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Telling the truth about a disease

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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, JANUARY 31, 2010

Telling the truth about a disease

Since testing positive for Huntington's disease almost eleven years ago, I have focused intensively on five people.

First, I worried about my mother and tried to do my best to assist her, even though she lived in the Midwest, far from my California home. She died in January 2006. By extension, I also tried to help my father, a Huntington's disease warrior who cared for her until the end and who died – spent from his years of caretaking – last September.

Each day I have faced the threat of HD, bolstered by my steadfast wife. [As I wrote in my previous entry](#), she chose to stand by me when it might have been much easier to leave and start a new life with another man.

Of course, I have also focused on myself in a daily struggle to stay healthy and emotionally stable. In 1998 I became an activist for the [Huntington's Disease Society of America](#) (HDSA), and for the past five years I have detailed my life by writing this blog.

Enter the “miracle baby”

Now my nine-year-old daughter approaches center stage in this Huntington's dilemma.

Unbeknownst to her, she became involved at the moment we conceived her in October 1999. As I have chronicled various times here, I had gotten tested in June 1999 because my wife and I wanted to start a family and eliminate the possibility of having a child with HD.

Only in late January 2000 did we receive a phone call from our geneticist informing us that our child had tested negative in the womb. If she had not, we would have seriously considered the wrenching choice of an abortion – taking place, by necessity, after the first trimester because of the time it took for the lab test to be performed.

We hugged each other and cried the day we learned of the negative test result. It was one of the happiest days of our lives. We called our daughter our “miracle baby.”

Processing difficult information

Over the years we have mainly not sheltered our daughter from HD, as we believe that in the long run living with the truth is the best way to lead a life and face its many challenges.

We hate the ignorance and exaggerated denial we have observed in other members of our extended family. My mother's brother and his wife never told their children about HD until my mother died, referring to her instead as a “mental” case. My sister never really wanted to discuss HD with me; her three sons grew up without understanding the genetic implications of

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

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[Heather's Huntington's Disease Page](#)

the disease. No one in their family has been tested.

Our daughter knew from about the age of two that her grandmother was ill. We would tell her that “Grandma has a boo-boo on her brain.” She understood very early on that “Grandma was born with the boo-boo.” The concept of a genetic disease had been planted.

One time, she said to me as we were cleaning her up in the bathroom: “My daddy is not going to get sick, because he does not have a boo-boo on his brain. And I won’t get sick either.”

My daughter remembers the time she spent with her ill grandmother during a couple of short trips back to my hometown. Since my mother died, my daughter has come up with a different interpretation. As she understood the genetic nature of disease more clearly, she concluded that I perhaps could inherit it and she too.

I let it go at that, not wanting to worry her too deeply about me or herself. I wanted to give her the chance to process her observations on her own.

From Santa to reality

It reminds me of how I responded to our daughter's questions last spring about Santa Claus. As I was driving her in the car one day, she told me that a boy at her school of the same age had learned from his parents that they, not Santa, brought Christmas gifts.

“I want you to tell me the truth,” she said. “Is that true?”

“You want the truth?” I asked, to be sure.

“Yes,” she replied.

“Joshua is right,” I said. “Mommies and daddies buy the gifts. Santa Claus is for small children, and you’re not a small child anymore. Do you ever see a teenager or an adult sitting on Santa’s lap at the mall? No. People give each other gifts to celebrate Christmas. Santa is only for small children.”

I was afraid that she might cry or be scandalized. I thought of going into a big spiel about growing up and learning new things. But I held my tongue. To my surprise, she didn’t seem the least bit hurt. She quickly went on to another topic.

A natural approach

Interestingly, while understanding that my wife and I would be buying her gifts, this past Christmas our daughter still insisted on writing and posting a letter to Santa. I told her that I mailed it.

My wife and I agreed that she is in a transitional phase – really wanting to grow up and assert herself, but also wanting to hang on to the happiest aspects of childhood. As parents, we quickly came to understand the importance of a child's capacity to both process information logically but also maintain comforting fantasies.

So my wife and I also do not force the issue of HD on our daughter. We have let the subject come up naturally.

We’ve taken the same approach with respect to sex. We’ve shown her a book on girls’ health that discusses, for instance, the menstrual period, feminine pads, and tampons. At the right moment we’ll show her another book that specifically discusses sex.

We know that the discussion of my gene-positive status, sex, and genetics will probably all come together within a short period of time.

The moment is fast approaching, because, as she becomes more exposed to my HDSA activism, she will start to ask more questions.

Meeting a boy with HD

A big moment for her came on January 22, two days before my wife ran the Carlsbad Half Marathon to raise money for HDSA-San Diego. That night the marathon organizers held a special pre-race reception for the "Heroes of the Marathon," individuals recognized for overcoming major challenges.

