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At Risk for Huntington's Disease

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## A gene-positive dad's reflections on Huntington's disease, parenthood, and the fragility of life

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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)
  - ▶ December (3)
  - ▶ November (3)
  - ▶ October (3)
  - ▶ September (3)
  - ▼ August (2)
    - ▶ ['Predicting' Huntington's disease in the heartland](#)
    - ▶ [A gene-positive dad's reflections on Huntington's ...](#)
  - ▶ July (1)
  - ▶ June (1)
  - ▶ May (3)
  - ▶ April (4)
  - ▶ March (2)
  - ▶ February (3)
  - ▶ January (2)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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## HD Links

WEDNESDAY, AUGUST 14, 2013

### A gene-positive dad's reflections on Huntington's disease, parenthood, and the fragility of life

Our "miracle daughter" Bianca, who tested negative in the womb for Huntington's disease in early 2000, recently turned 13.

As my wife Regina and I have watched Bianca transform before our very eyes into a teenager, I have contemplated the beauty and fragility of this miracle of life.

Bianca's latest birthday was doubly special: she became a teenager, and we again quietly gave thanks for her gene-negative status.

Had Bianca tested positive for HD, she might now be facing the scourge of [juvenile Huntington's \(JHD\)](#), a particularly cruel form of the disease caused when a gene-positive parent, [usually the father](#), passes on a more severe form of the genetic mutation, causing onset to occur as early as the toddler years.

JHD strikes while a person is still developing physically and neurologically. JHD can cause considerable pain, and some patients require operations for problems such as deformed limbs.

Few JHD patients survive beyond the age of 30, and some die during childhood.

Whenever I witness JHD families' terrible struggles, I breathe a sigh of relief that we as a family avoided such an immense burden on top of my race against the genetic clock.

### Nobody's exempt from life's challenges

However, as a father striving to provide Bianca with a safe, stable, and promising upbringing, I know that freedom from HD doesn't mean freedom from life's other risks. Regina and I must still help her negotiate not only the successes, but also the many challenges that lie ahead – and to know when to step back and let her handle them on her own.

We're also aware that each day illnesses of all sorts, genetic and otherwise, strike many teens and young adults. The other day I learned that a friend's son faces an incurable, though partially treatable genetic disorder. My heart sunk when I learned of the difficulties that await this young person.

The HD community faces many tribulations, but so many others suffer, too. Understanding this helps Regina and me to put our family's situation in perspective.

### Genetics, families, and ethics

Child-rearing provides the key to understanding a major human purpose: propagating the human species and aiming toward a brighter future.

[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 \(CA\) Affiliate](#)  
[HD Free with PGD!](#)  
[Stanford HOPES](#)  
[Earth Source CoQ10, Inc.](#)

## HD Blogs and Individuals

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

Today the study of genetics and the search for treatments for life-threatening genetic conditions such as HD constitute a new human purpose but also new, ever-more-nuanced definitions of conception and the family.

Regina and I faced the terrible possibility of bearing a child with the HD gene. In 1999, [preimplantation genetic diagnosis \(PGD\)](#) wasn't possible. Today it helps families eliminate HD forever from the family line

In the Genomic Era, families can take advantage of new scientific tools, but use of these tools also forces us to confront new ethical and moral questions.

### **Best strategy: honesty**

Regina, Bianca, and I rarely discuss HD as a family matter, but it does frequently come up in the context of my advocacy as a volunteer for the [Huntington's Disease Society of America](#) (HDSA) and writer of this blog.

In 2012 and 2013 the three of us took part in the local annual HDSA Hope Walk to raise funds and awareness.



*Kenneth (left), Regina, and Bianca Serbin with Allan and Jane Rappoport, the Serbin Family "Beat HD" Team in the 2012 HDSA-San Diego Hope Walk (photo by E. J. Garner)*

Bianca has also read several articles from this blog.

Responding first to Bianca's curiosity about my mother Carol's illness and eventual death from HD in 2006, I have always answered her questions about HD with explanations appropriate for her age at the moment. In so doing, I have relied on my knowledge of the science of HD and other families' experiences with its social impact – but also on my gut.

Seeing how [denial, stigma, and discrimination tear apart HD families](#) – including parts of my own – I have always adopted a strategy of openness and honesty in discussing Huntington's with not only my daughter, but other members of my extended family and my "HD family."

### **New vistas**

Parenting never ends. It requires constant attention, patience, and spousal teamwork. Each stage in the child's life is unique and demands creativity and receptivity on the part of the parents.

During our vacation in Europe last month, Regina and I made a special effort to open up new vistas to Bianca and become closer to her. She is striving to become independent, but, even though she may not admit it, she still needs and wants parental love and attention.

Now, as we prepare to return to the routine of school, I feel great pride in Bianca's good health and accomplishments.

However, I also worry about the many challenges of the teen years, and I wonder increasingly about her rapidly approaching young adulthood. She is just five years from entering college!

### Strengthening bonds

I feel extremely fortunate to have so far avoided the inevitable symptoms of HD. An HD-free life has allowed me to enjoy my HD-negative daughter and protected her from having to confront living with a symptomatic dad.

As I await potential treatment breakthroughs, I savor every moment.

With each passing day, I become ever more conscious of the fragility of life.

However, as long as I enjoy good health, I will work to the utmost to strengthen my bonds to my family and to share the demands and joys of parenting with my wife.

Posted by [Gene Veritas](#) at [3:30 PM](#)      

Labels: [denial](#) , [discrimination](#) , [gene-negative](#) , [gene-positive](#) , [genetic](#) , [genetic clock](#) , [Genomic](#) , [Huntington's disease](#) , [juvenile Huntington's](#) , [mutation](#) , [parenting](#) , [preimplantation genetic diagnosis](#) , [stigma](#) , [tested negative](#)

### 4 comments:

#### Anonymous said...

Beutiful article. So happy your daughter does not have hd.  
Let's pray that those who have I will eventually have a cure at hand. Thank you for sharing..God bless!

[4:54 PM, August 14, 2013](#)

#### Anonymous said...

Beautiful article. So happy your daughter does not have hd.  
Let's pray that those who have It will eventually have a cure at hand. Thank you for sharing..God bless!

[4:56 PM, August 14, 2013](#)

#### Greg J said...

Gene,

I love your articles and I've heard you talk. However, all kids are miracles regardless gene status HD or not. As a HD gene positive father of two at risk kids age 20 and 23, I'm glad we've been able to take the HD journey together as a family. It has made our family stronger in many ways. Please realize that all parents recognize the miracle status of their kids regardless of their HD gene status. Thank you for your advocacy for a cure and enjoy those teenage years.

[7:39 PM, August 14, 2013](#)

🌸 **Anonymous said...**

Gene, as always I enjoyed your article. I have followed you for many years and our stories are quite parallel. My daughter about to turn 14. However, she was not tested in the womb. I am your age and am so grateful to be "non symptomatic" as well. Tested in 2006. My hope is so clear and high of science right now! Its truly uplifting! Thanks for posting these stories about your life. They, too, give my courage

5:07 PM, September 04, 2013

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