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An HD Thanksgiving toast

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Serbin, Kenneth P., "An HD Thanksgiving toast" (2011). *At Risk for Huntington's Disease*. 112.
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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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About Me

MONDAY, NOVEMBER 21, 2011

An HD Thanksgiving toast

Thanksgiving is my favorite holiday.

Just when the year threatens to become frenetic, Thanksgiving intervenes with a hearty feast and family warmth.

When I was about twelve, I wrote a letter to my aunt Claralou praising her for the peaceful and welcoming atmosphere of her annual Thanksgiving celebration. She displayed my letter on her refrigerator door, and it appeared there again year after year as a remembrance of the true spirit of Thanksgiving.

My mother helped her and the other women with the turkey roasting in the oven for what seemed like forever, while my father, my uncle, and the other men drank beer, talked, and tended to us eight cousins stuffed into the house.

Nobody was a smoker, but on Thanksgiving my dad and my uncle would light up cigars and smell up the den where the football classics were playing on TV and I tried to learn how to use a nutcracker. One year they let us try a few puffs. I felt cool and manly.

Thanksgiving put the brakes on schoolwork, and, in college, when I spent the holiday on the East Coast, it saved me from completely exhausting myself.

I also like Thanksgiving because, of all the holidays, it has resisted commercialization the most. Aside from a trip to the supermarket for dinner items, the urge to buy is absent. (Black Friday is definitely not about Thanksgiving, but Christmas.)

Now in her 80s, Aunt Claralou still celebrates Thanksgiving in the same home, but, living in California with my own family, I haven't had the chance to spend the holiday there.

My parents are gone – my mother the victim of Huntington's disease in 2006 at the age of 68, my father, the "HD warrior," dead at nearly 82 from a broken heart a little more than two years ago.

Ever since we learned of my mother's diagnosis the day after Christmas in 1995, Thanksgiving has taken on a more profound meaning. For me, it really is a time to take stock of all the good in my life – even though I have lived in wait and dread of HD after testing positive in 1999.

Despite the enormous worries about our future, my family and I are thriving. My wife continues to work full-time as a teacher. Last weekend she ran her sixth half-marathon since taking up running in early 2010. Our "miracle baby," who tested negative in the womb, is performing well in sixth grade and preparing to take the private-school entrance exam. And, as I look to my 52nd birthday in less than two months, an age at which HD

 [GENE VERITAS](#)

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HD Links

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

[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 \(CA\)](#)

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had already stricken my mother, I have displayed none of the classic symptoms of HD.

Along with my wife and daughter, I have experienced the simplest yet profoundest joys of life ([click here](#) to read more). Last Saturday our daughter played her last soccer game of the season. As she played one of her best games, I doubled on the sidelines as the assistant coach and team videographer, and my wife cheered them on and made sure the half-time snacks were ready. Later in the afternoon we attended the year-end party, where I was moved by the girls' unity and laughter and the realization that we parents were a team just as united in our devotion to our daughters.






I feel a special debt of gratitude to the many people engaged in the fight against HD: the members and administrators of [the four organizations combating the disease](#); the HD people and their families fighting the good fight each day; the physicians and caregivers; and the scientists and pharmaceutical companies on a quest for treatments and a cure.

I am continually moved by the circle of close friends who pray for and support for me in numerous ways – especially [Norman Oder](#), the editor of this blog and my “HD alter ego.”

I also want to thank *you*, my readers, for sharing with me the harrowing odyssey of living gene-positive for a condition described as [“the devil of all diseases.”](#) In posted comments, on Facebook, through e-mail, and even in phone calls, you have expressed your unflagging support for me personally and confidence in our collective fight to defeat HD.

Knowing that you are listening, challenging, and cheering me on provides me with an immense emotional strength, and hearing about *your* valiant efforts against HD inspires me.

As I share both a ham and turkey with our guests on Thursday, I'll raise a toast of thanks to you.

Posted by [Gene Veritas](#) at 8:32 PM     

Labels: [caregiver](#) , [cure](#) , [daughter](#) , [diagnosis](#) , [father](#) , [gene-positive](#) , [Huntington's](#) , [mother](#) , [pharmaceutical](#) , [scientist](#) , [symptoms](#) , [tested negative](#) , [testing positive](#) , [treatments](#) , [warrior](#) , [wife](#)

4 comments:

Avid Reader said...

Thank you for this heartwarming post and for your continuous efforts in combating HD.

6:19 AM, November 22, 2011




Kara Faith Hammer said...

I enjoyed reading this, and could relate to a lot of what you said, but what I related to the most was the "Emotional Impact" bit. In fact, not 5 minutes before finding your blog on google, I was having a mini-emotional breakdown because I'm worried about symptoms starting, even though I probably won't have to worry about it for a relatively long time.

Anyway, just wanted to say thanks. I'm pretty much alone when it comes to HD, (I'm the last living person in my family to carry the gene, and the closest support group is 3 hours away) so it's nice to be reminded that I'm not *really* alone.

7:17 PM, December 07, 2011


 **Anonymous said...**

nfl and jhd what a combination I just realized I am not alone my son just fished his junior yr high school football yr with 8 sac's he is my pride and joy!! I live to watch him play. he has been watching espn since I can remember with paper and pencil little x's and o's all over :) knows all stats of all sports a true fan with passion for the sport! he says he will play in the nfl his sophomore yr of college and I, his biggest fan know he has what it takes. Trevor is at risk for jhd we live in a rural town in north Dakota not much publicity up here this is my first try at trying to reach someone anyone who would help make a little boys dreams come true. trevor as a little boy didn't play trucks, trains, or army men, only ball he played catch with his mom every single day!!! and I cant catch ha. idk where to begin on making his dream come true I hope anyone out there does.
love, mommy

Jolene@ndcandy.com

7:00 AM, November 05, 2014



 **Unknown said...**

God Bless you !

I completely understand what you're going through and your excitement !!

5:09 AM, October 21, 2016

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