One of the heroes was [Terry Leach, the 12-year-old boy with juvenile Huntington's disease about whom I had written in December.](#)

For the first time, I had invoked Huntington's disease as a lesson about life; I had used Terry's story to show her how some people struggle against the worst of odds. A couple of days later she asked to see the pictures I took of Terry, and she read one of my articles on him.

I had told her that we would be meeting Terry and that his family would be at the "Heroes" reception. At first she wanted to go, but in the hours leading up to the event she changed her mind. My wife believed that she was afraid to meet someone with a disease that she somehow suspected could affect me.

I wanted the encounter with Terry to be another learning moment for my daughter. After I explained to her the importance of honoring the heroes for their accomplishments, she did not protest any further.

I could tell that Terry was happy to see the people visiting him at his family's table, because when I bent down to say hello and hug him, he gave me a kiss on the face. A bit later I brought my wife and daughter over.

My daughter briefly greeted Terry. Because Terry can't speak, they couldn't converse. My daughter can be quite shy at times, so she slipped into her observational mode and quietly took in the situation. I took a couple pictures of her standing between Terry and his mother Angela.

It was the first time she had met someone with HD besides my mother.

Calling an audible

Afterwards, as we drove home, we talked about Terry. She wanted to know if Terry got to see his father. I explained that he, too, had HD and lived in another state.

"Does his dad visit him?" she wanted to know. I explained that he was like her grandmother and could no longer travel.

The next question was perfectly logical. But it still stunned me.

"Can you get Huntington's?" she asked me.

It was a question that I was probably expecting for a long time. I hadn't specifically prepared for it as one might for an examination or a meeting, but I made many mental notes over the years about how to discuss HD with my daughter. I had also played many scenarios through my mind.

I obviously wanted to avoid the denial and ignorance I had witnessed in my own family. Rather, I had positive examples of how other families had raised their children with full knowledge of HD. These families clearly appeared to deal best with the topic. Rather than try to escape, they confronted reality directly, no matter how dire the circumstances.

In 2008 I watched a presentation at the local HD support group by [Bonnie Hennig](#), a licensed clinical social worker specializing in Huntington's disease and children. She wrote a booklet titled *Talking to Kids About Huntington's Disease: A Book for People Who Know Children with HD in their Family*. I found myself agreeing with her assertion that families should discuss the disease, but always in terms that children can understand.

Yet I still had to think very carefully before responding to my daughter. My mind had to quickly compute all of the possible answers I might give and the effect they might have on her. I felt like a quarterback calling an audible at the line of scrimmage in a football game.

Could I get HD? After a brief pause, I said, "Yes, I can."

She still did not know that I was gene-positive – that her own dad also had a "boo-boo on his brain." But the question and response were solemn enough that she must have felt the import of what I had said. This was the first time that I had revealed the possibility to her.

She did not ask any more questions about me. And I did not volunteer any more information. As I discussed later with my wife, the flood of information about HD that night had been plenty.

Growing up strong







On Sunday, January 24, the three of us arose at 5:30 a.m. to get ready for the half marathon. I drove my family and another mother and daughter to Carlsbad. The girls saw their two moms get in position for the race, and later the three of us watched them cross the finish line.

This time my daughter wanted to see Terry again. We didn't see him anywhere near the start or finish lines. My wife then informed us that Terry and his family were at mile No. 3 cheering on the HDSA runners. Our daughter wanted to go there to see Terry, but we explained that we were not allowed to visit the race course because we would interfere with other runners.

I think she took a big leap forward that weekend. She saw her mother compete in a half marathon to raise money for a cause. She met a boy not much older than she who had HD. And she began to understand that HD threatens our family.

Wanting to see Terry again was a good sign. She was no longer so afraid. Nobody knows what the future holds. But, when HD begins to exact its toll on me, I think my daughter will be strong.

As best we can, my wife and I are trying to provide her with good examples of strength and honesty.

Posted by [Gene Veritas](#) at [2:50 PM](#)      

4 comments:

Michelle Routhieaux said...

Wow. That's pretty amazing. Your daughter is lucky to be gene negative but it will be interesting to see what her reaction to that news is down the line. Thank you so much for writing and sharing. It's quite helpful.

[1:41 PM, February 01, 2010](#)

Anonymous said...

hi,
my name is Meredith, and we are learning about HD in school.
I'm trying to research the question: why don't families like to
talk about HD?

i think this blog is very amazing, and helpful. thanks very
much.

-Meredith

[1:45 PM, March 03, 2010](#)



Unknown said...

I want to thank you for such an informed and heartfelt blog.
You are a courageous man and deserve much credit. I have
much to say about my brother who I think is in the middle
stages of HD. Is there another way I can communicate with
you, or do you prefer I state everything here? I am also a writer
and was negative on my gene test. Thanks again, Miriam

[1:06 PM, May 01, 2010](#)



Gene Veritas said...

Meredith and Mimi: I'm on Facebook. If you want to make a
friend request there, we can be in touch. Gene

[7:00 PM, May 17, 2010](#)

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