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The return of the Huntington’s whirlwind

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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.

THURSDAY, FEBRUARY 28, 2013

The return of the Huntington’s whirlwind

In my quest to avoid the symptoms of Huntington’s disease and aid the search for treatments and a cure, I frequently struggle to cope with powerful feelings.

As I’ve written before, I constantly aim to keep a balance in my life between “striving” for the HD cause and “chilling” by enjoying the simple pleasures of life.

However, both the fear of symptoms – I tested positive for the HD gene in 1999 and at 53 have now passed my mother’s age of onset – and the excitement about the real hope for treatments sometimes provoke a whirlwind of emotions.

After a ten-week hiatus from this blog and most of my HD advocacy last summer, I took my advocacy to new heights starting in the fall. Since then, I’ve fought to keep a steady course as I’ve confronted both depressing and exhilarating feelings.

Recently, however, the sensation of being caught in a whirlwind has returned.

People keep dying

The people I meet through my advocacy regularly remind me of the terrible suffering inflicted by HD.

To be an HD advocate requires compassion – but also the ability to absorb great pain.

In preparing my recent article on HD and adoption, I interviewed two of my “HD sisters,” women in their mid-40s with about the same degree of genetic mutation as mine. I was startled to hear them describe how the onset of cognitive impairment has severely restricted their lives. I could not help but wonder how my own life as a college professor, HD advocate, husband, and father will be affected when my own inevitable symptoms start.

For my article on two HD activists, I delved into the wrenching story of Karli Mukka, a 13-year-old who died of juvenile HD. To see children who should be flourishing cruelly cut down by HD sends a spike into my heart.

“Oh, not another one!” I exclaim to myself when I read on Facebook about the death of yet another juvenile HD victim.

Seeing these fighters in our community go down makes me vow to redouble my efforts.

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Huntington's Disease Society of America
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Hereditary Disease Foundation
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HDSA Orange County (CA) Affiliate
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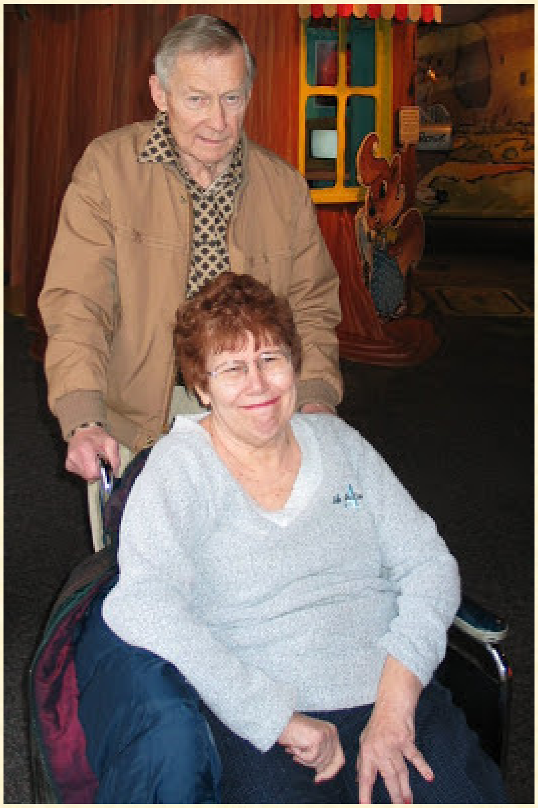
HD Blogs and Individuals

Chris Furbee: Huntingtons Dance
Angela F.: Surviving Huntington's?
Heather's Huntington's Disease Page

Such sadness seems unending. People keep dying of this horrible disease – with no treatments whatsoever to help them.

On February 13, along with the photo below, I posted the following about my own sadness on HD Facebook memorial and prayer pages:

Today marks the 7th anniversary of my mother Carol Serbin's death from HD. My father Paul, her "HD warrior caregiver," died three and a half years later. I miss them both terribly. I tested positive for HD in 1999. Our daughter tested negative in the womb. I had hoped treatments would come in time for my mother, but, sadly, they didn't. I continue as an HD advocate fighting to avoid onset and for the discovery of effective treatments.



