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At Risk for Huntington's Disease

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Dad, could you get 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.

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)
 - ▶ December (4)
 - ▶ November (1)
 - ▶ October (2)
 - ▶ September (3)
 - ▶ August (2)
 - ▶ June (2)
 - ▼ May (3)
 - ['Dad, could you get HD?'](#)
 - [A perfect day: the sunset of a meaningful life](#)
 - [Care versus cure: we can progress in both](#)
 - ▶ April (2)
 - ▶ March (2)
 - ▶ February (2)
 - ▶ January (3)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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 GENE VERITAS

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[Huntington's Disease Society of America](#)

WEDNESDAY, MAY 26, 2010

'Dad, could you get HD?'

On May 17 I came out to my nine-year-old daughter about Huntington's disease: I revealed that I was gene-positive.

My daughter already knew quite a bit about HD, but this was the first time she came to see how it can affect our family.

In January, after meeting Terry Leach, a 12-year-old boy with juvenile Huntington's, she asked me whether I could get the disease. I answered truthfully: yes, I could. But I didn't tell her that I had gotten tested. I wrote on that conversation in [a previous entry](#) in this blog.

My wife and I have let the question of HD come up naturally. Our daughter has known about the disease since her toddler years. On visits back to my hometown in the Midwest she spent time with her ill grandmother, who could not speak to or even hold her. When my mother died in February 2006, she attended the funeral with my wife and me.

The truth and painful emotions

On the 17th I picked up my daughter from school. Following our Monday routine, we headed for a local shop to get her favorite smoothie, with mango, papaya juice, and pineapple sherbet.

Normally we head right home so she can do her schoolwork and practice piano. But on this day we needed to stop at a Kinko's to make an enlarged copy of a school writing project she did with her mother on the book *The Landry News* by Andrew Clements.

It tells the story of Cara Landry, a fifth-grade girl unhappy because of her parents' divorce and her teacher's indifference about the education of his students. Cara learns the value of telling the truth and dealing with painful emotions by publishing a school newspaper. She writes articles about divorce and her teacher's subpar performance.

My wife and daughter produced their own version of *The Landry News* with articles about the book and photographs of themselves disguised as the main characters. I did the layout.

"Telling the truth about a disease" also happened to be the title of my above-mentioned blog entry on my daughter and Terry.

Antonio Gates and the Chargers

On the way to Kinko's we passed by the headquarters of the San Diego Chargers, one of the main benefactors of the San Diego chapter of the Huntington's Society of America (HDSA-San Diego). My daughter recognized the complex as the place where, in 2008, we attended the children's version of the *Shoot to Cure HD*, a free-throw-shooting contest and meet-the-players event to raise money for the chapter.

[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
[HDSA Orange County \(CA\) Affiliate](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

My daughter got one of the biggest thrills of her young life that day when we had our picture taken with the *Shoot* honorary chair, Antonio Gates, the Chargers' star tight end and a former college basketball standout.

As we reminisced about that day, she wanted to know about Gates' involvement with Huntington's disease. I explained that he dedicated himself to the HD movement because of the Chargers' commitment to HDSA. (Unbeknownst to her, a couple weeks earlier I had written about and photographed an [HDSA-San Diego press conference on HD Awareness Month](#) attended by Gates.)

She recalled that Bill Johnston, the Chargers' public relations director, also worked with HDSA. Bill's wife Ramona has HD, I told her.

Dad could get sick

Although children have excellent memories, their powerful and resilient minds also conveniently block out or reprocess difficult information to protect themselves and those they love. I knew this was happening with my daughter, because she didn't seem to have any recall of our January conversation about Terry or earlier discussions from her toddler and early childhood years.

So she asked a series of questions about HD. How old was Ramona when she got the disease? How old was Grandma? How does a person get HD?

I explained that HD is genetic: people are born with a problem, but it doesn't show up until later. Some get it early, like Terry; others, like Grandma, get it as adults.

"Could you get HD?" she asked.

