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At Risk for Huntington's Disease

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The Huntington's disease high-wire act

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

WEDNESDAY, JUNE 08, 2011

The Huntington's disease high-wire act

As a carrier of the gene for a deadly brain disease, I fight back with the instinctual urge for survival.

I dread the threat of that incurable killer – Huntington's disease – as I recall my mother's own struggle against it. For some 15 years, as I watched her lose the ability to walk, talk, and think, I looked into a genetic mirror that foretold my own future.

In the months before and especially after her passing in February 2006, I grappled with the fear of death. For the first time in my life, [I knew I would die](#), and that death would come only after a decade or more of suffering. I am reminded of that harrowing reality each time I see an HD person or communicate with HD-affected families.

I also nurture hope that scientists will discover an effective treatment – perhaps even a cure – and therefore make my gene-positive status at best irrelevant and at worst a manageable, chronic condition, like diabetes. In the meantime, I watch my health and take supplements recommended by the [Huntington's Disease Drug Works](#) program, try to [squeeze in as much life as possible](#) before my inevitable symptoms begin, and immerse myself ever more in my ["shadow career"](#) as a Huntington's disease advocate.

In this race against time, I oscillate between dread and hope while struggling to balance the many facets of my life: profession, family, health, faith, and activism.

Tough decisions

"So many tough decision and choices," wrote a good friend after reading about my shadow career. "You are like a tightrope walker, like the 'Man on a Wire.' Did you ever see that wonderful film? I recommend it – because living with a positive gene test as you are, balancing so many things, is a bit like what he does.

"And like him, you are an artist with a beautiful, amazing sense of living in the moment even while looking ahead."

I was long intrigued by the theme of *Man on Wire* but hesitated to watch it, perhaps fearing that it would indeed remind me too much of living gene-positive for HD. Last Sunday, June 5, I finally watched it.

In walking on a wire between the World Trade Center's Twin Towers in 1974, French aerialist Philippe Petit demonstrated how he lived out his ultimate fantasy joyfully – but also precariously, tempting mortality.

I know many people in the HD community performing their own, tragic tightrope acts – like the young adults pondering whether to test, couples debating the genetic risks of pregnancy, and caregivers weighing the decision to place a loved one in a nursing home.

[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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HD Blogs and Individuals

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

Whereas Petit chose to risk his life on the wire for 30 minutes and had to be coaxed off of it by the police, HD people and their families are forced onto the wire and cannot get off. Although many still find moments of joy, all long for the treatment or cure that will end this ultimately nightmarish act.

Passion vs. obsession

My own personal tightrope includes yet another kind of balancing act: between passion and obsession.

Since joining the San Diego chapter of the Huntington's Disease Society of America ([HDSA-San Diego](#)) shortly after my mother's 1995 diagnosis, I have put great passion into the cause.

But sometimes I lose my balance, and the passion becomes obsession.

After speaking at Alnylam Pharmaceuticals in Cambridge, MA, on May 17 and holding a potential cure in my hands in the company's lab, I couldn't wait to share my excitement with others in the HD community. On the plane ride back from the East Coast on May 21, I worked on a blog article about the Alnylam trip non-stop for six hours.

My passion remained on full throttle when I arrived at home. I practically ignored my family and other activities for the next several days. Only after I posted the [Alnylam article](#) on May 25 could I start to come down from the trip.

A radio interview

In the midst of the Alnylam trip and its aftermath I needed to decide whether to take yet another huge step out of the "HD closet": going on the radio with two other advocates to talk about the disease and our personal situations.

I consulted with my wife and weighed the potential impact of the interview on my family and job. After giving up so many dreams because of Huntington's disease, my wife doesn't want our family, including our 10-year-old, HD-free daughter, to deal with the disease until it's absolutely necessary.

My wife pointed out my obsession after the Alnylam trip. But she didn't want the rest of the family to become obsessed.

That night I had a very long and intense dream about HD involving my relationship with my daughter. In the dream, as in life, I wanted her to know the truth about HD. But I also wanted to protect and guide her.

I ultimately decided that the opportunity to speak out on HD was too important to pass up. There was no time to think through the consequences. I would deal with them, whatever they might be, as they arose.

In short, I would improvise – just as Petit improvised during the planning and execution of his walk between the Twin Towers.

So, on May 26, just hours after posting the Alnylam article, I participated in a half-hour interview on the Clear Channel radio network. I explained the symptoms of HD and my family's struggle with the disease, including my exit from the HD closet. ([Click here](#) for more on the program and to listen to the podcast.)

So far, I have received feedback on the interview only from people in the HD community. But I am preparing myself for eventual questions and

comments by others, including people at work, where only one trusted friend knows about my situation.

'HD doesn't have me'

As another good friend observed as we discussed HD and professional commitments, a very fine line exists between passion and obsession. Indeed, because of that fine line, it's very easy to fall off the tightrope.

This same friend pointed out that I must avoid letting my quest for the cure compromise my health. "You can't let the 'cure' kill you," he said.

I later remembered how, in a similar situation, some Huntington's disease caregivers become burned out or even die before their loved ones because they fail to rest or seek enjoyment.

As I walk the Huntington's high wire, I am reminded of the sage phrase repeated by a number of HD people I've had contact with in recent years: "I have HD – but HD doesn't have me!"

HD indeed had me for a while following my Alnylam trip and the radio interview.

But I won back control over the Memorial Day weekend. As we shopped with our daughter for items for a barbecue we were hosting for friends, my wife smiled and put her arm around me lovingly.

HD no longer had me. I was back in the fold.

Posted by [Gene Veritas](#) at [10:51 PM](#)      

Labels: [activism](#) , [advocate](#) , [Alnylam](#) , [caregiver](#) , [cure](#) , [gene-positive](#) , [genetic](#) , [genetic mirror](#) , [HD closet](#) , [Huntington's](#) , [Huntington's Disease Drug Works](#) , [incurable](#) , [mother](#) , [nursing home](#) , [survival](#) , [treatment](#)

2 comments:

Anonymous said...

Are you familiar with HD patients receiving occupational therapy to cope with functional limitations? I am doing a research paper on Huntington's and saw in the research that is it prescribed but have not been able to find any patients that have had it.

[4:21 PM, June 14, 2011](#)

Anonymous said...

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4:04 AM, March 18, 2012

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