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The mission of a lifetime

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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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THURSDAY, DECEMBER 16, 2010

The mission of a lifetime

How can people affected or threatened by a cruel and incurable disease help inspire the world of science to work for treatments and a cure?

I will humbly but purposefully attempt to meet this challenge when I give the keynote speech to Huntington's disease researchers from around the world at CHDI's 6th Annual HD Therapeutics Conference at the [Parker Palm Springs](#) hotel in Palm Springs, CA, on February 7, 2011.

I recently received the formal invitation to speak from Robi Blumenstein, the president of CHDI Management, Inc., which implements the goals of the [CHDI Foundation, Inc.](#), informally known as the "cure Huntington's disease initiative." Funded by an anonymous donor who has put tens of millions of dollars into the project, CHDI functions as a virtual biotech company and is the leading private source of HD research funds.

The conference will begin with my speech on the night of February 7. Taking place one day after professional football's Super Sunday, the four-day CHDI conference serves as the "Super Bowl" of Huntington's research.

At last year's 5th annual conference, which I attended ([click here](#) to read more), several hundred scientists participated. Dozens gave presentations regarding the latest breakthroughs in understanding HD and finding drugs to stop it. Representatives of the [Huntington's Disease Society of America](#) (HDSA) and the HD associations of other countries, as well as individuals from affected families and pharmaceutical companies, participated in the meeting. Another turnout of several hundred is expected for 2011.

An energizing task

Robi first mentioned the possibility of me as a keynoter during the 2010 conference. Robi, a regular reader of this blog, and I had met in July 2009, when I spent a day at CHDI's research headquarters in Los Angeles ([click here](#) to read more). Since then, we have periodically exchanged ideas about the HD cause.

The idea of taking on such an important task energized much of my Huntington's disease advocacy this year. I have been thinking intensely about the speech ever since. I've written most of this year's blog entries with an eye to garnering ideas for the keynote.

It's a huge responsibility, because, for 60 minutes, I will be representing the HD community. It's now abundantly clear that HD-affected families and the scientists are inextricably linked. The families *need* the scientists to stop HD, and the scientists *need* the families to confirm their research through clinical and observational trials.

Just this past Tuesday, December 14, I did my annual battery of cognitive testing at the HDSA Center of Excellence for Family Services and Research at the University of California, San Diego. For two hours, under the

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

guidance of a volunteer pre-med student, I performed such exercises as repeating series of numbers forward and backwards, creating lists of words beginning with a particular letter, and discerning patterns of diagrams.

These tests help measure whether symptoms such as dementia have begun, and they provide raw data to researchers studying brain imaging and other aspects of HD.

Finding a new dimension

In my speech, I will need to illustrate the many common challenges faced by HD families. This year I've become especially attuned to the suffering of affected and gene-positive individuals by spending many hours reading the stories they have posted through Facebook HD groups such as "Ri Hdsa" and "hd family."

As I write my speech, I've followed the fate of a child hospitalized with severe juvenile HD and read the messages of a young, affected woman fearful that she'll never be loved and be able to have children. There are many other stories like these.

I also must prepare a speech that brings the human side of the disease home to the researchers who are accustomed to focusing on their lab work. Building on past keynote speakers such as the HD-positive former NBC correspondent [Charles Sabine](#), I must discover a new dimension of the presymptomatic HD person and provide the scientists with some new insight into the disease and their goal of eliminating it.

Exiting the HD closet

At the keynote, I will take my biggest step ever out of the HD closet. I long remained in that closet for fear of discrimination at work, on insurance questions, and in the health care system.

As I did [in Brazil in June](#) and at [Vertex Pharmaceuticals in September](#), I will speak in public using my real name. The first two speeches didn't receive any outside publicity beyond my blog, but my CHDI presentation will be seen by people from around the world and likely generate comments on the web. I am also mulling whether to post a video of the keynote on the web.

I made the 2010 talks and other forms of more public advocacy a trial run for the CHDI talk and the likely greater impact it will have. In the coming days I also will consult trusted friends and professional colleagues on the question of exactly how to become more public and how to deal with the effects, both positive and negative.

So far, speaking out publicly has helped make more people aware of HD, but it has also caused me stress as I worry about long-term, as yet unforeseeable consequences on my family, my job, and my psyche.

