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At Risk for Huntington's Disease

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Smelling the flowers at Thanksgiving

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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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HD Links

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[International Huntington Association](#)
[Huntington's Disease Drug Works](#)

WEDNESDAY, NOVEMBER 25, 2009

Smelling the flowers at Thanksgiving

Thanksgiving is a time to slow down and reflect on all the good in our lives.

As I wonder about when I will follow in my deceased mother's footsteps and develop Huntington's disease, one thing I am most grateful for is the opportunity to spend time with my nine-year-old daughter.

She is our "miracle baby"; she tested negative for HD while still in the womb.

One of the keys to life – and especially to living with a gene-positive status for a devastating brain disease – is seizing the moment. Each moment is unique and will not return.

We must smell the roses – but also appreciate many other kinds of lovely scents and scenes nature and our lives have to offer.



One recent afternoon I decided to surprise my daughter by taking her to the San Diego Botanic Garden. The pictures you see here are hers.

My daughter loves seeds and plants. Shortly after she started to walk, at around ten months, I started to take her to a local park. There she discovered all kinds of plant parts to collect. I was her assistant. She learned to make "soup" with these interesting ingredients. Often we had to bring everything home for her to keep.

Two years ago I helped her with her first science fair project. She planted

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seeds and measured and graphed the growth rate of several species. This past year she studied pollution flowing into the Tijuana Estuary and the Pacific Ocean.



These days we still bring home sticks, pine cones, petals, and her beloved seeds.

I sometimes tell her she's going to be a botanist.

For many years, my wife and I didn't talk about our daughter's genetic test. After worrying so much about HD's impact in so many aspects of our lives, we wanted to enjoy her without the disease's ugly possibilities marring the one area of our life that was normal.



Lately, though, as she has matured, the consequences of our decision to have her tested have become powerfully present. *She is free from HD.*

A couple days ago my wife recalled how, before the genetic test, she had often felt the baby's kicks and wondered whether we would continue with the pregnancy. Had she tested positive, we would have contemplated an

abortion, which we oppose on moral grounds but recognize as necessary in some cases.



Now, as she flowers like the beautiful plants that she loves to photograph, our daughter will soon start learning about her father's gene-positive status.

Perhaps her budding interest in nature will help her comprehend and accept my own biological reality.

But that story is for another day. For now, I want to enjoy her photographs and her own beautiful life.



Posted by [Gene Veritas](#) at 9:46 PM



1 comment:



🌀 **Confessions of a Mother, Lawyer & Crazy Woman** said...

Hello - What a lovely post. I wanted to stop by and tell you I appreciate your blog. My father was just diagnosed w/ HD and

I am trying to determine my future path and make sense of all of it.

8:16 AM, November 30, 2009

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