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At Risk for Huntington's Disease

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## When the pain brings a smile

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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](#)

SUNDAY, JANUARY 24, 2010

## When the pain brings a smile

Today I write in tribute to my wife and to the tens of thousands of other individuals around the world who face the prospect of seeing a spouse or other family member struck with Huntington's disease.

You see, only hours ago my wife – with just a few months of training and still recovering from a painfully strained back – ran a half marathon to raise money for the [San Diego chapter of the Huntington's Disease Society of America](#). Just a few weeks shy of her 43rd birthday, she had never before run in a race. In fact, she hadn't even really run at all.

Living gene-positive for Huntington's, I spend a lot of time worrying about my health and wondering about the impact on my family when my symptoms start. Huntington's affects everybody with a positive test for the genetic defect.

### Doing whatever is necessary

But only now am I really beginning to appreciate how much my wife stands behind me.

She made it through the 13.1-mile Carlsbad Half Marathon without reinjuring her back, but she pulled a calf muscle. I had to help her sidle back to the car and, as I write, I can hear her limping down the hallway.



*My wife in her HDSA-San Diego t-shirt at the Carlsbad Half Marathon (Gene Veritas photo)*

[International Huntington Association](#)  
[Huntington's Disease Drug Works](#)  
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## HD Blogs and Individuals

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

A few minutes ago she came in to my home office to give me a hug and a kiss. I congratulated her once again on the race.

“I want you to know that I’ll do whatever is necessary to stop you from getting HD,” she said.

### A life of hard knocks

Things could have been far different.

It was just three years into our marriage, in late 1995, when my wife learned that I was at risk for Huntington’s. That’s when we received the news that my mother had HD and I had a 50-50 chance of inheriting the condition ([click here to read more](#)).

Suddenly our future seemed dim. Starting a family became an extremely complicated affair, with me first testing positive for HD in 1999 and then, less than a year later, having to wait several agonizing months to learn whether the baby she was carrying also had HD.

In 1995 my wife could have taken the easy route and left me.

After all, she had already made an enormous transition in her life by moving from South America to marry me. Here some people shunned her because of her immigrant status, but she overcame that barrier and others to achieve what few immigrants in her field of teaching have attained: whereas many immigrants are pigeonholed to work with non-native English speakers, she obtained a job teaching American-born students in an all-English classroom.

A good deal of her ability to persevere comes from growing up in a country where most people lived in poverty. Forced on hard times and with no welfare system or food stamps to back them up, during her teen years she and her family often ate a diet of only rice, beans, and vegetables.

On January 18, Martin Luther King Day, we celebrated the removal of the braces she wore the past two years to straighten teeth gone crooked in youth. At the time, her family could not afford even basic dental care.

### Standing by her husband

So, you see, my wife has known very hard times. And then Huntington’s disease threatened to plunge her into yet another dark period. The thought of me becoming symptomatic eats away at the tranquility that she fought so hard to construct.

In my nearly 15 years of experience with the HD community, I have heard many stories of divorce ([click here to read the painful story of how one relationship ended](#)). In 1995 my wife was just 28 and could have started a family with another person. She could have gone back to her native land. She could have utterly avoided the potential nightmare of Huntington’s disease.

But she stood by me.

Before our daughter was born, each month we attended the local Huntington’s support group. We both had a difficult time watching HD patients struggle with chorea (shaking of the limbs), cognitive impairment, and other problems such as the inability to speak. Usually the second part of the meeting consisted of small group discussions for caregivers, the affected, and the at-risk. Hearing spouses speak of the daunting, daily task of HD caregiving struck fear in my wife’s heart.

### Regaining strength

We would often leave those meetings depressed and hopeless.

Worst of all for my wife was watching my mother's symptoms progress. For me, seeing my mother was like looking into a genetic mirror, my own future with HD. When my wife looked at her, she could not escape the likelihood that her husband would succumb to the same terrible conditions.

She knows all too well what the caregiving could become, after seeing my father, [a Huntington's disease warrior](#), care for my mother for 15 years.

Yet somehow we regained our emotional strength after support group meetings and after extended visits from my parents, who lived in another state. Looking back on it, I see that my wife's dedication and companionship provided the positive energy necessary for both of us to keep going.

### **From dreams to reality**

Last month we celebrated our 17th anniversary, and our daughter is now nine-and-a-half.

Along the way, the threat of HD has forced us to give up many of dreams, such as purchasing a home in her homeland, moving away for better (but perhaps less secure) job opportunities, and having more children. Our daughter tested negative in the womb, but my wife has felt the deepest of frustrations at not having another child.

Turning 50 last month, I have already surpassed the age at which my mother's behavioral and psychiatric symptoms probably started. She died four years ago this month, at age 68. Knowing that HD could be imminent, we focus on keeping me healthy, raising our daughter, and enjoying life.

### **Accomplishments and pride**

For many years my wife did not attend support group or any HDSA functions. Rather, I attend support group or work on a myriad of HDSA-San Diego activities, while she cares for our daughter and handles many of the household tasks, all in addition to her own full-time job.

Now that our daughter has become less dependent on us, my wife has stepped up her involvement with the HD movement. [Last fall she hosted a Board Appreciation Night for HDSA-San Diego at our home](#). Board member [Sally Cravens](#), who regularly runs in HDSA-San Diego events and has brought in thousands of dollars in donations, inspired her to run in today's Carlsbad event.

It was literally painful for my wife to prepare for and run the race. But she's not complaining. On the contrary, she has smiled and had a wonderful glow on her face all afternoon and evening. As she put it, "I can put up with the pain." What's most important is supporting the cause.

She's accomplished a lot – completing the race and raising funds and awareness for HDSA.

And she's made me one very moved and proud husband.

Posted by [Gene Veritas](#) at [10:10 PM](#)      

2 comments:

 **Anonymous said...**

Your wife has inspired me too. Aren't we so lucky to have people around us who love us so much... even if the future is uncertain. Thank you for sharing.

3:56 AM, January 25, 2010

⌘ **Anonymous said...**

My husband, too, ran the Carlsbad 1/2 Marathon yesterday on behalf of his HD positive sister, nephew and niece. He began training in July as a non-runner at 55 years old, and was pleased to finish the course yesterday- with his sister's picture on his back.

Our oldest daughter and her boyfriend were volunteering at the nourishment table at the Finish line, while our youngest daughter and I stood and cheered the runners coming and going at the 3 mile mark.

We were blessed to be a part of this effort to bring a cure for HD.

Thank you, and your sweet wife for your part in this project of hope!

9:09 AM, January 25, 2010

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