

University of San Diego

Digital USD

---

At Risk for Huntington's Disease

Department of History

---

10-21-2011

## Huntington's disease and the financial jitters

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., "Huntington's disease and the financial jitters" (2011). *At Risk for Huntington's Disease*. 108.

<https://digital.sandiego.edu/huntingtons/108>

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).

# 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)
- ▼ 2011 (33)
  - ▶ December (2)
  - ▶ November (4)
  - ▼ October (4)
    - [Huntington's disease in the news and entertainment...](#)
    - [Huntington's disease and the financial jitters](#)
    - [BDNF and 'Neurobics': building a 'beautiful mind' ...](#)
    - [Making sense of Huntington's organizations, and a ...](#)
  - ▶ September (2)
  - ▶ August (1)
  - ▶ July (2)
  - ▶ June (2)
  - ▶ May (4)
  - ▶ April (4)
  - ▶ March (3)
  - ▶ February (3)
  - ▶ January (2)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

FRIDAY, OCTOBER 21, 2011

## Huntington's disease and the financial jitters

As I've written before, living with the deadly gene for Huntington's disease is like [a high-wire act](#). Fearful that HD's terrible symptoms could start any time, I walk the tightrope while juggling job, family, HD advocacy and, along with my wife, our finances.

As I have described in a number of articles since beginning this blog in January 2005, [HD is a killer of dreams](#). Although the threat of HD has caused me to grow in many ways and to enjoy life more fully, it has also led us to abandon many plans, including having a second child after we went through the trauma of testing our first baby in the womb. (She tested negative and today is a healthy eleven-year-old.)

If it weren't for the specter of HD, which took my mother's life in 2006, [I could have advanced much further in my career](#). My wife and I could focus on saving for retirement rather than building up an "HD war chest" to compensate for the deep losses in income expected after the onset of symptoms forces me to stop working in the near future.

I'm almost 52, the age at which my mom already had symptoms.

### Turning the crisis to our favor

The fear of HD has caused us to fret about our finances. We agonize over big purchases, and even bigger decisions such as refinancing our home turn into weeks- and even months-long discussions.

Our fears increased greatly in the recession that began in late 2007 and got much worse in 2008.

Like many Americans, we were reeling from the stock market crash, which eroded our savings. We were stunned at both the enormity of the crisis and the massive stimulus program, financed with borrowing from foreign sources.


But, hopeful about a recovery, we sought to turn the short-term crisis to our long-term advantage.

In 2009, during the early months of the administration of President Barack Obama, we took advantage of extremely low interest rates to refinance the mortgage, taking out extra money to build a swimming pool and carry out other home improvements. (I jokingly referred to the project as the "Obama stimulus pool.") The risk was well worth it: the huge savings from the lower interest rate made the pool affordable, and I [took up swimming again](#) to bolster my brain against HD onset.

### Economic pain

In a state with a [real unemployment rate of more than 20 percent](#), we were thankful to have jobs.

## About Me

 GENE VERITAS

[View my complete profile](#)

## 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.](#)

## HD Blogs and Individuals

[Chris Furbee: Huntingtons](#)

[Dance](#)

[Angela F.: Surviving](#)

[Huntington's?](#)

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

However, we started to feel the economic pain not long after we took our first swim in the pool. For the first time in nearly two decades as a university professor, I received no raise during the 2009-2010 academic year. The next year my wife, a teacher in the San Diego school district, took a 3.7 percent pay cut that remains in effect. Like many others facing pay freezes and cuts, we're also paying more for benefits.

To compensate for the lost pay, the school district cut five days off the school year and cut hundreds of millions of dollars from its budget. Now, with California sinking ever deeper into crisis and forcing additional school cuts of tens of millions of dollars, the San Diego district leadership may cancel even more classes. Last week, the superintendent declared that the district might need to declare itself insolvent. Teachers will likely face further salary cuts.

As we feared yet another drop in family income, my wife and I also worried about the quality of education our daughter is receiving in the public schools. We quickly became frustrated with the middle school that she entered in September. Class sizes are large (36 per class), and the school does not offer placement tests to ensure that all students have access to the proper level of instruction. It offers only a few honors sections.

Frustrated and convinced that the school crisis will last for many years, my wife and I decided that our daughter will apply to private schools.

### Extending beyond our reach?

Annual tuition and other expenses at these schools could cost as much as \$30,000. To afford it, we would need to forfeit all saving for retirement – the biggest portion of our HD war chest. Because we put pre-tax dollars into retirement, every dollar we stopped saving would be taxed at about a third. That would make the real cost of the most expensive private school closer to \$40,000.

That was getting well beyond our reach, especially when we also need to save for our daughter's college expenses.

Once again, we decided to refinance our mortgage in order to borrow enough money to pay for about half the cost of six years of private school (grades 7 through 12).

Because we refinanced for the pool, this time we must max out on the mortgage: we will be borrowing about 75 percent of the value of the home. We bought the house in 1999 and saw its value more than double during the real estate boom of the early to mid-2000s. Even in today's depressed market, it's still worth about two thirds more than the original price, thus allowing us to take out substantial cash upon refinancing.

In addition, interest rates have dropped to near historic lows. We'll have a rate below 4 percent – a bargain when compared to forfeiting saving for retirement and the HD war chest.

### Risk exposure

Nevertheless, unlike the pool project, this round of refinancing has left me with the jitters. Taking out such a big loan, with a mortgage payment of hundreds of dollars more per month, conjures up memories of how little disposable income we had after our first property purchase in 1994. That was *before* we learned that my mom had HD.

The future of our economy seems even more uncertain than it did in 2009.

And I worry about exposing the family to too much financial risk precisely as I progress towards the probable onset of HD.

In fact, as I write this article, it seems like sheer lunacy!

How will we pay for private school and a bigger mortgage, save for our daughter's college and our retirement, build the HD war chest, and run the household if I must go on state long-term disability, which would pay, at most, only 65 percent of my salary (this income, at least, would be tax-free) and run out after age 65? I might be able to supplement disability with Social Security and Medicare benefits, but, as I wrote earlier this year, [HD people struggle to obtain, and are sometimes even denied, those benefits.](#)

### Helping while I can

It's a huge gamble – but one that we feel we must take.

It only makes sense when I remember that we are providing for one of the best investments in our daughter's future: an excellent education.







Born HD-negative, she was our “miracle baby.”

But she is no longer that baby. She stands on the verge of adolescence – and is now only five years away from filling out her college applications.

She is HD-free, but could still feel the disease's impact because of the stark possibility that I could become disabled and therefore less able to support her during her high school and college years

I desperately await news of the key research breakthrough that will save me from the dementia and other devastating symptoms of HD. I want to see my daughter graduate from college and build a life of her own.

If HD prevents me from enjoying those moments, I will at least have done my part to help her get there while I could still help.

Posted by [Gene Veritas](#) at [10:30 AM](#)      

Labels: [brain](#) , [daughter](#) , [dementia](#) , [disability](#) , [gene](#) , [HD war chest](#) , [HD-negative](#) , [Huntington's](#) , [Medicare](#) , [mother](#) , [Obama](#) , [onset](#) , [research](#) , [Social Security](#) , [swimming](#) , [symptoms](#) , [tested negative](#) , [testing](#) , [wife](#)

No comments:

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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