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The complications and stress of success

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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.

SUNDAY, SEPTEMBER 09, 2007

The complications and stress of success

Living with a positive test result for the Huntington's disease gene requires a constant juggling of life's many demands and opportunities. What many would see as unambiguous success, for instance, actually causes new complications and stresses.

Take this blog. I haven't posted here in several months. I would *like* to write several times per week. But job, family, chores, exercise, taking care of a new puppy, volunteering for the Huntington's Disease Society of America (HDSA, www.hdsa.org) – and success – have frequently left me without time to write.

The complications of success

In the past few months, unimaginable professional success has further diverted my focus from HD. I received an all-expenses-paid three-month trip to write a book, won a prize for another book, and have garnered numerous other accolades. I'm entering the prime of my career. The joys of such achievement have occasionally allowed me to forget my mother's death at the hands of HD last year as well as my own at-risk status.

Success has created greater opportunities, but also made HD an even bigger factor in my professional life.

For the first time in 14 years, I have the chance to move to a better job. In my current job I've been but a cog in a mediocre machine, while the offer of a new job would allow me to join a team of people who truly appreciate my skills and want to employ them fully in an exciting work environment. I'd gain great prestige, a position of international leadership in my profession, and a 70-percent raise. I'd ultimately be positioned for a shot at the top jobs in my field.

The decision sounds like a "no brainer" – until you consider that I very likely could develop HD symptoms in the next few years. I'm 47, and my mother's first symptoms, emotional outbursts, probably started around that time. By her early 50s, she had chorea (shaking), had stopped speaking normally, and could no longer take care of herself.

With that possible scenario in mind, should I take on a challenging new job? Unlike my mother, I know that I'm at risk, and perhaps I can stave off the symptoms until my sixties by eating and sleeping properly, exercising,

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GENE VERITAS

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HD Links

Huntington's Disease Society of America
International Huntington Association
Huntington's Disease Drug Works
Huntington's Disease Lighthouse
Hereditary Disease Foundation
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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

and taking supplements recommended by the Huntington's Disease Drug Works program (see www.hddrugworks.org).

However, because HD is a 100-percent genetically caused disease, there is no guarantee that I won't get my first (noticeable) symptoms tomorrow morning.

The stress of success

The challenges of moving my family to another state, facing a higher mortgage, starting a new job, and certainly working longer and harder hours might not be worth it, especially since stress itself might trigger or worsen symptoms.

The financial rewards become far less significant when we consider that my wife would face a $30,000 cut in salary and lose some benefits, for example, an excellent retirement that we're counting on for our future. Those losses are outweighed by my gains, but *only* if I remain healthy. If we had to rely on her lower salary and my much lower unemployment-related disability pay, we might face a bigger crunch than if we just stayed put.

Because of HD, just thinking about this opportunity has generated stress and enormous pain, frustration, and outright anger. I've frequently wanted to blurt out to my colleagues and the interviewers, who are anxious for me to accept the offer, that I can't easily embrace this wonderful opportunity *because I'm at risk for a deadly brain disease*.

Paradoxically, I've chosen to stay in the "HD closet" precisely because revealing my status likely would lead potential employers to discriminate against me. Legally they can't, but, in reality, they'd avoid a job candidate who might not be able to work more than a few years.

By moving, I'd also lose connections with the local HDSA chapter and a group of caring individuals with whom I share a life-and-death struggle. I could certainly volunteer for the chapter in my new city, but I doubt whether I could have the same impact that I've had over the past nine years. It would take time to become part of a new team, and the demands of the new job would leave precious little time for activism.

Tough choices

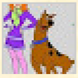
I'll be weighing the pros and cons of the job offer with my wife, close friends, and with you, my readers, in the coming weeks. Like many people affected by HD, I continue to prepare for the worst but live as best as I can. That attitude gives me eternal hope and keeps me professionally active and always in search of new job opportunities. But while I know that money and prestige are great boosts to anyone's ego, they can't solve the challenge of living at risk.

Giving up one's dreams very early is one of the cruelest realities facing HD families. This hits especially hard when I think of my mother's death at age 68 and of friends who have recently passed from the "at risk" to the “symptomatic” category. “You’re not just contemplating a job – you’re contemplating your whole life,” my wife tells me.

