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Dreaming of victory

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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.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▼ 2007 (7)
 - ▶ December (1)
 - ▶ September (1)
 - ▼ April (1)
 - ▶ [Dreaming of victory](#)
 - ▶ March (3)
 - ▶ February (1)
- ▶ 2006 (4)
- ▶ 2005 (17)

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MONDAY, APRIL 02, 2007

Dreaming of victory

The night after I wrote my previous entry (click [here](#) to read the article) on the *New York Times*' recent front-page article on Huntington's disease, I dreamt that the United States had won the Iraq war.

I read about it on the front page of the *Times* while sitting in a coffee shop. Everybody around me was reading the same page-one headlines. Next to the words was a photo of a V-E Day parade from 1945. Like the newspapers in *Harry Potter* movies, the picture came alive with moving cars and a soldier kissing a woman among falling confetti.

The United States was once again the undisputed leader of the world after smashing two evil powers. Nobody would mess with us as we led the world into a new era of unending peace and unbounded prosperity. I felt immense relief from the fear, unpredictability, and violence of war.

Finding the parallel

When I awoke the next morning, I knew immediately that the war in Iraq was my personal war against HD. Reading and writing about a major article on HD in one of the world's most influential newspapers had triggered a powerful fantasy about the utter defeat of Huntington's – another daunting effort – and the violence it wreaks on people's minds and bodies and the lives of their loved ones.

Since discovering in late 1995 that my mother had HD, I have hunkered down in an emotional bunker. I have struggled to fight HD by dealing with my mother's long decline and death (last year – click [here](#) to read the article), becoming an activist for the Huntington's Disease Society of America, and wondering each day when the symptoms will start.

I tested positive for HD in 1999.

I am so fearful of the disease that I believe I must keep persistently vigilant so that it will not strike me. I put in long hours thinking about how to increase public awareness about HD and also the fundraising so necessary to keep scientists working towards treatments and a cure.

Dreaming forward

Seeing Huntington's disease get such massive and rare publicity allowed me to come out of the bunker for a few hours to try to glimpse what my life would be without this disease.

That vivid, surreal dream and the almost indescribable peace it produced in me felt so *real*.

People in the HD community told me how they became overjoyed in 1993 when the huntingtin gene was discovered after years of intense research. But 14 years later we still seem so far from a cure. We're back in the

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bunkers.

But we are all fervently praying and hoping for the announcement that an effective treatment or cure has been found. The defeat of HD will be a truly historic moment for a human race that seeks liberation from disease.

In the meantime, I must learn to fantasize and dream more often in order to get through the weary days of fear and struggle. And I need to channel the energy of those fantasies and dreams into the fight for a cure.

Posted by [Gene Veritas](#) at [11:14 AM](#)



3 comments:

Anonymous said...

wow!...have just read through your blog...what an amazing and inspiring story..and beautifully written.

[2:01 PM, April 08, 2007](#)

Anonymous said...

HD is such a tragic disease that symptoms last for years. I pray for a cure.

[2:42 PM, April 14, 2007](#)

Adi said...

Hello, This is my first time visiting here. Your blog is a nice,I thought I would leave my first comment. :)

Greets from

[Kenali dan Kunjungi Objek Wisata di Pandeglang](#)

[6:08 AM, October 12, 2009](#)

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