington's disease, one of the toughest things for me is to attend the local support group.

I began attending the San Diego group in January 1996, a few weeks after learning of my mother's diagnosis for HD and the fact that I had a 50-50 chance of inheriting the disease.

At the monthly meetings, my wife and I always saw people afflicted with various stages of HD.

From those very first meetings, I remember one man, probably in his early forties, whose body moved uncontrollably the entire meeting. He was sitting in front of us, and he kept shifting in his chair and lifting it up and down, causing it to move back towards us.

He and I later had a phone conversation. He could still talk, but he spoke slowly and with a kind of quiet stammer, typical of many HD people, who ultimately lose the capacity to communicate. A computer programmer, he explained that he had to quit working after he was unable to finish an important project.

Seeing him and so many other HD people sent a paralyzing chill through my body. This, I knew, could be *my* future: shaking, unable to work, and dependent on my wife and others.

I always wanted to turn away from HD people, but there they were confronting me with their progressively listless expressions and struggles to maintain their humanity as their brains melted away.

I witnessed HD's relentless attack on my own mother during visits back to my hometown outside of Cleveland, Ohio.

In San Diego, my wife and I always left support group feeling as if we had just departed from the wake of a loved one. The horrific symptoms of HD and the threat of an early death seemed to stalk us in the car as we drove home. It always took me a few days to feel normal and unthreatened by HD.

## Protecting our privacy

But we kept going back. I needed to learn about HD in order to pass on caregiving advice to my father and sister back in Ohio, and I wanted to absorb every bit of information about how to prevent the disease from affecting me. I also knew that we had strength in numbers. Both my wife and I found comfort in sharing our fears with other members of the group, which frequently subdivided into smaller groups for the affected, the at-risk, and the caregivers.



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

## HD Blogs and Individuals

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

We were regulars for several years. Even so, I was extremely guarded in sharing my most personal details. I decided to get tested (in June 1999) without airing the idea to my at-risk friends, and I told none of them about my gene-positive result. I did reveal that our daughter had tested negative in the womb (in January 2000), but provided no details about that process, including the fact that I had decided on testing mainly because we wanted to have a child.

I wanted to protect my privacy in order to avoid someone at work or in my profession finding about my situation, so my wife and I adopted a policy of secrecy.

### Returning to my roots

At the time of our daughter's birth in mid-2000 I was becoming ever more deeply involved as a board member for the [local chapter of the Huntington's Disease Society of America](#). Combined with our daughter's arrival, that big life change left us little time for support group. My wife stopped attending in order to watch the baby. I attended monthly board meetings instead.

Last October, after twelve and a half years on the board, I decided to resign in order to devote time to other aspects of the HD movement. I also want to enjoy life and my family more before the inevitable symptoms start.

Now I have returned to my roots in the movement: the support group. In 2010, I began exiting the HD closet, and last month I decisively left it after delivering the keynote address to the "Super Bowl" of HD research in Palm Springs, California, and putting the [speech online](#). The meeting was sponsored by the CHDI Foundation, Inc., informally known as the "cure Huntington's disease initiative."

I'm looking to my fellow support group members to help me make this momentous transition in my life. And I want to support others in their travails with Huntington's disease.

### 'I am gene-positive'

I volunteered to speak before the group on February 28. The topic: "a gene-positive activist copes with the threat of HD."

I had taken months and countless hours to prepare for my speech in Palm Springs to some 200 of the world's leading HD researchers. I was on edge for weeks. Yet I had achieved a state of calm on the day of the event.

Not so on the day of my talk to the support group. I felt very uneasy about speaking before this much smaller and much more intimate audience of about 40 people.

"I am gene-positive for HD," I told them very early in my talk, which repeated many of the main points of my CHDI presentation.

For the very first time, I explicitly revealed my status to the support group.

I explained how I had created the pseudonym "Gene Veritas" for this blog and was now "unmasking" Gene to reveal my real identity.

### Connecting with my 'HD family'

Revealing the truth of my genes to this familiar group of people moved me profoundly. Long-time caregivers watched intently. People who had tested negative after years of fear had knowing looks on their faces. Just a few feet from me sat several people with very noticeable symptoms – but not bad enough to prevent them from attending, unlike former members of the group now in a nursing home. They understood everything I said.



These people lived in my community, and we shared so much in common in our long struggle against HD.

With great sadness, I mentioned my parents' long fight together against Huntington's. I recalled my mom's death in 2006 and how my dad, the "HD warrior," was never the same man after she died. He passed in September 2009.

Everybody understood. I felt naked as I shared my feelings and experiences, and I felt deeply connected to everybody in the room.

It was as if I were speaking to one, big extended family.

### **A new theme: denial**

I introduced another theme that had never been so openly discussed at the support group: denial.

I pointed out that I had engaged in my own form of denial in part by keeping my gene-positive status a secret and adopting a pen name. (But I *have* [confronted denial in this blog](#)).

In fact, perhaps more than anything else, coming out about Huntington's caused the discomfort I felt before, during, and after this talk. In exposing the truth to others, I could no longer hide it from myself.

The threat of HD has moved again to the forefront of my life, and for good, until an effective treatment is found.

