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Ten reasons to cure HD

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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, APRIL 29, 2010

Ten reasons to cure HD

Huntington's disease? Never heard of it. Why should I care?

As with so many diseases, once you learn a bit about HD, you get a twinge of fear and sympathy. But in our hectic world it seems insignificant. Yes, an estimated 30,000 Americans have HD, but millions suffer and die from cancer, heart disease, and AIDS. Whereas Rock Hudson's death from AIDS and Michael J. Fox's diagnosis of Parkinson's disease gained great publicity for those causes, HD lacks association with a celebrity.

But numbers and publicity are deceiving. The story of HD is far more compelling and complex than most people could imagine.

As the [Huntington's Disease Society of America](#) prepares to mark HD Awareness Month in May, here are ten reasons why we need to *cure HD now*.

1. HD kills. While many diseases can be treated or cured, HD cannot. The 30,000 individuals affected will die a slow, ugly death. As it destroys the brain, HD robs people of their ability to walk, talk, think, and care for themselves. HD strikes people in the prime of life. Many kids and teens also get it.

2. HD threatens many people. In the U.S. at least 150,000 more people are at risk and will die if they get HD. Worldwide nearly a million people have HD. It affects both sexes and all ethnic groups.

3. HD painfully strikes at families. Every day tens of thousands of caregivers and relatives carry the difficult burden of helping their ill loved ones do simple tasks like bathe, eat, and dress. Looking after a person with HD is like caring for a toddler who doesn't grow but rather regresses. Moreover, it splits families that disagree about whether to learn their fate or to live without knowledge of a gene-positive status.

4. HD results from a genetic defect. We all have the huntingtin gene, but in some people it has mutated. Because HD is purely genetic, the children of an affected parent have a 50-50 chance of acquiring it. The defect is not merely a tendency; its presence inexorably brings on the illness.

5. HD involves major ethical issues. Those in the HD community have long suffered great discrimination such as job loss and denial of insurance, even though the disease is officially considered a disability. In the post-genomic world, HD raises questions about the ownership and use of genetic codes, medical confidentiality and insurability, access to new treatments and cures, and the increasingly sensitive issue of genetic testing for people at risk and their unborn children.

6. HD is a model disease. HD is on the cutting edge of biotechnology. The ten-year quest to discover the HD gene, concluded in 1993, was a

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HD Blogs and Individuals

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crucial stage in the Human Genome Project. The hunt generated many new research techniques, the discovery of aberrant proteins that harm the brain, and the production of revolutionary “transgenic” HD mice. Today companies such as [Isis Pharmaceuticals, Inc.](#), of Carlsbad, CA, are experimenting with the latest emerging generation of potential drugs in the effort to stop HD at its genetic roots. HD research generates extraordinary teamwork in the usually ultra-competitive scientific community. Dozens of labs and doctors from around the globe and thousands of families afflicted with HD participate in the effort to find a cure.

7. HD is about the brain. HD research increases understanding of our most vital organ.

8. HD research helps many other diseases. HD research has had an impact on the study of cystic fibrosis, Lou Gehrig’s disease, some forms of diabetes, and other diseases and neurological disorders. HD research could help stop Alzheimer’s, Parkinson’s, and the effects of stroke. Successful treatment of these many diseases will lower taxes and health insurance costs for everybody.

9. HD is an “orphan” disease. Historically, large drug companies have preferred to focus on products that reap huge returns and publicity but do not save lives. Despite its scientific importance, HD research receives relatively little government money. HD highlights the need to value lives over glamour and profit.

10. HD’s cure offers hope for a disease-free world. Woven genetically into every cell of those it affects, HD is a horrible killer of the brain. Although the process is painstakingly slow for families hit by HD, the research is making great strides. In the biotechnological era it is time to speak of a new human right to be free of disease. The treatment or cure of this most puzzling illness will be a historic breakthrough leading to a better quality of life for all.

*Help spread the word **now** about the urgent need to stop HD by sending your relatives, friends, and co-workers the link to this article.*

Posted by [Gene Veritas](#) at 7:51 PM



2 comments:



Tellie said...

Dear Gene,

I have enjoyed reading your blog for the past few months! It's great to have a spokesperson for some of the tricky issues that HD Positive people face. Your post about "coming out of the closet" was especially significant to me, since that is an issue with which I am present dealing.

I am 55 now -- I was tested when I was 50. I have two daughters (now 21 and 26) who knew that I was tested then, but thought that I had the results "put on hold." However, I secretly went back and got the result, since I sure that I was negative. It was positive, and I kept that secret from almost everyone, including my daughters for 5 years.

Recently, I became involved in an HD drug research study, so it

became necessary to tell my daughters. They were fine with it, and it is great to be able to discuss it with them. I also told one of my brothers, who has not been tested. Now, I find myself facing the idea of coming out of the closet, because, as you said, there is a relatively short time where we can be proactive. I still have (most of) my mental and communication skills, and this would be a great time to speak out about HD.

I am still employed, although at a lower level than I once was, and really don't want to share this information with coworkers and boss.

I suspect that I will gradually start telling people, and there will be a variety of reactions.

4:07 PM, May 02, 2010

 **Anonymous said...**

This is a very compelling story, and blog!

This "coming out of the closet" issue is so profound in many HD families.

I imagine that it is a toss up. You don't want to upset or hinder your family members, but you also don't want to miss out on opportunities to contribute to research efforts.

I am studying HD epidemiology in Canada and I am very interested about this "coming out of the closet" issue. I am 'counting' the HD patients who live in my province and am aware that I will most likely under-count because of this issue and many more similar issues. The result of under-counting can lead to less attention for the HD community.

There is a fine balance between altruism and personal/family benefits. What a complex situation.

Thank you for your story Tellie. And thank you for your blog Gene. This is so very important.

2:53 PM, May 03, 2010

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