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Passing on the Huntington’s disease advocacy baton to the next generation

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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.

MONDAY, JANUARY 23, 2017

Passing on the Huntington's disease advocacy baton to the next generation

In the fight against Huntington's disease, a familial condition that can plague generations, each generation must pass on the advocacy baton to the next.

I feel as though I've started my handoff to my daughter Bianca.

HD has profoundly affected my family in multiple ways. My mother was diagnosed with HD in 1995 and died from it in 2006 at age 68. I tested positive for the genetic defect in 1999, and have been racing against the genetic clock ever since. Bianca, thankfully, tested negative in the womb in 2000.

At 57, an age when my mother had chorea (involuntary movements) and severe cognitive loss, I am blessed to have remained symptom-free. However, because HD gene carriers inevitably develop the disorder, I know that, unless scientists discover an effective treatment, I will someday become ill.

HD families must stick together to confront the devastating symptoms, caregiving demands, and difficult challenges the disease brings, but it's by no means easy.

Avoiding the denial that prevents family solidarity and feeds ignorance about the disease, my wife Regina and I have revealed to Bianca at appropriate moments how HD has impacted our family. We have done so gradually but always honestly. Often, we spoke about HD in response to her questions. (To read more, click here and here.)

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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) 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

Gene Veritas (aka Kenneth P. Serbin) with daughter Bianca and wife Regina (2016 family photo)

A biology assignment

Now 16, Bianca is a healthy and vibrant high school junior. She has frequently read this blog and over the years has participated in several fundraising events for the San Diego chapter of the Huntington’s Disease Society of America (HDSA-San Diego).

Her gene-negative status means that the threat of HD stops with me. Of course, she is concerned about my health, and she is deeply saddened by the plight of juvenile HD patients. She has volunteered for HDSA-San Diego.

Last week she worked on an assignment for her high school biology class titled “A Day in the Life: A Study of Human Genetic Disorders.” From a list of diseases, she chose HD. Drawing on medical and scientific sources, she wrote a four-page summary of the biology of HD, symptoms, its rare status, age of onset, and potential treatments.

Life with HD

For the required creative component of the assignment, Bianca wrote an imaginary patient journal titled “Life with Huntington’s Disease,” from the perspective of this blog, her conversations with me, and her observations over the years.

Bianca captured the sadness, anger, and fear associated with HD. In one excerpt, she wrote:

Today was a bad day. It has been hard lately to ignore HD. I wish I could say I don’t think about it all the time, but I do. Especially now that Mom is getting worse. She can barely walk at this point. Dad helps her eat, shower, use the bathroom, and dress herself. It’s hard for me to see my mom act in a more childish manner than my three-year-old daughter. It’s hard for me to see my mom this way because I know that I will one day experience the same thing. I feel exceptionally lonely nowadays. I know others who struggle or who have struggled to take care of someone with HD, but I somehow feel like my situation is unique, somehow worse than everyone else’s.

However, Bianca also portrayed the strength and hope of HD families and advocates, writing:

Perhaps the best part of having HD is getting to meet so many people who are involved with the cause. The Huntington’s Disease Society of America is one of the most supportive groups of people I have ever worked with. Few know the struggle that accompanies this disease. It’s nice to be able to talk to people who do, people who have lost loved ones, as I have, to this horrible sickness, people who, like me, are at risk.

Bianca Serbin (photo by Gene Veritas)

Honesty and family solidarity

Reading Bianca’s words, I know that HD is forever seared into her consciousness.

I was deeply moved by her decision to write about our family’s struggles with Huntington’s. I am very proud of her.

The experience reinforced the necessity of accurate, patient, and, above all, honest communication within Huntington’s families.

In our conversations last week many powerful memories came to the fore. Bianca told me that one of her earliest recollections was of us visiting my parents’ home in Ohio (she was three) and seeing my father and me help my mother after she fell on the floor.

Bianca learned from me last week how the disease could potentially affect other members of our extended family.

As I looked at her, I felt an immense sense of relief that she is HD-free. I also felt wonderful anticipation: in less than a year she will be applying to college.

‘Don’t worry for now’

At the conclusion of our conversation the night before Bianca turned in the assignment, we discussed the fact that the greater the genetic defect (gene expansion), the earlier the onset.

We inevitably focused on my potential age of onset, ranging from the late forties to the late sixties.

“Hopefully I will get sick only in my late sixties,” I told Bianca.

"Or maybe you'll get sick even later – or not at all!" Bianca responded optimistically.

We discussed the hope of clinical trials.

A bit later, determined not to let all this hinder her life plans, I told her gently: "Don't worry about HD for now. That's something off in the future."

Bianca and Kenneth Serbin (family photo)

Posted by Gene Veritas at 10:43 PM

Labels: advocacy , Bianca Serbin , biology , caregiving , denial , Gene Veritas , HD gene carrier , HDSA-San Diego , Huntington's disease , Kenneth P. Serbin , solidarity , symptoms , tested negative , tested positive , treatments

3 comments:

LeeJ said...

Thanks for sharing this Ken.

8:48 AM, January 24, 2017

Caroline said...

Great post.

11:10 AM, January 25, 2017

new commerce said...

Good to see that you take initiative to confront this situation. I have been helping a friend deal with HD - it is a difficult journey.

2:33 AM, February 28, 2017

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