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Face to face at the Huntington's disease convention

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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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HD Links

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

TUESDAY, JUNE 21, 2011

Face to face at the Huntington's disease convention

I've known about Huntington's disease ever since my mother's diagnosis in 1995. For just about as long, I've been affiliated with the [Huntington's Disease Society of America](#) (HDSA). I joined the [HDSA-San Diego](#) support group in 1996 and served on the chapter board from 1998 to 2010. Last month I visited HDSA national headquarters in New York, where I gave an informal talk to the staff about my struggles as a person who is gene-positive for the disease.

Still, work and travel commitments have prevented me from ever participating in the organization's annual convention.

That's about to change this coming Thursday, June 23, as I travel to Minneapolis for the 26th annual convention, held at the Sheraton Bloomington Hotel.

A record 1,000-plus registered individuals are expected to attend. I am looking forward to meeting people from other HD-affected families, brainstorming on how to strengthen our cause, and sitting in on several workshops and other activities scheduled for the June 24-25 agenda. Among others, these include explanations of the disease, caregiving issues, advocacy, and a major session on the latest research developments. ([Click here](#) for a complete list.)

It should also prove highly rewarding – and hopefully plain fun, also! – to solidify some of the many online friendships I have developed over the years through this blog and my presence on Facebook.

A pivotal year

I'm bracing myself emotionally for what should be a very poignant experience.

In June I normally visit Brazil to conduct research as a professional historian. However, for the first time in a quarter century, I am skipping my annual visit to the country that is my second home and the birthplace of my wife. (She and our HD-free ten-year-old daughter arrived in Rio de Janeiro last Saturday after we spent a short vacation together in Florida visiting the Harry Potter theme park at Universal Orlando.)

This leaves me sad and reminds me once more of how HD has stolen many of our dreams as a family.

It also symbolizes the big shift in my life as I more carefully focus my efforts to help scientists in their quest for treatments and a cure.

In that respect, this year has become pivotal. On February 7 I delivered the [keynote address](#) to some 250 scientists, physicians, pharmaceutical company representatives, and others at the 6th Annual HD Therapeutics Conference in Palm Springs, CA, on February 7. On May 17 I gave a similar

[International Huntington Association](#)
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[Hereditary Disease Foundation](#)

[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)

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presentation to about 50 scientists at Alnylam Pharmaceuticals in Cambridge, MA, and held a sample of the company's [potential drug in my hand](#).

At the HDSA convention on June 25 I'll take part in the traditional candle service, where representatives of the community light candles for the various groups within the HD community. My candle will represent "the hope of people living with HD."

For me, this will be a great moment of solidarity. I will also be thinking of my mother, who died of HD in February 2006.

I know, too, that I'll probably see scores of HD people – each one a reminder of my future as I await the inevitable onset of symptoms that characterizes HD.

Is a convention necessary?

Echoing the critical remark I read on Facebook yesterday, some might question the wisdom of holding a convention when so many HD families are in dire need. Attending a convention is beyond their means financially and/or logistically. They need help in the HD trenches.

Indeed, last month I wrote a blog article titled "[S.O.S. for Huntington's disease families](#)." The article discussed the loss of income and extremely burdensome caregiving costs faced by these families. The demand for assistance far exceeds what HDSA can provide with its \$8 million annual budget.

HD families should always question the goals and activities of the organization. Indeed, they *are* the organization. Only in this manner can our organization improve.

Over the years I have attended conventions and meetings of various kinds for professional or other reasons. Conventions are only as good as the people who attend and the ideas they contribute.

I am looking forward to the HDSA convention, because, in addition to the reasons I outlined above, it will provide me with the opportunity to meet people face-to-face, to see their body language, to build trust and camaraderie, and to exchange ideas freely.

I believe that this kind of contact can reinforce teamwork and strengthen our movement. Hopefully it can also bolster our hearts and souls.

As always, I'll have my camera, voice recorder, and camcorder in hand to capture some of the highlights of the convention, and I'll be blogging on the results upon my return.

* * *

Speaking of conventions, it's time to sign up for the World Congress on Huntington's Disease, to be held in Melbourne, Australia, from September 11-14. Interested scientists and members of the HD community can obtain more information about this all-important event by [clicking here](#).

* * *

In my last article, "[The Huntington's disease high-wire act](#)," I neglected to mention that a book with a similar title, [On a High Wire, Without a Net! Living with Huntington's Disease](#) was published in 2009 by HD activist and writer Susan E. Lawrence. Susan also wrote [Sheltered from the Storm: Preparing for the HD Onset](#). Both books are valuable resources for our community.

* * *

This is my 101st posting in this blog! I began *At Risk for Huntington's Disease* in January 2005. Let us all hope that sometime within the next 100 postings we can celebrate a major breakthrough towards a treatment for HD.

Posted by [Gene Veritas](#) at 9:14 PM      

Labels: [Alnylam](#) , [Brazil](#) , [caregiving](#) , [cure](#) , [daughter](#) , [gene-positive](#) , [Huntington's](#) , [mother](#) , [onset](#) , [research](#) , [scientist](#) , [solidarity](#) , [symptoms](#) , [treatment](#) , [wife](#)

3 comments:

 **Anonymous said...**

Hey! So glad you will be attending this year. I am here now and look forward to meeting you.

[10:38 PM, June 21, 2011](#)

 **Laura said...**

Enjoy reading your blog. I'm looking forward to the convention and hopefully the chance to meet you!

[4:55 AM, June 22, 2011](#)

 **Anonymous said...**

Great Blog today! I too have been reading the comments going around about HDSA not doing enough for families and how perhaps we can do more. I hope we do not silence those comments and we let them continue to bring new ideas to HDSA. I am constantly reminded that the staff at HDSA does not have HD in their family and they do not know what we go through each and every day. I, like you wake up every morning scared if I am going to start showing symptoms. I, like you am watching my mom die from HD and I, unlike you look at my 3 kids and pray every day that they will not get HD when they grow up. We need to remember that the staff at HDSA were hired to support our efforts in fighting this disease. We need to stand together with them and move forward.

[9:20 AM, June 22, 2011](#)

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