

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

11-4-2012

The definitive step out of the Huntington's closet

Kenneth P. Serbin
University of San Diego

Follow this and additional works at: <https://digital.sandiego.edu/huntingtons>



Part of the [Nervous System Diseases Commons](#)

Digital USD Citation

Serbin, Kenneth P., "The definitive step out of the Huntington's closet" (2012). *At Risk for Huntington's Disease*. 137.

<https://digital.sandiego.edu/huntingtons/137>

This Blog Post is brought to you for free and open access by the Department of History at Digital USD. It has been accepted for inclusion in At Risk for Huntington's Disease by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.

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.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▼ 2012 (26)
 - ▶ December (2)
 - ▼ November (3)
 - [HDSA's renewed commitment to critical research](#)
 - [Designing the best drug possible to defeat Hunting...](#)
 - [The definitive step out of the Huntington's closet](#)
 - ▶ October (1)
 - ▶ September (2)
 - ▶ August (2)
 - ▶ June (2)
 - ▶ May (1)
 - ▶ April (2)
 - ▶ March (3)
 - ▶ February (3)
 - ▶ January (5)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me

 [GENE VERITAS](#)

[View my complete profile](#)

SUNDAY, NOVEMBER 04, 2012

The definitive step out of the Huntington's closet

Today I take my most definitive step out of the terrible and lonely "Huntington's closet": using my real name, I have published an article about my struggle against HD in a mainstream media outlet.

Titled "Racing Against the Genetic Clock: A historian carrying the gene for Huntington's disease hopes to galvanize increased support for brain research," the article appears in today's online edition of *The Chronicle of Higher Education*. It will also appear in the November 9 print edition.

"Scholars often shift focus over the course of a career to pursue a discovery, a new job, or a need for variety," begins the article, which explains my exploration of the history of science as a way to expand both my advocacy and career. "For me, it was learning that I will, at some point, develop a terrifying, untreatable, fatal brain disorder."

With great sadness, I wrote of my mother's demise, the discovery that I had inherited the HD gene from her, and my ongoing advocacy to raise awareness and increase funding for research towards treatments.

"At 52, I have reached my mother's age of onset," I conclude. "I cherish each moment of health. As I contemplate my intellectual legacy, I encourage others to join the race to protect our most important natural resource – our brains – and strive for a world in which science conquers disease."

You can read the full article by [clicking here](#).

For the public, and in my professional circles, I willingly share that that Gene Veritas is Kenneth P. Serbin. I will still write this blog as "Gene Veritas" (the "truth in my genes"), my trademark in the HD world, the persona that in many ways symbolizes the struggles of our community and, indeed, *all* disease-gene carriers.

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.](#)



Gene Veritas, aka Kenneth P. Serbin, at Alnylam Pharmaceuticals in 2011.

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

An arduous and painful transition

I had hid in the HD closet ever since my mother's diagnosis in late 1995.

Many times I wanted to shout out to the world about my mom's terrible downfall and my own potentially frightening future with the disease, but, fearful of genetic discrimination, I always kept quiet, swallowing my difficult feelings about HD.

In 2010, however, after the passage of federal health care and anti-genetic discrimination legislation, I started making public speeches about my predicament.

My gradual exit from the HD closet has proved arduous and painful.

On October 25, the day I received the news of my article's acceptance for publication, and for a few days thereafter, I felt especially overwhelmed and apprehensive.

I thought of how tens of thousands of *Chronicle* subscribers will have access to my article, and many more people may read it by simply viewing it for free on the publication's website.

Above all, I worried about how to tell my co-workers and superiors. With the *Chronicle* article, I will be deliberately demolishing the near-perfect firewall that I painstakingly constructed between my professional life and HD advocacy.

Some may be shocked to learn of this hidden dimension of my life, and they will likely worry about me, too.

Luckily, when I inform them about the article, I'll also tell them that my latest checkup with my neurologist, on October 30, ended with a clean bill of health on the HD front. I'm not *required* to do so, but, after revealing the terrible symptoms I could suffer, I also want them to know of my success so far in remaining asymptomatic ([click here](#) to read more).

Controlling my own story

In the last few days, however, I achieved a sense of calm, and, in the final hours before the publication, even a bit of jubilation.

I've been able to rely on my wife, close friends, and members of the HD Facebook community for moral support.

In anticipation of the article's appearance, I actively sought their advice about how to reveal the article to my colleagues. They've all helped me put this moment in perspective.

For those who advised against coming out, I've described the *Chronicle* piece as a "preemptive strike." Rather than let others learn about my HD status by stumbling upon it on the Internet, hearing through the rumor mill, or becoming aware only when my symptoms start, I am taking the initiative to "control the narrative of my own story" about HD.

This approach provides me with the opportunity to properly educate friends and colleagues about HD and perhaps even build a support network to assist me should I become disabled.

Feeling lighter

Although this definitive step out of the closet remains a momentous event for me, I have come to see it as an opportunity to expand the Huntington's cause and to help defeat the very stigma of HD that originally sent me fleeing into the closet.

I will also feel immense relief and joy at being able to talk openly about HD at any time and with any person.

In discussing the *Chronicle* piece with a close professional colleague and friend the other day, I was thankful to hear his prediction that this experience, fraught with so much doubt about the balance between advocacy and privacy, would ultimately bring me closer to my wife.

Indeed, far too much of our energy has gone into insulating ourselves instead of reaching out for the support we need on a personal level and in terms of the cause.

I nearly cried after my friend assured me that I would feel an immense burden lifted from my shoulders.

"You're going to feel lighter," he said with confidence.

Amen to that!

I know the road ahead is unpredictable, and that I will feel many things besides lighter, but for now, I'm just glad I can tell people how I'm racing against the genetic clock.

(I dedicate this article to the memory of my mother Carol Serbin, who died on February 13, 2006, after a long battle against HD, and of my father Paul Serbin, the "HD warrior" who tirelessly cared for her for more than ten years and who died with a broken heart on September 25, 2009. I know my parents would have been proud of my *Chronicle* article.)

Posted by [Gene Veritas](#) at 7:59 PM      

Labels: [advocacy](#) , [asymptomatic](#) , [brain](#) , [closet](#) , [coming out](#) , [disabled](#) , [genetic clock](#) , [Huntington's](#) , [mother](#) , [neurologist](#) , [research](#) , [science](#) , [stigma](#) , [symptoms](#) , [treatments](#) , [wife](#)

3 comments:

 **Anonymous said...**

Greetings from Romania and we all hope that cure will come fast! Keep up the good works!

[2:44 AM, November 05, 2012](#)



Jamie Reno said...

I am really proud to know you, Ken.

[10:47 AM, November 17, 2012](#)

Anonymous said...

Thank you Gene for your good work. Your blog is like being with a good friend who provides both hope and information about H.D.

[8:27 AM, November 23, 2012](#)

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

Subscribe to: [Post Comments \(Atom\)](#)