She believes that I am now beginning to understand her frustration at not having a second child. Having two children was her dream, but we abandoned the idea because of the stress involved in testing the child before birth – an experience we know all so well from having our first daughter, who tested negative (see my previous entry on this topic by clicking ***here***). As my wife concludes about the dreams we’ve given up because of HD: “They’re so real and so close to you, yet they’re so far away.”

Posted by Gene Veritas at 9:51 AM

6 comments:



Angela F said...

Coincidentally - I have also recently been in the middle of a bit of a job dilemma. I have really struggled with whether to go for it or not - the extra money and step up into management could help us to better afford PGD IVF. But it would mean longer hours, more stress and much less job satisfaction.

It's much less complicated than your situation but the knowledge of being HD positive is undoubtedly influencing my decision just as it is yours. I am not going to apply for the job - although we could really do with the money, I don't want my life to be about work and I don't want any more stress.

I thought, when I made and remade this decision (because I keep going over it still), that maybe my career ambition had died when I got those results. But I don't think it has - there are different opportunities in my current position which I will take advantage of because I do like my current job and there is still a lot of scope within it.

Good luck with it. It sounds like a very difficult decision when things are so uncertain and because of the distance involved. If you stay, you're going to have to work hard not to be forever wondering. And if you go, you're going to have to work hard not to be watching your every step in case it has started.

Lots of love
Angela x

2:41 AM, September 10, 2007

Anonymous said...

I'm a working actor living in LA.

If there's one thing being an actor has taught me is that you really have take each day as it comes. There's so much uncertainty and rejection in the business it's easy to get down on yourself.

Especially when I try to predict the future. I have no idea if and when my phone will ring. I just have to hope and pray that it does.

It drives my wife (who is not an actor) nuts. She wants to plan for the future and I really can't.

What I can do, when I'm not working, is spend time with our three year old son. Yesterday we assembled a bookshelf from Ikea together. Later we made banana bread.

It doesn't sound like much, but it was a great day.

And I never could have planned it.

Taking the short view has really helped me cope with HD. I'm gene positive. I've got a few more good years, but who the hell really knows what's going to happen?

All I can do to is make the most of each and every day.

9:41 AM, September 10, 2007

Anonymous said...

Taking the new job certainly will add to your stress. Moving away from friends will also be difficult. These will be your support network when you do show symptoms. Having a support network is incredibly important. My sister in law had to move her family due to financial reasons. Her husband has HD. While they are in great financial shape where they are now, it is very difficult taking care of her family without the support network of friends and church members that she had previously.

One thing on the pro side of taking the new job: will the added prestige help in advocacy for HD awareness and cure? Think of it: if Jack Welch, shift worker in a factory announced he had HD, who would care, except his small circle of family and friends? But if Jack Welch, CEO of General Electric announced he had HD, everybody would hear about it. Plenty of people would suddenly be willing to give time and money to the cause. I'm not saying your new job would have that same level of fame and prestige, but you get the picture.

At any rate, it is a very tough decision. HD steals so much from all of us.

9:34 AM, September 11, 2007

Webrep Tweak said...

I understand your feelings and recently wrote my own blog post on dealing with not only my possible HD condition but my fathers diagnoses.

Everything about the disease is unfair but you have to decide how you want to live your life and not be governed by fear. I was motivated by the fear and not thinking clearly. Today I live my life with the future in mind and to the fullest possible. Wish you the very best.

wtfyme.com

9:40 AM, October 03, 2007

Anonymous said...

i have a quesion bu im not sure how to word it. can employer look into your family medical history and see someone in our family had it and not give u a job based on that?

5:33 AM, April 14, 2008

Unknown said...

Hi,
I am The assistant editor with anxiety.net. I really liked your site and I am interested in building a relationship with your site. We want to spread public awareness. I hope you can help me out. Your site is a very useful resource.

Please email me back with your URl in subject line to take a step ahead and to avoid spam.

Thank you,
Kathy
kathy.anxiety.net@gmail.com

10:06 AM, January 07, 2010

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