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In the midst of the hurricane

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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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 GENE VERITAS

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SATURDAY, SEPTEMBER 19, 2009

In the midst of the hurricane

When I write about my experiences living at risk for Huntington's disease, the themes usually hit me in the face.

But sometimes so much is happening that it all seems like a big jumble in my mind, as if a hurricane is passing by, threatening to fling heavy debris at me or to sweep me up in its powerful winds. When I get this feeling, I feel I must hunker down and concentrate on the essential aspects of life – such as survival and family – just as I once did while taking shelter in the interior bathroom of a condo during a real hurricane.

I started to get this feeling a couple weeks ago after talking to a young man who has begun to experience HD symptoms. He had moved to San Diego to seek assistance from the [local chapter of the Huntington's Disease Society of America \(HDSA\)](#), and he had some ideas he wanted to share about a project.

A couple of people in the chapter tried to follow up with him but got no response. Finally, I decided to call.

Just 22 years old

"How are you?" I asked, trying to start of the conversation politely with a person I had never seen nor spoken to before.

"Not good," he said.

"Do you have HD?" I asked.

"Yes. I just spent a week in the hospital because of psychiatric problems from my HD."

He didn't even tell me his idea for a chapter activity. It was now irrelevant because of his medical difficulties. He was leaving San Diego in a few days to return to his hometown in another state.

"There's nobody here to take care of me," he said. "I can't take care of myself anymore, and my family back home is going to care for me."

He was only 22. HD had cut him down at the start of his life, precisely at the moment when people dream of a better future for themselves and for the world, a time when most people feel invincible. Unless an effective treatment or cure is found, he likely will die before he is 40, after many grueling years as a witness to his own demise.

Wanting to reach out

I thought of how lucky I have been to have approached 50 without suffering any overt symptoms of Huntington's. I wanted to spring into action immediately. I wanted to interview this young man and present his

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words and photograph to the blogosphere. I wanted to redouble my efforts to make sure that neither *I nor anybody else* faces the same fate.

The young man departed without me having a chance to follow up, and I turned my attention to other HDSA matters.

I especially needed to return to my reportage on the project that today provides the biggest ray of hope for the HD community: the research supported by the CHDI Foundation, Inc.

In preparation for an article on the CHDI drug pipeline, I have been reviewing the audio interviews that I recorded with CHDI researchers in Los Angeles on July 20 ([click here to read my initial feelings about the visit](#)).

Transcribing the future

These are not your ordinary interviews. A team of Ph.D.s in the sciences provided me with an overview of their efforts to stop HD. They stand at the cutting edge of science, and, if successful, their project would make history.

I need to get this right. I must understand these interviews with exactitude – for myself and for the many people in the HD community who do not yet know of CHDI's efforts or have only a vague notion of the researchers' progress.

Transcribing an interview is painstaking; the process usually requires several hours of work per hour of recording. This has taken longer, as the scientists' many technical terms and highly complex descriptions make the material almost like a foreign language.

I am also transcribing my future, for better or for worse. The disease processes described by the scientists are perhaps already devastating my brain cells and putting me on the same path as my mother, who died of HD in 2006 after losing the ability to walk, eat, and talk. And the treatments they are investigating could rescue me from the disease.

Like my difficult feelings about people with Huntington's disease, all of this information puts more force into the emotional hurricane of my own life as gene-positive for HD. Like a hurricane's destructiveness, the outcome is unpredictable.

Making vital connections

It's vital to spread the word about CHDI and also about the activities of gene-positive people like me.

As Dr. Robert Pacifici, the chief scientific officer of CHDI Management, Inc., explained, the organization is building a database that will help build better connections between HD researchers and the broader scientific community.

CHDI also seeks to learn more about the behavioral patterns of patients and at-risk individuals.

In Dr. Pacifici's words, the sharing of information allows researchers to leverage it for the benefit of finding a treatment or cure more quickly. Someone, somewhere, could make that eureka connection.

It's so important for us in the HD community to make connections too – in this case, with the researchers, with the donors who support our cause, with people suffering other diseases, and, above all, with each other. In doing so, we can all help make that final big connection that will end this disease.

If I can find him, I want to talk to the 22-year-old man with HD again. He's certainly been tossed about in his own emotional hurricane. He and so many others need a strong hand to help them make their own connections.

Posted by [Gene Veritas](#) at [9:15 AM](#)      

1 comment:

 **Anonymous said...**

Hi Gene, I have commented before on your blog, but did not leave my name. Am at risk, but feel like I have escaped. Lost many family members and losing more. Feel alone in my grief and in my guilt of feeling like I survived. I smile, I laugh, cry, and feel so alone when I think of my family members. They fought the true battle. Found a support group here in Virginia ,it is helping. I hope you find that young man. I still feel guilty when I am around others that have huntington's and so far I don't. I hope that I can be a blessing to them. Thanks your sharing your life.

[3:43 PM, September 19, 2009](#)

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