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At Risk for Huntington's Disease

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Observing the cure in progress

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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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HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)

WEDNESDAY, APRIL 09, 2008

Observing the cure in progress

In a couple of hours I will tour the innards of the company that could save me from the ravages of one of the cruelest diseases to afflict humanity, the disease that took my mother's life two years ago and which will very likely destroy my own brain.

Isis Pharmaceuticals, Inc. of Carlsbad, California is working to develop a drug that will halt Huntington's disease at its root cause: the genetic process leading to the making of bad proteins that somehow kill brain cells.

By visiting Isis I'm trying to tackle HD head-on by learning yet more about the disease and then hoping to inform the HD community of this potential scientific breakthrough.

Genetic pioneers

I want to walk in the midst of scientists who, whether they think about it or not, have my life and the lives of hundreds of thousands of at-risk and affected HD people around the world in their hands. I want to meet the men and women who could be the heroes for the families who are struggling so valiantly against HD but who are powerless to stop its genetic onslaught. The people at Isis are the genetic pioneers who could introduce us to a whole new vista of hope and health.

I want to witness firsthand the making of what would be a miracle for the HD community – and millions of people affected by numerous other neurological diseases.

I want to observe the cure in progress.

Making sense of antisense

Yesterday I prepared for the visit to Isis by interviewing Dr. Janet Leeds of the Cure Huntington's Disease Initiative, Inc (CHDI). CHDI is funding the Isis project, and Dr. Leeds is the project's scientific manager. We discussed the two biggest challenges of the project: first, administering a drug that will not interfere with the normal function of the huntingtin gene (a gene that everybody has but which has gone awry in HD people) and, secondly, delivering the drug to the brain.

I also learned that scientists have been thinking about the technology being studied by Isis – a technology to make an antisense drug – since the 1970s, and not only since 2002, as I wrote in my previous entry here.

So I spent a part of the evening studying a report from Isis that describes the similarities and differences between antisense technology and a more recent technology, developed after the discovery of RNA interference in 2002. I hope to learn more about these two technologies today.

[Huntington's Disease Lighthouse](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
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[Heather's Huntington's Disease Page](#)

Wanting to help

The attempt to grasp all of this technical information and the anticipation about my visit to Isis caused me to sleep fitfully last night. I dreamt that I had to make a presentation to Isis scientists that would convince them to hire me to help them market their firm to the world. They were highly skeptical, but then I gave a passionate speech about the need to relate to people on a human level. They began to listen.

I am not a scientist, but I urgently want to help in the effort to cure HD. I depend on the cure, and so do my wife and daughter. I refuse to let this disease ruin my life and prevent me from seeing my daughter grow up.

Posted by [Gene Veritas](#) at [6:27 AM](#)      

2 comments:

Anonymous said...

Gene,

I am a nineteen year old college student and I am also at risk for acquiring HD. I have not been tested so I am not 100%, but I have had to watch my father die in front of my eyes for all of my life. If Isis can truly come up with a way to cure this horrible disease, I will know that there is a God.

Brriney

[11:14 PM, April 15, 2008](#)

Anonymous said...

Dear Angela,

Hey, my name is Sahar, I am with www.WeAreHD.org. There are a prolific group of members on the website that I know would be keen to read your blogs. I have been reading your blogs on Huntington's Disease and I think that [WeAreHD.org](http://www.WeAreHD.org) will be of great interest and use to you. Amongst us, there dedicated users that will avidly read your blogs and it would be great if you could come and leave your comments/thoughts.

Below I have given the guest access information. Look forward to hearing from you.

website: www.WeAreHD.org

username: guest1

password: weare1

Best,
Sahar

[4:14 PM, June 19, 2008](#)

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