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Dreams for a better future: an opportunity we Huntington's disease people and our families are denied

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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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THURSDAY, SEPTEMBER 15, 2016

Dreams for a better future: an opportunity we Huntington's disease people and our families are denied

Because of its devastating medical and social impact, Huntington's disease often forces affected individuals and their families to abandon their dreams.

After learning of my mother's diagnosis for HD in 1995 and then testing positive for the deadly gene in 1999, I became aware of how the disease could damage family finances.

HD families not only lose the income of the affected individual; they also bear the costs of caring for that person, including nursing home fees. Sometimes the caregiver quits his or her own job in order to stay at home with the patient. Sometimes an exhausted caregiver even dies before the HD person.

Fearing such consequences, my wife Regina and I abandoned the idea of buying a retirement home in her native country of Brazil, in order to save more money to pay for my future care.

Our daughter tested negative for HD in the womb and is today a healthy 16-year-old. Unwilling to repeat the long and psychologically traumatic process of prenatal genetic testing, we decided to have no more children. That decision was especially painful for Regina.

Delving into the cause for a cure to save my deteriorating mother, I was compelled to add a new, fundamentally different dimension to my academic career: in addition to Brazilian history, I now also study the history of science, technology, and medicine. In this blog I have tracked the development of HD research, chronicled the HD cause as a social movement, and documented the new and harrowing human experience of living in the gray zone between a genetic test result and disease onset.

This new dimension has brought many rewards, but I often fantasize about what my career would be like if it weren't for HD.

A diversion and a trigger

Brazil, my research passion, became simultaneously a diversion from and a potential trigger of HD onset. I eagerly looked forward to the escape to the wondrous culture of Brazil during my summer research trips.

However, with both HD and my intellectual legacy on my mind, each spring I prepared feverishly for those trips, packing into my schedule as many research tasks as possible – including meetings with Brazilian Huntington's advocates. On the plane south, I worried about whether I was doing the best thing for my health. Relaxation and exercise in San Diego seemed more beneficial than living in hotels and eating restaurant food

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while exposing myself to the pollution and winter weather in the São Paulo megalopolis, where I did a lot of my work.

Facing HD, I couldn't help but wonder if each trip might be my last.

Going international

As I became more deeply involved in HD advocacy and this blog over the past ten years, I lost some passion for Brazil research.

My mother's death in 2006 figured heavily in that equation. As I watched her succumb to HD, I knew I would be the next to be stricken by the inevitable symptoms.

Research on Brazil sometimes seemed irrelevant. However, I kept at it, continuing a string of annual research visits stretching from 1986 to 2010, and again in 2013, 2015, and 2016. Today I consider myself bi-cultural, and my network of contacts in Brazil has made my HD advocacy international.

A new perspective

Lately, I've entered yet another stage of my journey with HD.

This year marked the tenth anniversary of my mother's death. With time, memories of her struggle have become less frightening.

At the same time, something more important has occurred: at 56, the age at which my mother had involuntary movements and was losing her cognitive abilities, I have yet to develop any of the classic, visible signs of HD.

Scientists are getting closer to explaining the reasons for different age of onset in people like my mother and me who have the same degree of genetic defect (click here to read more). Unlike my mother, I've had the advantage of knowing that I carry the gene. So I have cared for my health more conscientiously.

After testing positive at age 39, I was convinced that I would by now have symptoms that would prevent me from working and traveling to Brazil.

I have been extremely lucky. As a result, my perspective has changed. I feel more optimistic about life because of the wonderful blessing of health that I currently enjoy.

Also, while in 1995 there was a dearth of potential HD remedies, today researchers run clinical trials in the quest for remedies to alleviate HD and perhaps even make it a manageable disease, thus allowing people to lead normal lives.

Having gotten this far, and looking back on two decades of advocacy, I am also somewhat more at peace with the fact that HD will inevitably strike me.

I know I am fighting the good fight. Ultimately, I cannot control my fate.

Taking a break from the cause

I took a break this summer from the HD cause. I devoted much of it to working on a long-gestating book project on former revolutionaries in power in Brazil, including Dilma Rousseff, the president of Brazil impeached in March and removed from office on August 31 by a vote of the Brazilian Senate. To grasp this important moment in Brazilian history, I have immersed myself in the events, including watching live video.

I had started the research on this project shortly after learning of my mother's diagnosis. I had never imagined that at 56 I would still be able to write.

Focusing fully on Brazil again this summer, I felt in my element.