"Yes," I said as we were exiting the car to enter the copy shop.

For the first time ever I saw my daughter do a double-take.

"Then that means *I* could get HD?!"

"No, you can't get HD. Mommy and I had you tested, and you don't have the genetic problem. I have the genetic problem."

"So, you *MIGHT* get HD?" she said with a mixture of emphasis, earnestness, and optimism. She needed badly to protect me somehow and to reassure herself that everything would be okay.

"Yes, I *might* get sick," I replied with my own emphasis on *possibility*, not *probability*.

I didn't tell her that *everybody* with the Huntington's defect sooner or later develops the disease, although she might be able to draw that conclusion from what I told her about Terry, my mom, and age of onset.

Dealing with the fallout

Back in the car after making our copies, I asked her if she was concerned about HD. Did she want to talk about it? No, she said.

She was already changing the subject to something about her world of play.

For the very first time I had revealed to my daughter that I was gene-positive for Huntington's disease. In the past I used to say that Grandma had a "boo-boo on her brain." Now I used the word "genetic" and "problem."

It was also the very first time that I referred to a “test” for HD. She probably doesn’t yet understand the process of medical testing, but, as a fourth-grader who takes lots of tests, she’s already quite familiar with the general idea.

Later I took my wife aside and explained what had transpired. During dinner shouldn’t we ask our daughter whether she has any questions or concerns? No, my wife said: let her continue to ask the questions on her own.

The rest of the week our daughter got angrier about things than usual. And on Saturday she revealed that she had told a friend at school that I could get sick. That evening my wife and I argued about whether we had made the right choice in not discussing HD at the dinner table.

Information and support

The timing of my revelation to my daughter is crucial, because in 2010 I want to come out about my gene-positive status ([click here](#) to read more). As I go public, my daughter will need more information about HD.

She already knows, for instance, that I take the dietary supplement creatine as a preventive measure against HD. (Creatine is recommended by the [Huntington’s Disease Drug Works](#) program.) She commented that the store clerks will think that I buy creatine for muscle build-up like everybody else. But *we’ll* know it’s for HD.

For now my daughter seems to be okay with my revelation. I don’t have any of the classic symptoms of HD, and we’re living our lives as normally as possible. A couple of nights ago she and I played charades in the living room.

But as she learns more about HD and likely sees me fall into its abyss some day, she will need much emotional support.

And I will need it from her, too.

No perfect formula

Nobody can formulate the perfect language for telling a child about a parent’s at-risk status for a disease, especially a cruel and devastating one like Huntington’s.

My wife and I have developed a creative tension between us on this issue. Like the lessons learned by the budding journalist in *The Landry News*, I believe that telling the truth is the best approach. It makes me angry to remember how my mother’s side of the extended family denied that she had a brain disease and attributed her situation to [“mental problems.”](#)

But my wife is right, too: the truth needs to be told in steps. Just as it took time for our daughter to go from “boo-boos” to “genetic problems,” so will it take years – and maybe even a lifetime – for her to fully comprehend what Huntington’s disease means for me and our family.

Posted by [Gene Veritas](#) at [10:46 PM](#)      

2 comments:

[Michelle said...](#)

I think creating false optimism with possibility and not probability is kind of evil. Done with the best of intentions but it creates toxic hope.

Nobody ever told me I could get HD. I just knew. And the information I had came from my own research. Sneaking around watching videos I'd found before my mom woke up, printing articles at school and hiding them.

She's gonna find out. And she should have someone to go to who's been through it and who's not scared to tell her the truth. Someone who's not you. A safe person. You know? My safe person was Jane. The one who said yes you could die and yes it's scary and I'm gonna be here with you through it.

Keep up the fight, Gene.

2:13 AM, May 27, 2010

 **generic cialis said...**

Well i guess that a situation like this it's very hard, but at least seems that your daughter it's enough mature at least to know the truth, I'm pretty sure that she will make it well, good luck.

10:19 AM, May 18, 2011

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