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'Crying a few million tears' for the fallen victims of Huntington's disease

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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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WEDNESDAY, NOVEMBER 09, 2016

'Crying a few million tears' for the fallen victims of Huntington's disease

Huntington's disease relentlessly attacks the brains of its victims and in other ways wearies many of us involved: advocates, caregivers, gene carriers like myself awaiting onset, young people pondering genetic testing.

Knowing at 56 how fortunate I am to have remained healthy beyond my deceased mother's age of onset, I took a "break" from advocacy over the summer. ([Click here](#) to read more [September 15 blog article]).

However, on October 24 the hard reality of HD hit home once again.

Responding to a request from the [Huntington's Disease Society of America](#) (HDSA) for information on this blog's impact in the "landscape of HD communication," that morning I wrote a long e-mail detailing how *At Risk for Huntington's Disease* has reached thousands of people via both the web and Facebook.

Since I began writing in January 2005, the blog's 230 articles have garnered more than 650,000 page views. More than 3,200 Facebook friends also have access to the blog in 60 HD-related groups.

"I think one of the most important aspects of the blog has been the wide range of topics it has covered: my family's struggles with the disease (mother dying, me testing positive, [my daughter] testing negative, etc.), the many social implications of the disease, advocacy issues, and the search for treatments," I observed.

Reviewing the blog's history reminded me of many painful moments in my struggle and of the HD community's collective suffering.

A nervous stumble

That afternoon, I had my annual HD checkup with a neurologist.

As with past checkups, in the hours before the visit, I became apprehensive about my performance on the various neurological tests.

One involves walking heel-to-toe along a straight line. This year I began that test with a bit of a nervous stumble. I wondered if that might be an early sign of onset.

I regained my balance and successfully completed the walk. I was going to suggest to the doctor that I repeat it, but she told me that I had done fine.

The other tests also went well.

Fortunately, she once again declared me symptom-free.

Tensing up at support group

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[HDSA Orange County \(CA\)](#)

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HD Blogs and Individuals

[Chris Furbee: Huntingtons
Dance](#)

[Angela F.: Surviving](#)

[Huntington's?](#)

[Heather's Huntington's
Disease Page](#)

Naturally, I felt greatly relieved.

However, I faced yet another challenging HD moment that evening: the annual research update at our local support group, from Jody Corey-Bloom, M.D., Ph.D., the director of the HDSA [Center of Excellence](#) for Family Services and Research at the University of California, San Diego.

Each year I record Dr. Corey-Bloom's talk, later posted here and on Facebook. Striving to produce a video of good quality, I tensed up as I focused in and out and turned the camera to follow Dr. Corey-Bloom's movements. This was vital information for the HD community.

With the rest of the audience, I intently listened to her presentation of the latest research breakthroughs and news of the crucial clinical trials that provide hope for effective treatments and perhaps even a cure. The update included a detailed discussion of the historic gene-silencing Phase I trial by Ionis Pharmaceuticals, Inc. ([Click here](#) to read more about the Ionis trial.)

Given the many projects in progress, Dr. Corey-Bloom spoke for 90 minutes, her longest update ever.

Seeing HD-affected support group attendees reminded me of my good fortune but also of the inevitability of my own onset, if a treatment isn't found.

You can watch Dr. Corey-Bloom's update in the video below.



Update on Huntington's Disease Research 2016: A Presentation by Dr. Jody Corey-Bloom

from [Gene Veritas](#)

1:32:31

[Update on Huntington's Disease Research 2016: A Presentation by Dr. Jody Corey-Bloom](#) from [Gene Veritas](#) on [Vimeo](#).

'A life-long Holocaust'

Still pondering the exhausting moments of October 24, the next morning I was jolted by a powerful comment on my September 15 article ["Dreams for a better future: an opportunity we Huntington's disease people and our families are denied."](#)

The words speak for themselves:

I am in nearly the same situation as the author of this blog. I am now 59 years old and will be 60 in February. 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 person 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."

These words not only rekindled my desire to defeat HD; most importantly, they also inspired compassion.

Sarah falls to HD

A diagnosis for Huntington's disease forever changes the lives of affected individuals and their families.

Without an effective treatment, thousands of people around the world continue to succumb to HD.

On October 17, Huntington's took the life of 37-year-old Sarah Brook of Tamworth, England.

Many in the HD community became familiar with Sarah's struggle on "[Sarah's Dream](#)," a Facebook page run by her mother Gail and stepfather Jeff. "Sarah's Dream" is also the name of a motorcycle the family used in the effort to raise funds and awareness. According to Gail, Sarah's first symptoms appeared in her early twenties. Sarah's father died of HD at the age of 35.

"This is the saddest time of my life," Gail wrote on Facebook. "Nothing could compare to the loss and heartbreak I feel. [...] It's the wrong way round, this shouldn't be happening. I can't bear the thought that I'll never see her again. I want to hold her so much."

Sarah's funeral took place on November 3. Her body was cremated.

"We've put her near the TV," Gail wrote of Sarah's ashes, held in an urn. "She's always liked her telly, and [we] will scatter them in the place she chose, when we feel ready.

Despite their enormous loss, Gail and Jeff will continue in the fight against HD.

"We've been married for 33 years and he adopted Sarah, knowing that she was at risk of HD," Gail wrote me in a Facebook message. "We have agreed to carry on with Sarah's Dream, in memory of Sarah."

We need to find a way to wipe away the tears of HD. Perhaps we can be heartened by the profound dedication to the cause displayed by Sarah's family.



Above, a collage of photos of Sarah Brook. Below, Jeff Brook riding Sarah's Dream (family photos).



Posted by [Gene Veritas](#) at 3:25 PM

Labels: [advocacy](#) , [awareness](#) , [blog](#) , [caregiver](#) , [cure](#) , [gene carrier](#) , [genetic](#) , [HDSA](#) , [Huntington's disease](#) , [Ionis Pharmaceuticals](#) , [Jody Corey-Bloom](#) , [neurologist](#) , [onset](#) , [research](#) , [Sarah Brook](#) , [support group](#) , [symptoms](#) , [treatments](#)

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