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Huntington's makes page one

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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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SUNDAY, MARCH 18, 2007

Huntington's makes page one

Today was a very important moment for building awareness about Huntington's disease: the *New York Times*, one of the world's most influential newspapers, ran a long page-one story about a young woman's brave decision to be tested at age 23 (click [here](#) to read the article).

It's rare that HD gets such attention. Most people have not heard of HD, or they have only a vague notion of it. Like a lot of orphan diseases, it just doesn't register with people. After I recently wrote a friend a long letter about my own gene-positive status, his response referred to "Hodgkin's disease."

I myself have tried to bring HD to the *New York Times*' attention. A couple of years ago I submitted an article about my experience with HD to the paper's Sunday magazine and then to its science section, but I allegedly had nothing new to say about the disease. Luckily, in September of 2005 the *Washington Post* published an article about my story written by Dr. Martha Nance of the Huntington's Study Group (click [here](#) to read the article).

So I was thrilled to see reporter Amy Harmon's well-written portrait of Katie Moser. The article outlined the history of HD in Katie's extended family, the pros and cons of testing at such a young age, and the ways in which Katie has coped with living at risk. Harmon especially captured the psychological trauma people experience before and after testing.

Like me, Katie Moser faces a very long road of wondering when and how her symptoms will start. As I did, she may someday face the difficult decision of testing her own child for the genetic defect that causes HD. I think about HD every day. It's a lifelong curse on me and my family.

But is there really a trend towards increased testing among young people, as the article claims? The reporter cited no empirical evidence to back up this claim. If young people indeed do want to get tested more, it's simply the result of the availability of a test for HD (starting only in 1993) and the recent appearance of preimplantation genetic diagnosis (the testing of embryos). Their parents could not even dream of these possibilities. Interviews with more young at-risk people, including those who have had children, could have shed more light on the purported new trend.

The article also did not discuss some other important facets of the HD story. Did Katie attempt to line up all of her insurance coverage before testing? Why does research on HD and other rare diseases receive so little funding when, especially in the case of HD, they could provide the key to curing other diseases? Why, in fact, is HD so little known and understood? And why does it carry such a horrible stigma?

I've been writing on HD for nearly ten years and reading about it even longer. I didn't see anything new in today's piece. The article could have really driven home the point that HD is one of humanity's cruelest

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diseases. As a friend of mine observed, the article could have connected with more people had it explored HD more forcefully.

I make these criticisms because the paper gave the reporter more than ample space – some 4,700 words – to explore HD fully. According to her own video on the newspaper's website, she spent a year following Katie's life.

But I still commend Harmon and the *New York Times* for bringing valuable exposure to Huntington's disease. This, in fact, is the paper's second article on HD in recent months. On November 14, 2006 it ran an article that described the stark descent of filmmaker Chris Furbee and his mother into the hell of HD. You can read that article by clicking [here](#).

I urge the New York Times and the media in general to increase their coverage of HD and related diseases and of medical research in general. Tens of thousands of American families are affected by HD, and many million more people will get Parkinson's, Alzheimer's, and other neurological disorders. Whether we realize it or not, we are all in this struggle together.

Posted by [Gene Veritas](#) at 9:34 PM



2 comments:



The Dan said...

Before commending Katie for anything people really should know the facts. At the time of her testing for HD her mother was in a legal battle with Katie's aunt for custody of Katie's cousin. Katie was tested for HD and didn't tell her mother, father or either of her two brothers until she could use the information in court in an effort to help her aunt regain custody of her cousin. They were trying to argue that because Katie had HD her mother had to have HD and therefore it made her unfit to take care of her niece. Katie is an incredibly manipulative person and is using her disease to get her 15 minutes of fame.

1:52 PM, April 01, 2008

Anonymous said...

I share your frustration about the lack of knowledge and attention that HD receives.

I am the wife/caretaker of a husband with HD and also care for my sister-in-law who has HD. It is not easy for people to understand HD or even to care. I can tell them personal horror stories, but then they look at my loved ones and think "so they move a lot, it could be worse". Their ignorance speaks volumes. I do encourage you as I do my HD loved ones to quit dwelling on the future of what will happen to them with HD and live only for today! Sometimes I feel they/we (myself included) dwell so much on the future that we don't enjoy today.

My husband and I have six children (3 boys, 3 girls; we did not know of HD until I was pregnant with the 6th child), none have been tested or plan to be tested before they become symptomatic. They know the risks, they know the probability of being HD positive, but I refuse to let them dwell on the horror

and suffering of the future. I believe that a cure is right around the corner and if not a cure--something to improve quality of life to minimizing the effects of HD.

I explained to them since they were little that they are not assured of tomorrow so why worry about 30-40 years from now.

Lets just get through today, lets just live for today and let tomorrow happen as it comes.

12:43 PM, April 16, 2008

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