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One year out of the terrible, lonely Huntington's disease closet

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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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MONDAY, NOVEMBER 04, 2013

One year out of the terrible, lonely Huntington's disease closet

Today marks one year since I definitively exited the terrible and lonely Huntington's disease closet.

On November 4, 2013, my article "Racing Against the Genetic Clock" appeared online in the *The Chronicle of Higher Education*, the first time I shared my story in a mainstream publication ([click here](#) to read the article). It was also published in the November 9, 2013 print edition.

By revealing publicly that Gene Veritas was Professor Kenneth P. Serbin, a historian who specializes in Brazil, I took one of the most important steps in my 15-plus years of HD advocacy.

I no longer hid the potentially devastating truth about my genes: I carry the mutation for Huntington's and will inevitably develop its deadly symptoms.

After guarding the secret of my risk for HD ever since my mother's diagnosis in late 1995, I could fully engage in the battle against, as I wrote, "the stigma and fear surrounding Huntington's and other neurological disorders. In so doing, I also hope to help galvanize increased support for brain research."

I also could finally begin to integrate my academic career with my HD advocacy and my growing, profound interest in the history of science, technology, and medicine.



Gene Veritas (aka Kenneth P. Serbin) (photo by Bianca Serbin)

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Over the past year, I have made important strides in my advocacy.

With the publication of my family's story, many people within my circle of friends and professional colleagues learned in detail about the challenges posed by orphan and genetic diseases, not just the symptoms but the serious social implications.

For the first time, I publicly raised funds for the cause, bringing in more than \$16,000 to the [Serbin Family Team](#) at the April 14 [Team Hope Walk](#) of the San Diego Chapter of the Huntington's Disease Society of America (HDSA).

At the [University of San Diego](#) (USD), my employer, I spoke openly about Huntington's disease. Through colleagues I even learned of other families in the area facing the risk of HD. ([Click here](#) to read the feature story on me and my family on the university's website.)

In the spring, I participated in the first meeting of faculty members aiming to establish an undergraduate concentration in medical ethics. I've also discussed HD and genetic testing with a USD biologist studying the [ethical dilemmas raised by genetic practices](#).

The highlight of my academic work this year took place at the World Congress on Huntington's Disease from September 15-18 in Rio de Janeiro, Brazil. I gave a presentation on coping with HD. I also [reported on the event](#) and posted more than [30 videos](#) I had shot. In São Paulo, on September 21, I delivered a speech on HD and bioethics.

As I [wrote](#), "I felt vindicated in my decision to go fully public about HD ... and meld my professional and personal lives with my advocacy."

Concern about health care

On October 16, as the U.S. Congress voted to end the two-week government shutdown resulting from Tea Party Republicans' attempt to block Obamacare, I published a blog article describing how I had revealed my gene-carrier status to my health plan.

At the suggestion of one of the leaders of the HD movement, I sent a copy of my article to Speaker of the House John Boehner, who has dueled politically with President Barack Obama over the Affordable Care Act.

"I am dismayed at how the national debate over health care has taken an unhealthy and highly unproductive turn," I wrote to Boehner. "Having seen my mother succumb to Huntington's disease, and facing the threat of that disease myself, I have witnessed firsthand, and experienced, the terrible drama of our inadequate system of care for people with neurological and other disorders that carry a large stigma.... Please do your utmost to bring better care for all Americans and create a more productive national dialogue." (So far I haven't gotten a response.)

On October 20, the Brazilian newspaper *O Estado de S. Paulo* published a Portuguese-language opinion piece by me discussing my message to Boehner and the embarrassing behavior of the U.S. political leadership. I wrote that citizens like me were anxious to see the country get back on track with its economy and health care system.

A scholar-advocate

Last night, I spoke to a good friend and long-time professional colleague who provided frequent support over the past two-and-a-half years as I prepared to make my definitive exit from the HD closet.

"Tomorrow is the first anniversary of my article in the *Chronicle*," I told him.

“Are you glad you did it?” he asked.

“Of course!” I responded.

“And the sky didn’t fall!” he rejoined.

Indeed, the days of the terrible and lonely HD closet are now in my past.

The memories, however, are still fresh. And when the nation debates health care as it did again recently during the shutdown, I fear a return to that painful period of my life in which I felt compelled to hide the threat of HD.

I also know that thousands of HD families around the world remain in the HD closet – because of lack of knowledge about the disease, stigma, fear, and the devastating symptoms.

I now refer to myself as a “scholar-advocate.”

Very soon I plan to even better integrate my identity, setting up an e-mail signature with both my real name and pseudonym and links to HDSA, my blog, and my *Chronicle* article.

With this new dual public identity, I will forge ahead as I seek to promote collaboration in the HD community, greater awareness about the disease and its many challenges, and an end to the fear of sharing our stories.

Posted by [Gene Veritas](#) at [8:29 AM](#)      

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1 comment:

 **Jimmy Pollard said...**

Happy outaversary, Gene!!!! Well done, Ken!!! Keep on keepin' on!!!

Jimmy Pollard

[12:26 PM, November 04, 2013](#)

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