I also spoke of the deep denial of HD in my extended family. It led my mom's brother and his wife to tell their children that mom had "mental problems." My sister and I no longer talk because of deep disagreements about HD and caregiving for our parents. (I told the group that she found out about HD *after* having her three sons and has lived the past 15 years in HD limbo, as no one in her family has been tested for the disease.)

### **A challenge**

I told the group that the time had come for me – and for everybody else in the HD community – to take off our masks. It is time for the "faceless faces" of HD people to reveal their situation and end the stigma of Huntington's disease, as Florida HD activist and filmmaker James Valvano has proposed in his latest project ([click here](#) to read more). (You can also find James on Facebook.)

I issued a challenge to myself and everybody in the room: we all needed to get our relatives, friends, and acquaintances involved in the HD movement.

More than ever, there is hope of an effective treatment, I told the group, summarizing some of the impressive advances reported at the CHDI meeting. Clinical trials are being planned for at least two major approaches to stopping HD at its genetic roots.

However, without involvement by the community in clinical trials, all the scientific skill and money in the world will not stop HD. The researchers need people to test their drugs for safety and efficacy.

### **How to combat denial**

After the talk, I answered questions and posed some of my own to the group.

I wanted to know: how could we end the denial of HD in our families?

The ideas flowed. One fellow activist, who recently tested negative after years of fearing the disease, proposed that we stand with signs at high-traffic street corners telling people about HD and the need to stop it. Another participant said that we should share our experiences with denial and help one another strategize on how to combat it.

Someone else pointed out that families should ensure that "Huntington's disease" is listed as the cause of death on their loved ones' death certificates. Often health care workers or officials have omitted HD, further pushing the disease into the darkness.

Others pointed out that it's important not to judge those who don't – or won't – join the cause. "Every HD patient is different," said one participant.

### Compassion and hope

I also wanted to know: should I try to help stop denial in my own extended family? Should I send a DVD of my CHDI speech to my sister and my uncle?

A number of people said that I definitely should, but with a cover letter explaining my situation and the disease.






Another person disagreed strongly. It was more important to seek the help of those who already showed solidarity with the cause.

Yet another said that, if someday my relatives have questions about HD, they might not seek advice from me, but from someone else in the HD community. It was important to let the relatives take the initiative.

Others expressed what might ultimately be the most important approach: to present HD as something that is *not shameful*, to *have compassion* for people like my sister, and to deliver the new *message of hope* made possible by the latest scientific breakthroughs.

It was time to go, but we had taken a step towards overcoming one of the biggest obstacles to the success of our cause and the discovery of effective treatments.

For me, the talk reinforced my goal of motivating people to overcome denial and join the cause.

Posted by [Gene Veritas](#) at [11:21 AM](#)      

Labels: [at-risk](#) , [caregiver](#) , [caregiving](#) , [CHDI](#) , [closet](#) , [daughter](#) , [death](#) , [denial](#) , [diagnosis](#) , [father](#) , [gene](#) , [gene-positive](#) , [Huntington's](#) , [mother](#) , [nursing\\_home](#) , [support\\_group](#) , [symptoms](#) , [tested\\_negative](#) , [wife](#)

### 3 comments:



#### **Unknown said...**

Thanks for sharing and for the work you do in highlighting HD. Support Groups are just that - people can't be forced to attend. It is most important that the Group is there when people feel they are ready. People with HD share the disease but they are all individuals and have to be respected for their individuality.

[3:55 PM, March 04, 2011](#)



#### **Unknown said...**



Dear Gene Veritas, et al,

Thank you for your blog and your unwavering dedication to the HD cause. The truth will always strike at our hearts. Some may contest it, but eventually, it permeates us and refuses to be denied.

I am caring for my son who was diagnosed in 2008 after many illnesses, accidents and difficulties coping with his afflictions (HD is on his father's side). I am also an activist, radio talk show host and support group leader for HD. I saturate myself with research daily, yet I must spoon-feed my son only bits of information about what he is facing, lest exasperating him with depression and despair. Mother's intuition tells me he already knows his fate if an effective treatment or cure is not found soon. It's hard to know when to hold back and when not to when it comes to the damn truth about HD. With family and friends I know when to restrain once I see their eyes glaze over as they check out from my audience. It's too much information for them to process, but I keep publishing it anyway.

We divorced 20 years ago, which left my sons and me out of the loop and protected from HD reality until now. His new wife and family just recently placed father in a nursing home, again guarding us from the ugly truth about HD. I'm only now learning how horrible this disease truly is. Our support group is one year young, so the evidence of progression hasn't hit yet. I feel fortunate about that, but I know this recess is only temporary.

I thank God for you and many others who have come out by removing the mask to reveal the true face of HD, brilliant faces that are intelligent, articulate and creative, beautifully made in every way. People with HD must be protected not from truth but from the evil of ignorance and so I revel in the challenge to educate all who are ready to listen.

HD veritatem in solidarietas,

Melissa Biliardi

5:16 PM, March 04, 2011

**🌀 Anonymous said...**

Hi there! I just want to let you know we believe there is a cure to HD! For more information please go to this link and give my Aunt a chance to live and many other with this horrible and lonely disease! Hanna's Ride!

<http://www.facebook.com/groups/489904731025174/>

Jessica Van Dyk [jeffjessv@gmail.com](mailto:jeffjessv@gmail.com)

8:14 AM, July 23, 2012

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