A pivotal moment

At this moment, three important points in my life are converging: the end of an extremely busy and productive year on the HD front (for me personally and for the cause as a whole); the holidays and my 51st birthday on December 31; and my preparation to kick off the CHDI Super Bowl.

The holidays will be especially poignant because this December 26 marks the 15th anniversary of the day I received the news of my mother's diagnosis. February 13 – one week after the CHDI meeting – will mark the fifth anniversary of my mother's death.

The CHDI keynote will be a pivotal moment. In many respects it marks the culmination of those 15 years of my personal battle to avoid Huntington's

disease and to build support for the cure.

My life's mission

This speech symbolizes my life's mission: a personal struggle against a cruel and fatal disease that cut short my mother's life at age 68 and likely will similarly inflict itself on me – and, somehow, a joining of hands with the researchers pioneering the newest frontiers of science in order to unlock the mysteries of Huntington's and by extension other brain diseases.

The aftermath will open a new phase in my life as I seek to become a more effective advocate. This will involve the *big* effects of becoming ever more open about my HD-positive status, but also the *small* effects of action in one-on-one conversations, in venues such as the local HD support group, and in writing about the scientific work that I fervently hope could save me and thousands more from the ravages of Huntington's.

Posted by [Gene Veritas](#) at 8:02 PM



Labels: [advocate](#) , [Brazil](#) , [Charles Sabine](#) , [CHDI](#) , [closet](#) , [cognitive](#) , [cure](#) , [death](#) , [dementia](#) , [diagnosis](#) , [gene-positive](#) , [Huntington's](#) , [mother](#) , [Robi Blumenstein](#) , [support group](#) , [symptoms](#)

7 comments:

⌘ Jimmy Pollard said...

Gene!!! Although over my career I've spoken about all kinds of topics, HD-related and otherwise, of far, far less importance to me personally and to a greater community, I do know what it's like to be totally consumed looking ahead to a speech for months. But I can only imagine the degree of your focus and thought you are giving this one. As a regular reader of your blog, it's clear you'll do an awesome speech and, I suspect, one that will be memorable to the entire extended family. I guess all that's left to say to you is, "Break a leg!"

Jimmy

6:10 AM, December 17, 2010

⌘ Anonymous said...

Gene, I have read your blog intermittingly over the past year and just wanted to congratulate you from afar on this great opportunity. I have no doubt you will represent the HD community extremely well and with great impact. I think it is great you have the courage to "out" yourself, you are an inspiration.

Robin

11:14 AM, December 17, 2010

⌘ Anonymous said...

Hi Gene,

I want to express how grateful we of the HD (extended) family are for your dedication and willingness, to express our concerns

through your own experiences of life with HD.

I too think the speech will go well.

Oh! Happy Birthday on the 31st.

Love Jeri

11:16 AM, December 17, 2010



Unknown said...

Gene:

Thank you, thank you!

Try not to think about the FACT that, as you make your speech, you will be carrying the weight--and the hopes--of many of us in the HD community on your shoulders. Instead, think of all of us sending you our good wishes, like helium to float the balloon of this step of your advocacy. Float high, brother!

Beverly

7:33 AM, December 18, 2010

Anonymous said...

Gene -

Congratulations on your upcoming speech. A powerful opportunity for you and for the entire HD community. I recently attended a World Parkinson's Disease Congress in Scotland that was a wonderful combination of persons with Parkinson's combined with the scientists and clinicians who treat and find cures for the disease. The opening ceremony was probably one of the most impressive, motivating, and inspiring opening sessions of any event I had been to. I think you will want to look at it for ideas and inspiration as you develop your own thoughts for your Super Bowl talk. It is somewhat long, but please make sure you make it through to see Bryn Williams and Gavin Hastings at the end...they were, like you, voices from the community and made a strong call to arms to the scientists and clinicians.

I hope you enjoy and I look forward to seeing you in Palm Springs.

Dan

7:17 AM, December 25, 2010

Anonymous said...

Whoops...here is the link to the video for the Parkinson's meeting (the video is at the bottom of the first page)

Dan

7:18 AM, December 25, 2010

Anonymous said...

<http://www.worldpdcongress.org/>

7:20 AM, December 25, 2010

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