

University of San Diego

Digital USD

---

At Risk for Huntington's Disease

Department of History

---

11-21-2018

## This Thanksgiving, appreciating stable health and new plans for Huntington's disease advocacy

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., "This Thanksgiving, appreciating stable health and new plans for Huntington's disease advocacy" (2018). *At Risk for Huntington's Disease*. 260.

<https://digital.sandiego.edu/huntingtons/260>

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](mailto:digital@sandiego.edu).

More

[Create Blog](#) [Sign In](#)

# 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)
  - ▶ December (2)
  - ▼ November (2)
    - [This Thanksgiving, appreciating stable health and ...](#)
    - [Roche announces first sites for key Huntington's d...](#)
  - ▶ September (2)
  - ▶ July (1)
  - ▶ May (1)
  - ▶ April (2)
  - ▶ March (3)
  - ▶ February (3)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

## About Me

 GENE VERITAS

[View my complete profile](#)

## HD Links

[Huntington's Disease Society of America](#)  
[International Huntington Association](#)

WEDNESDAY, NOVEMBER 21, 2018

## This Thanksgiving, appreciating stable health and new plans for Huntington's disease advocacy

This Thanksgiving, I am especially grateful for good health – and all that it enables me to enjoy.

At my annual neurology checkup on October 31, the doctor told me that I remain asymptomatic for Huntington's disease. My more extensive annual Enroll-HD examination earlier in the year also showed no symptoms.

I tested positive for the HD gene in 1999. Next month, I turn 59. At that age, my mother had already been diagnosed and was rapidly losing the ability to walk, talk, and care for herself. She died in 2006 at the age of 68 after a long struggle.

I never imagined that at this point I could still pursue my passion for writing, teach at the university, and support my family.

As I frequently tell students, colleagues, and my family, “health is first.” Without it, achieving goals and handling responsibilities can become very difficult, if not impossible.

### Studying the history of the HD cause

I am putting the final touches on a book in my field of Brazilian history, scheduled to be published next June, *From Revolution to Power in Brazil: How Radical Leftists Embraced Capitalism and Struggled with Power*. I began the research more than two decades ago, not long after learning of my mother's HD diagnosis. Seeing the project come to fruition is thrilling and profoundly fulfilling.

With the Brazil project complete, I will carry out my long-gestating plan to shift my main scholarly focus to the history of science, technology, and medicine. Last month I proposed a new, multi-year research project, titled “Racing Against the Genetic Clock: A Social, Scientific, and Personal History of the Huntington's Disease Movement.”

I aim to study how key facets of the movement intertwined with major developments in the biotechnological and medical revolutions of the past 200 years. I believe that the HD cause can serve as a guidepost for other disease communities and inform key bioethical questions related to them.

I also want to help the HD community reflect on its path through history.

More than ever, my scholarly work and HD advocacy will meld. ([Click here](#) to read more.)

### Seeing our daughter enter college

[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.](#)

## HD Blogs and Individuals

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

On a personal level, good health allowed me to join my wife Regina last August in helping our [HD-free daughter Bianca](#) set up for her first semester at the [University of Pennsylvania](#), where she is studying in its College of Arts and Sciences.

I had always feared that HD would prevent me from experiencing this special moment – just as HD had stopped my mother from interacting with Bianca as a baby and young child.

I am more determined than ever to see Bianca graduate from college and find her way in life. I'm hoping that [GENERATION HD1](#), the historic Roche Phase 3 clinical trial of a gene-silencing HD drug, will result in an effective treatment not only for patients, but as a preventive measure for presymptomatic gene carriers like me. Roche hopes to enroll the first volunteers starting in early 2019.

Looking ahead, I hope to retire on my own timeline – not because of HD.



*Regina, Bianca, and Kenneth Serbin (aka Gene Veritas) during Penn Family Weekend, October 21, 2018 (family photo)*

### The preciousness of life

I've been extremely fortunate to reach this point without HD symptoms—or other significant health problems. Many HD brothers and sisters of my generation are struggling with symptoms.

Like so many in HD families and other difficult situations, I've learned to value each moment of life.

Others face different health issues. At this time last year, I lost two wonderful friends about my age, generous supporters of the HD cause, taken quickly and unexpectedly by other conditions. I've missed them dearly, and think about them daily as a reminder of the preciousness of life.

Tomorrow, I want to enjoy Thanksgiving.

God and nature willing, I'll awake the next day ready to love my family, continue the fight to defeat HD, and dream of a day when a cure frees me to assist people less fortunate.

Happy Thanksgiving! And the best of health for you and yours.

Posted by [Gene Veritas](#) at [12:03 PM](#)      

Labels: [asymptomatic](#) , [clinical trial](#) , [diagnosis](#) , [Enroll-HD](#) , [gene carrier](#) , [gene-silencing](#) , [GENERATION HD1](#) , [genetic clock](#) , [health](#) , [Huntington's disease](#) , [presymptomatic](#) , [Roche](#) , [symptoms](#) , [Thanksgiving](#) , [treatments](#)

No comments:

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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

---