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A Huntington's Christmas story: ten years of wondering

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Serbin, Kenneth P., "A Huntington's Christmas story: ten years of wondering" (2005). *At Risk for Huntington's Disease*. 17.

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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)
- ▶ 2006 (4)
- ▼ 2005 (17)
 - ▼ December (2)
 - [A Huntington's Christmas story: ten years of wonder...](#)
 - [A Thanksgiving visit: a time to reflect on HD](#)
 - ▶ September (2)
 - ▶ July (1)
 - ▶ May (1)
 - ▶ April (1)
 - ▶ March (4)
 - ▶ February (3)
 - ▶ January (3)

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SUNDAY, DECEMBER 18, 2005

A Huntington's Christmas story: ten years of wondering

For the past ten years Christmas has come with a tinge of sadness in our family, as we remember the bad news about my mother.

It was the day after Christmas in 1995, and life seemed good. I was getting established in my career, and my wife and I were talking about starting a family. We were in our thirties and had few worries.

Then I opened a letter from my sister. "It's a relief to finally know what Mom has," it read.

This letter came as a surprise to me. For some time I had known something was wrong with my mother. My dad had mentioned that my mother's legs were shaking uncontrollably at night. She and my father, who live three time zones away, had paid us a two-month visit earlier in the year. One day my mother was very depressed and angry, so I gave her a massage to try to lift her spirits. She said she felt better, but I sensed that there was more to the story than just depression or a quirk of personality. I urged my father to take her to a specialist. He did but failed to keep me fully abreast of the doctors' reports.

I immediately called my sister. "What does Mom have?" I asked.

"You mean they didn't tell you? Mom has Huntington's disease."

Huntington's disease? I had never heard of it. I at first felt good that we finally knew what was wrong with my mother. My coaxing my dad to get her help had brought results.

Then my sister explained that Huntington's was an inherited genetic disorder. She and I had a 50-50 chance of having it. And if we had it, our kids would face equal odds of losing their bodies and their minds.

My sister has three sons; in 1995, they were ages ten, eight, and six. What a terrible blow it must have been for her to learn that they were at risk for HD!

I rushed into the next room to tell my wife. One of the first things I said was that we might have to put off having children. We were devastated.

That same day I called one of my mother's doctors to get further details on Huntington's. I told him that I wanted to get tested immediately. He cautioned me not to do so, because of the risk of losing my job or not being able to get certain kinds of insurance. A person at the local chapter of the Huntington's Disease Society of America gave me similar advice and invited me to attend the monthly support group meeting.

That fateful December 26 I felt gripped with fear as I lay in bed worrying about my mother and my own future. My wife hugged me as she had never

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done before.

And so began ten years of wondering.

How long will my mom hold out? She has experienced a steady decline to the point where she is now virtually helpless and living in a nursing home.

When will an effective treatment or cure be discovered? The HD gene was discovered in 1993 and literally scores of research breakthroughs have been made by some of the world's most interesting scientists, but there is still nothing that effectively stops or controls the disease.

How and when will my own symptoms start? After living in denial for several years, I got tested in 1999 because we wanted to start a family. I am gene positive. Having this defect means that I will develop symptoms, perhaps as soon as in the next few years. As the years have gone by, I have become increasingly anxious. The worry becomes more acute at the Christmas-time anniversary. It's also a few days before my birthday. Each year we're reminded that time keeps ticking, and the probability of my illness increases.

Worst of all, this year Mom won't spend Christmas at home for the first time in her 68 years. Instead my dad and my sister will celebrate with her at the nursing home.

This year there will be no gift of a treatment or cure. My dream is that I awake some December 26 to hear the news that Huntington's disease has finally been stopped.

Posted by [Gene Veritas](#) at [2:35 PM](#)



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