I *did* feel guilty this summer about not responding immediately to some requests for help from members of HD families.

However, I also recalled how many HD people give up on their dreams. I thought specifically of one asymptomatic gene carrier who decided to put advocacy aside and dedicate himself fully to a promising career.

"I have a right to self-fulfillment, too," I told my psychotherapist. "I have given up so much because of HD. I really want to finish my book on Brazil."

All HD-affected individuals and their families have the right to their own dreams!

That's what we in the HD community are fighting to restore.

A stark reminder of HD

The gravity of our struggle hit home again on September 13, when Laura Rivard, Ph.D., invited me to attend a screening of the HBO documentary *The Lion's Mouth Opens* in her course Ethical Issues in Genetics at the University of San Diego. (In a future article, I will explore HD and bioethics in the context of Dr. Rivard's course.)

The film portrays filmmaker-actress Marianna Palka's decision to test for HD. Before class, Dr. Rivard's students also watched a video of me, produced by one of her former students, in which I discuss my own experiences with genetic testing (click here to watch the video).

The scenes with HD people moving uncontrollably starkly reminded me of my mother – and once again of my own terrible burden as a gene carrier.

Our biggest dream: an effective treatment

After we watched Marianna learn from a geneticist that she carries the HD gene, I answered students' questions.

One asked: "Do days ever go by when you totally forget about your diagnosis, or is it always in the back of your mind?"

"It's almost always in the back of my mind," I responded.

However, I added: "I haven't blogged since May. This is one of the longest periods I've gone without blogging."

I explained that my Brazil book had priority over the summer.

"I've been able to put Huntington's disease aside for the first time in many years," I said. "It's really nice to wake up some days and think about Brazil instead of Huntington's disease."

After leaving Dr. Rivard's class, I remembered that the battle for treatments continues. It's a battle that we need to win.

Like others affected by HD, I don't want to become a financial and caregiving burden for my family. And like others, I want to experience the joys of family milestones, such as seeing my daughter graduate from college and start adult life without the worry of an incapacitated father.

An effective treatment will make that possible. Right now, that is our biggest dream.

Posted by Gene Veritas at 6:40 AM

Labels: advocacy , asymptomatic , Brazil , career , caregiver , clinical trials , death , diagnosis , financial burden , genetic defect , Huntington's disease , Laura Rivard , mother , onset , symptoms , The Lion's Mouth Opens , treatment

4 comments:

LabratJen said...

So glad to hear that you took some time to work on your personal, professional dream. Welcome back, I missed your updates. Fight on, HD Warrior!

5:45 AM, September 16, 2016

Anonymous said...

Feliz em tê-lo de volta. Você é uma luz que inspira muitas pessoas!

Sou um fã brasileiro, espero que um dia possamos comemorar a cura juntos!

Um abraço!

5:14 PM, September 22, 2016

Bev said...

I always enjoy and learn from your blog, and I am glad to see that you can take a much-deserved break from all the advocacy you do on our behalf.

9:02 AM, October 13, 2016

Anonymous said...

I am in nearly the same situation as the author of this blog. I am now 59 years old and will be 60 in Feburary. Huntington's Disease killed my father & half my family. My sister is dying now in an extremely horrible case where she is burning so many calories that she looks like a skeleton. I have actually had continual muscle contractions all my life since I was about 25 years old, but nothing else. I've been able to live my life and work and function normally (although, I never married or had children). I've wondered my entire life when it would happen to me. Now, at almost 60, I wonder if this is it, and this is all that will happen, and I wonder why. Why did it kill so many people in my family and not me?

I can't really imagine a more horrible experience in a family. I had a doctor once tell me that he had never seen a single person come out of a Huntington's family who wasn't emotionally damaged for life. He described it as a kind of "Life-long holocaust" where you live your entire life watching one persona after another die the most horrible deaths, and unlike the Jews,

you don't have anyone you can blame."

I have cried a few million tears in my life, but now approaching 60, I am able to see some things I could not have seen years ago. I look at myself and my family, and I realize that none of us are the people we would have been without this disease. We all became so much "more." We all learned to truly "see" people, to feel empathy with all people suffering, to appreciate all the small moments and the good things in life. We all embarked on a life-long journey to find meaning and to understand our place and purpose in this world. And, when I look around and see all the various kinds of suffering in this world, it makes me think that maybe this has always been the reason and the purpose for it--to cause us to become "more."

9:18 AM, October 25, 2016

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