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At Risk for Huntington's Disease

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## Giving up my dreams

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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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 GENE VERITAS

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THURSDAY, FEBRUARY 03, 2005

## Giving up my dreams

Huntington's disease hits people in their prime. Knowing that the genetic defect is harming my brain and that I need to prepare for the day symptoms will strike, I have sadly relinquished many dreams.

One of the most difficult to let go is my career. Considering the pressures, I still turn in a solid performance at work. But I no longer have the energy or the time to strive for the top of my field. Like most professionals of my generation, I grew up desiring success and recognition. But as my life has become dominated by the drive for the cure and the need to take care of my health, my professional ambitions have waned. A wonderfully fulfilling part of me has disappeared for good.

The time I used to put in at night for my job I now spend reading on HD.

Professional gatherings are tough to attend, because I resent successful colleagues who advance without the burden I carry. I always rush home early to spend time on HD issues or with my family.

I only apply for jobs that are near adequate care facilities for HD people. Every application turns into an excruciating discussion with my wife about a move's impact on our planning for HD.

I sometimes think that moving ahead professionally will somehow help me in the cause to stop HD. But I'm probably deluding myself.

More often I tell myself that career is irrelevant without good health. Better to spend time exercising, resting, and eating well than worrying about a better job.

The threat of HD has changed me for good. Even if the cure comes before I fall ill, I will have lost a large chunk of my life wondering about HD.

I used to define myself as a seeker of success. But HD has killed my passion for work. Now I am mainly a person living at risk.

Posted by [Gene Veritas](#) at 9:50 PM



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