12-20-2015

'Twas the morning after Christmas – and Huntington's disease hit us like a ton of bricks

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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.

About Me

GENE VERITAS

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SUNDAY, DECEMBER 20, 2015

'Twas the morning after Christmas – and Huntington's disease hit us like a ton of bricks

I dedicate this article to the repose of the brave souls who have lost the fight against Huntington's disease.

Twenty years ago this holiday season, my wife Regina and I received news that changed our lives forever: my mother Carol Serbin had been diagnosed with Huntington's disease, and I had a 50-50 chance of having inherited the genetic defect that caused the deadly disorder.

It happened the morning after Christmas 1995.

As I took stock of that year and looked forward to 1996, I felt calm and accomplished and, despite my habitual caution, even swaggered a bit. I was savoring that extra-special, carefree holiday feeling of the college professor: finals were over, grades were in, and I had a month off.

I felt immensely privileged. In addition to winter and summer breaks devoted to reading and relaxation, my position afforded me annual trips to pursue historical research in the country that had become my second home: Brazil. I felt confident as I neared the half-way mark to tenure, which would provide me job security.

In five days, on December 31, I would turn 36. Regina, who was 29, and I had purchased a condo near the university. It was just a few minutes' drive from the beach in San Diego, a city with spectacular scenery and perhaps the world's best climate.

My achievements gave my parents great pride and vicarious fulfillment. My father Paul had moved our family from Cleveland to Anaheim in June 1966, but, two weeks later, missing home and regretful that we kids would grow up far from our doting grandparents, packed up everything and moved us back. Regina and I now could live the California dream he had pined for. She and I talked of starting a family and saving for a vacation home in Rio de Janeiro, where she grew up.

At around midday, everything suddenly changed. In a phone call with my sister in Cleveland, I received the greatest shock of my life: my mother had HD.

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

Paul and Carol Serbin around the time of her diagnosis with Huntington's disease (above, family photo) and a decade later as the disease ravaged her mind and body (below, photo by Gene Veritas, aka Kenneth P. Serbin)

We had never heard of Huntington's disease. According to my mother's doctors, the disease was untreatable, inexorably destroying her brain. It was causing her to shake uncontrollably – and to lose her mind.

Learning that I had a 50-50 chance of carrying the bad gene instantly put all of our hopes and dreams on hold.

Would we be able to start a family? Could we still buy that condo in Rio? In bed one night shortly thereafter, as I became gripped with fear, Regina held me tightly.

Kenneth and Regina Serbin after his dissertation defense, University of California, San Diego, 1992 (family photo)

Still symptom-free

Each year since, Christmas has brought a sorrowful reminder of my mother's diagnosis – and of the risk I face. After much personal reflection and discussion with Regina, I got tested for HD in 1999, and unfortunately learned I was a carrier of the defective gene.

Through more than 200 articles in this blog since 2005, I have told the story of my family's battle, chronicled the scientific movement to defeat HD, and explored the challenges of individuals, families, and society coping with this vexing, tragic disease.

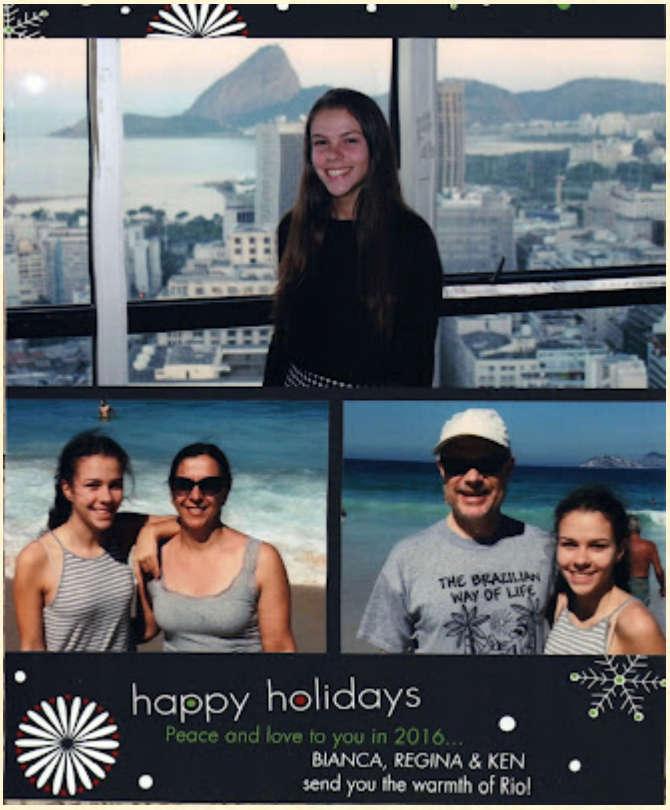
As the 20th anniversary of our initiation into HD approaches, I recognize how fortunate I am to have remained free of the classic symptoms. This month I turn 56, an age when my mother faced the triad of HD problems: chorea (uncontrollable movements), cognitive difficulties, and emotional and behavioral disorders.

