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Coming down from coming out: recharging the activism batteries

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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, FEBRUARY 27, 2011

Coming down from coming out: recharging the activism batteries

After giving the speech of a lifetime about facing the threat of Huntington's disease, I need to recharge my batteries.

As readers of this blog know, it's been an intense few weeks. On February 7, I told a meeting of some 250 HD researchers and supporters of the search for a cure that I am gene-positive for the cruel and deadly brain disease that took my mother's life in 2006.

I had finally gone public after 15 years of hiding my situation. I'd feared genetic discrimination in the workplace and the insurance and healthcare systems.

I still have such fears, but they've diminished somewhat, thanks to the passage of the Genetic Information Nondiscrimination Act in 2008 and the healthcare legislation of 2010, which by 2014 will prohibit denial of coverage to people with pre-existing conditions.

And, because I'm in a race against time as I await an effective treatment, I've committed to a bolder stance

Less than a week after my speech, I posted a video of it on this blog. I followed up a week later with an extensive article about the meeting, the "Super Bowl" of HD drug discovery, including videos of my interviews with two leading HD researchers.

In preparing the presentation, I kept thinking of how I was "writing my life." From mid-December, when I began the speech, until now, I've revisited the many memories of my parents and my fears of HD. And I've braced myself for the emotional and social impact of leaving the HD closet.

Now I'm taking stock of the whole experience. But it's not easy to process so many difficult thoughts while handling the many responsibilities of work, family, and community. And there is no "right" or "wrong" way of handling an exit from a closet, especially when in the case of a little-known yet highly stigmatized brain disease like HD. So I don't yet have any clear conclusions.

In these last few days I *did* know one thing for sure: I needed to rest up for the next stage of my activism in support of greater public awareness about HD and the need to find treatments and a cure.

Adrenalin mixed with worry

Sharing my story with the scientists who hold my future in their hands left me exhilarated. My keynote speech moved many in the audience to tears.

A number of the scientists later came up to me during the four-day meeting in Palm Springs, California, and said the speech had brought

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home the reality of HD and inspired them to redouble their efforts.

Later I was interviewed on camera for a forthcoming video about the urgent need for the HD community to participate in clinical and observational trials. Without such help scientists will lack the data they need to develop effective drugs.

I was interviewed by Charles Sabine, a former NBC-TV foreign correspondent and now the international spokesperson for the HD movement. Charles is also HD-positive.

The online video of my keynote speech drew an unusually high number of visits to this blog. People expressed thanks and support.

The speech and my coverage of the meeting brought an adrenaline rush, but also worry about the possible long-term consequences of coming out. I couldn't point to anything specific, but felt exposed and a bit defenseless. The day after I put the speech online, the emotional overload gave me heartburn.

Translating the science

I had little time to think about the impact of the speech, because I immediately had to shift my focus to comprehending the new research data presented by the scientists. I dedicated each minute of my free time on the weekend of February 19-20 to the update on the meeting.

Although my speech marked a personal milestone, translating the science into language understandable for the HD community presented an equally significant challenge. It is the scientists who will find the solution to HD. The HD movement has become my life's work, and a big part of that involves informing people of the scientific progress and inspiring them to get involved.

To produce that article I had to get into my special writing zone. It's a huge challenge to write on HD research, because I was trained in history, not science. The scientists speak in their own highly technical language, and I had to get the translation just right. So I imagined myself somehow fine-tuning my brain for the task.

I relish the challenge, because that kind of stimulus could partially protect my brain against HD's attack on my mental abilities, including my great passion for writing.

But reporting on the search for treatments also makes me painfully aware of how the disease harms the brain years and even decades before the classic symptoms kick in. It's painful to look at scanning images that illustrate how HD shrinks the brain by causing neurons to die.

In these last few weeks I've often felt as if I'm in a daze.The need to deny the reality of HD sometimes makes me feel as if it's all *un*real, as if I'm floating above myself, my predicament, and the scientists and am looking down at it all.

Coming down from coming out

Every beat of the heart requires a rest, so I've also spent time more time than usual decompressing.

At one of the dinners for the scientists, the host hotel, the Parker Palm Springs, served a fantastically good wine. Or was it my exhilaration that made the wine taste better? I copied the label information on a napkin: "Hangtime. 2008 Pinot Noir. Arroyo Seco. Force Canyon Vineyard."

"Hangtime" refers to the period the grapes remain on the vine. It also

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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
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

refers to enjoying the company of good friends and good wine.

I couldn't find the 2008 vintage of Hangtime in San Diego, but I bought a few bottles of the 2009 vintage to share with my wife and friends.

Each sip reminded me of the speech and the commingling of my hopes with the scientists' efforts to find a cure. I want so badly for those feelings of hope – and feelings of *freedom from HD forever* – to hang endlessly in time.

I'm going to track down a bottle of that 2008 vintage and keep it as a remembrance of the meeting. I'll uncork it the day the scientists have found an effective treatment that saves everybody in the HD community from its devastating symptoms.

Keeping a balanced life

As many readers of this blog may have concluded, I'm a workaholic. That keeps me focused. But sometimes I let my activism consume me. Then I must remind myself that, no matter the circumstances, life requires balance.

A few weeks ago our "miracle baby," who was born HD-negative in 2000 after we had her tested in the womb, lamented the fact that I had not taught her how to throw a ball properly.

After work one afternoon, I stopped at Target to choose a cushy ball the size of a softball. I took my daughter to the park, and we practiced tossing it back and forth. When it was time to go, I made her throw it to me and catch it three consecutive times without a miss before we could leave.

In the days that followed, thinking of the ball became the antidote to my workaholism.

It's also a reminder that my daughter needs me.

Keeping the balance is a huge challenge, because for me to be with my family in the long run, I must spend time away from them in the short run working for the cause. However, although scientists are increasingly optimistic about a treatment, nobody can predict exactly how or when they will find one.

Looking ahead

So now it's time to recharge my mental, emotional, and physical batteries for the next wave of activism. The keynote speech is already creating new opportunities for me to contribute to the cause.

Tomorrow evening, February 28, I will speak to the local HD support group on my coping strategies.

In early May I will make a similar presentation to the annual convention of the Northern California chapter of the Huntington's Disease Society of America.

I'm also planning a trip to Cambridge, Massachusetts, to visit the headquarters of Alnylam Pharmaceuticals, which is getting ready to apply for permission from the federal government to conduct human trials for its potentially revolutionary remedy, an RNA interference drug, to stop HD at its genetic roots. I will write about Alnylam in future articles.

As I step up my public advocacy, I'm embarking on a new phase in my life. More than ever, I'm going to need large quantities of positive energy.

Posted by Gene Veritas at 2:44 PM

Labels: advocacy , Alnylam , brain , closet , coming out , cure , discrimination , gene-positive , Huntington's , neuron , pre-existing condition , research , RNA interference , scientist , stigma , symptoms , trial

1 comment:

Anonymous said...

Dr. Veritas,

I received your blog from Dr. MacDonald.

This is a test comment on your website.

Thanks, --Tricia

7:35 PM, February 27, 2011

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