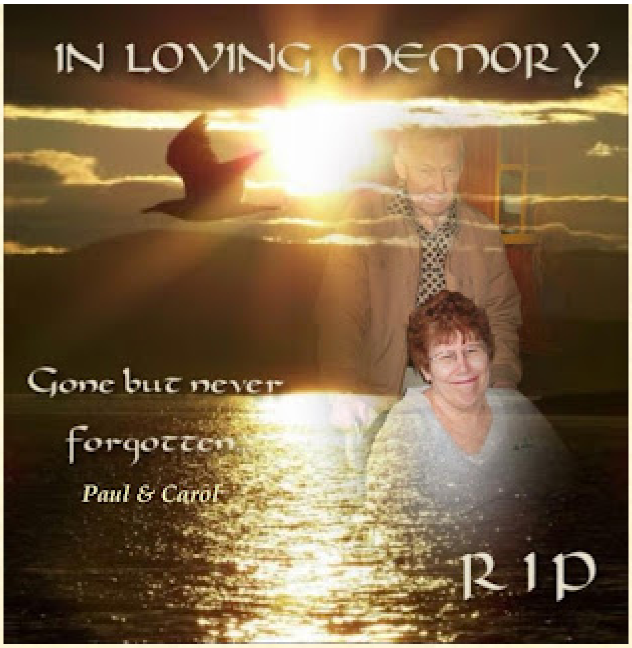
A tribute and a Valentine's gift

Solidarity has soothed the emotional pain.

The loving comments on my parents' photo from HD friends and acquaintances brought great comfort. Wrote one woman:

Look at the smile on your Mom. I have noticed that no matter how sick these people are, they manage to still smile. My daughter is one of them. Such brave people. Sending Hugs your way Gene, all the way from Canada.

I could not have imagined a more lovely tribute to my mom and dad than the artistic reinterpretation of my parents' photograph posted on the HD prayer page by Rebecca Rose, who lost an adult daughter to HD in 2009 and a 9-year-old granddaughter in January 2012.



On February 14, Valentine's Day, I received a wonderful gift from sports talk show host Chick Ludwig, a friend of some 35 years, who interviewed me during a segment about HD on his program on WONE radio in my home state of Ohio.

The joy and excitement of reconnecting with Chick in such a special way and sharing my story with a live radio audience left me overwhelmed.

Looking to the World Congress

Solidarity has also helped recharge my advocacy batteries

In response to the Portuguese version of my definitive coming-out article in the mainstream media, Paulo Vannuchi, a survivor of brutal torture during the Brazilian military dictatorship (1964-1985) and the country's minister of human rights from 2005-2010, wrote me a long and moving personal e-mail, pledging to support the cause in any way possible.

I was thrilled that a man with great political influence and a record of defending the disabled could help the HD cause in Brazil, my wife's homeland and my "second home" after nearly three decades of studying its history and people.

The world's fifth most populous country with nearly 200 million people, Brazil has an estimated 13,000-19,000 HD patients and 65,000-95,000 at risk of carrying the gene, making it a key player in the effort to globalize the search for treatments through the so-called Enroll-HD program.

Indeed, Rio de Janeiro, Brazil's second largest city, will host the 2013 World Congress on Huntington's Disease from September 15-18. I will speak in at the congress on the topic of coping with the knowledge of living with the mutant gene.

Paulo and I have begun to brainstorm how to raise the profile of the congress and awareness about the disease in Brazil, where the community is even more closeted than in the U.S. and whose Huntington's association has only minimal resources. (I will explore the reality of HD in Brazil in a future article.)

After 25 straight years of living in or visiting Brazil, I declined to travel there in 2011 and 2012. I'll spend a good part of this year planning a very special return: to attend the congress, my first ever HD event outside the

U.S., alongside other HD people in the land I love as much as my own. I'm very happy that I'm finally able to meld the professional and personal sides of my life with my advocacy.

However, planning for the trip could also cause anxiety. As a Brazil specialist, I feel an immense responsibility to help make the congress a success.

Managing feelings

As I once again negotiate the twists and turns of the HD whirlwind, I've worked extra hard to take care of myself emotionally.

Like a lot of guys, I'm often in denial when it comes to managing feelings.

I wrote in my blog notes:

You men out there: do you take care of your feelings? Do you take care of yourself? Are you always trying to be the hero? The problem-solver? Are you listening to what your spouse says about HD, taking into consideration her feelings?

Luckily, throughout most of my journey with HD I have had the support of a (female) psychotherapist, my "mind coach." I also take medication for depression and anxiety.

Joining an HD support group just one month after learning of my mother's diagnosis of HD in late 1995 was one of the most important things I've ever done.

Likewise, seeking psychological assistance has helped me deal with the numerous ups and downs of living at risk for Huntington's disease.

Keeping calm in a whirlwind is not easy. However, with friends, love, and support, we can keep forging ahead.

Posted by Gene Veritas at 9:51 PM

Labels: advocacy , anxiety , cognitive , cure , depression , disabled , Enroll-HD , feelings , gene , genetic , Huntington's disease , juvenile Huntington's , mother , mutation , psychotherapist , symptoms , tested positive , treatments

2 comments:

Lynnie Keathley said...

Such courage...thank you Gene.

12:28 AM, March 03, 2013

Anonymous said...

My dad has HD and we had no idea it was in my family was at risk until recently. My brother and I have children already. We are both in our 30s and can only hope the time bomb doesn't hit us. A whirlwind everyday...

12:25 PM, March 19, 2013

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