As I watched her decline and ultimately die of HD in 2006, after nearly two decades of suffering, I never imagined that I would reach this stage symptom-free. At my recent, annual visit to my neurologist, she found no signs of the disease.

I have much to be thankful for. I savor every moment like a sip of fine wine.

Regina, an educator, just obtained her administrative certificate, which qualifies her to shift from teaching to a job as principal. Our beloved daughter Bianca, who tested negative in the womb, will *not* develop juvenile Huntington's. She's a hard-working high school student, choral singer, and field hockey player.

Still able to pursue my professional passions, I am writing a book on ex-revolutionaries in power in Brazil and advocating with the rest of the HD community for better care and the discovery of effective treatments.



The Serbin Family 2015 Holiday card (family photos)

A lonely holiday

However, I know that I am not in the clear. Because I carry the bad gene, I *will* develop HD.

As an advocate, each day I share in the suffering of other families hit with Huntington's.

This Christmas season, as I celebrate my family's accomplishments, it's lonely without my parents.

Because of HD, my mother could never really hold baby Bianca. HD took Carol's life when she was just 68, robbing her of the opportunity to watch Bianca grow into a young woman.

I can't share with my mom the success and many happy moments that she desired for me.

I also miss my father, the "HD warrior" who cared for Carol daily for more than a decade as her symptoms worsened and died with a broken heart three years after her death, in 2009.

Awaiting the gift of a cure

In 1995 we were so young, full of plans and hopes!

Huntington's disease took away our innocence. In those first months after learning of my mother's diagnosis, I began for the first time to comprehend mortality and the preciousness of time.

Because of HD, life became something very different from what I imagined it might be.

As I look back on the past 20 years, however, I recognize that for many, with or without HD, a smooth path cannot be predicted. And I recognize that life has brought me many good things.

Unlike my mother, who had no inkling that HD was ravaging her brain, I have had the chance to build a strategy to avoid onset and plan for the many social implications of the disease.

While my mother developed HD before the gene was even discovered in 1993, I live at a time when historic clinical trials might turn HD into a disease that can be managed like diabetes and other conditions.

This Christmas, as I commemorate the birth of Christ, I am thankful that my parents gave me the gift of life.

I look forward to a future holiday season when Huntington's disease families can rejoice in a cure.

Merry Christmas and Happy Holidays!

Gene Veritas at the San Diego shore (family photo)

Posted by Gene Veritas at 3:07 PM

Labels: behavioral , Brazil , California , Carol Serbin , chorea , Christmas , cognitive , cure , gene carrier , Gene Veritas , genetic defect , Huntington's disease , Kenneth P. Serbin , Paul Serbin , symptom-free , symptoms , treatments

4 comments:

Anonymous said...

Merry Christmas to you and your family. This blog is great. That you for it. May 2016 bring us a CURE!!!!!!

6:30 PM, December 20, 2015

Anonymous said...

Merry Christmas and Happy Birthday!!

5:58 AM, December 21, 2015

Anonymous said...

Thank you for posting this blog. My husband (55) has just begun showing symptoms of this devastating disease. Our four children are all at risk. 26 23 20 &16
We were never told about this disease until a dying Uncle told us-after I asked) what his mother had and he told us possibly Huntingtons Disease. Our lives changed forever that day. This holiday, i'm feeling so sorry for myself-- just thinking about what the future has in store for me- our family. Makes me sick that back in the day people were just so ignorant . The past generations called it the family curse. Out of my husbands siblings- three have HD out of four- my mother in law- two brothers all passed within the last 5 years from HD- last Great Aunt(out of 21 children) passed a few years ago (98) - she had some movements but not bad-not sure if she had it or not. Out of the cousins related to GG-mom who was the carrier (died in '95) my husbands siblings are the only ones we know of that were tested- one uncle has two daughters who are at risk (not sure if they were ever tested) the other uncle was never married or had children and the Uncle that died from cancer at age 68 was never tested but he could have been in the gray zone- his two children never had children- this disease has to stop.
We had my husband tested so our children can make smart decisions about their future and that their significant others are aware.

10:09 AM, December 21, 2015

Anonymous said...

Great blog post, as always. Thank you for advocating for us and sharing your story. You're so brave and inspiring.

Merry Christmas, happy new year and happy belated birthday!

I hope 2016 brings great advances in the fight against HD

4:54 AM, January 06, 2016

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