

University of San Diego

Digital USD

---

At Risk for Huntington's Disease

Department of History

---

5-16-2013

## Memories of genetic testing: from my mom to Angelina Jolie

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., "Memories of genetic testing: from my mom to Angelina Jolie" (2013). *At Risk for Huntington's Disease*. 153.

<https://digital.sandiego.edu/huntingtons/153>

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@san Diego.edu](mailto:digital@san Diego.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)
  - ▶ December (3)
  - ▶ November (3)
  - ▶ October (3)
  - ▶ September (3)
  - ▶ August (2)
  - ▶ July (1)
  - ▶ June (1)
  - ▼ May (3)
    - [Strangling of patient in nursing home a shuddering...](#)
    - [Do we need to shock the world to strengthen the Hu...](#)
    - [Memories of genetic testing: from my mom to Angeli...](#)
  - ▶ April (4)
  - ▶ March (2)
  - ▶ February (3)
  - ▶ January (2)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

## About Me

 GENE VERITAS

[View my complete profile](#)

THURSDAY, MAY 16, 2013

## Memories of genetic testing: from my mom to Angelina Jolie

My family's experiences with genetic testing for Huntington' disease rarely stray from my daily thoughts.

The day after Christmas in 1995, I learned that my mother had tested positive for HD, a condition I had never heard of. The devastating news that she was afflicted with an untreatable, fatal disorder set me on a quest to learn all I could about it and help find a cure.

In June 1999, I tested for HD primarily because my wife and I wanted to start a family. Sadly, I was gene-positive. That information changed my life forever, altering my career path and thrusting me into a [race against my own genetic clock](#) – and for the cure.

In January 2000, our daughter tested negative in the womb – one of the happiest moments of our lives. Now, as she enters the teen years and becomes independent, I realize how our decision to test her 13 years ago has liberated her and us from ever having to worry about HD affecting her or her own potential children.

Lately, I've been reliving the powerful emotions of those three experiences and reflecting on how genetic testing has both provided important life-planning tools for HD families and forced them to make the kinds of difficult decisions I have made.

When I read in an HD Facebook group about someone who has tested negative, I at first become extremely jealous and even a bit angry. Then I feel relief for that individual and his or her family and send on a note of congratulations.

When I see news of a positive test, I feel the need to offer comfort and encouragement – and to redouble my advocacy efforts.

### Don't rush, sit with your emotions

An instructive lesson on the promise and perils of genetic testing came in the presentation by genetic counselor Lauren Dennis on "HD and Genetic Counseling" at the February 25 San Diego-area support group meeting.

"Basically we're giving you a yes or no to a situation where there's no cure," Lauren said as she started her overview of the counseling and protocols involved in the testing process. "We're really looking into that crystal ball to give you that information. Once you have that information, there's no going back. We want to make sure that you're in a good place to get that information and be able to cope with it."

This approach stems in large part from the risk of suicide associated with HD testing, Lauren explained.

## 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](#)

Among many key points, she emphasized that individuals should not rush into testing.

“We don’t want this to be an impulsive decision,” she said. “Sometimes people pick up that phone and call us: ‘Gosh, I just learned that Huntington’s disease was in my family last week.’”

Such people sometimes want to test immediately, she said.

That scenario starkly reminded me of my own wish to undergo testing right after learning of my mother’s test and diagnosis for HD.

However, as I learned then, and as Lauren explained during her presentation, counselors often ask people like me to first learn more about the disease and the need to plan regarding potential issues like insurance coverage, career, and family planning

“You really need to sit with the emotions and the idea of what that result would mean for you and how it will impact your life,” she continued, referring to the required one-month wait between submitting the DNA sample from a cheek swab and obtaining the results. “You need time to do that.”

### Limitations

As I listened to Lauren’s presentation and the subsequent Q&A session, I recalled the many other facets of my family’s experiences with testing.

Lauren explained that each individual or family seeking counseling is unique, so advice is offered on a “case-by-case basis.”

Ultimately, genetic testing is only the start of a family’s journey with HD, she concluded.

“That’s a huge limitation of genetic testing,” she said. “We can give you the yes or the no. We can’t tell you the when. We can’t tell you what age. We can kind of gauge from the family history – it might be similar.... We can’t tell you where, exactly what symptoms you’re going to have, or how severe they will be or how long your progression will be. That is a limitation. We don’t have *that* magic crystal ball.”

Lauren’s presentation is an excellent introduction to testing for any HD family interested in learning more about the process. You can watch it in its entirety in the video below.



### Huntington's Disease and Genetic Counseling: A Presentation by Laurer Dennis

from [Gene Veritas](#)

35:04

### **New meaning**

In definitively exiting the terrible and lonely “HD closet” over the past six months, the history of my family’s three HD tests has taken on new meaning.

As an HD advocate and historian, I’ve always had concern about the impact of genetic testing on society in general.

Now, after my employer, the University of San Diego, published an official [website article](#) on March 1 about my journey with HD, I’ve begun to implement my long-desired plan to more formally explore the history of science, technology, and medicine and link with university programs relevant to that area and HD research.

Recently I met with faculty members in charge of the university’s brand new neuroscience major. This is a hot field. Projected to take in 20 students its inaugural year, the program has already attracted some 100 students interested in the major.

In a couple years, after some careful planning and lots of research, I hope to teach a course on the history of the brain, which would be highly useful for neuroscience students. Also, as chair of my department, I am helping to lead the search for a new faculty member in the history of science, technology, and medicine who could potentially build additional bridges to neuroscience and many other campus programs situated in one of the world’s leading biotech hubs.

### **Medical ethics**

Last month, the university [posted an article](#) about a new student-designed website, [Genetics Generation](#), that aims to provide impartial information about genetics and engage the general public in conversations about genetics and ethics.

One of the site’s ethics case studies, titled “Huntington’s Disease and Personal Autonomy,” is like a page ripped out of my family’s story: a young, gene-positive man and his wife want to test their unborn child for the HD mutation.

However, unlike our story, this hypothetical couple encounters hesitation from their doctor, who counsels against obtaining information for a condition that may not affect the child until adulthood.

The case study ends with a reader’s poll: “if you were the doctor, what would you decide?”

[Click here](#) to read the entire case study and to register your vote.

I contacted the biology professor, Dr. Laura Rivard. The students produced the website as part of her course, Ethical Issues in Genetics. Our e-mail conversation led to an invitation for me to participate in a planning meeting for a new, multidisciplinary academic concentration in medical ethics.

As the healthcare and biotech industries continue to grow, the concentration would provide students with urgently needed perspective and reflection on matters such as the transformation of the healthcare system and issues in genetics.

I will join future planning sessions and offer my expertise on HD wherever it might be useful to students and fellow faculty.

Building these larger connections via my work as a professor will help me extend my HD advocacy to new spheres and highlight HD's pioneering role in genetic testing and genetics research.

### Walking in another's genetic shoes

This past week the often terrible impact of genetic testing hit home once again as I heard the news that world-famous actress Angelina Jolie had revealed in *The New York Times* that she had undergone a preventive double mastectomy because she had tested positive for BRCA1, which sharply increases the risk of breast cancer and ovarian cancer.

I imagined how difficult it must have been to have received the news of her test, but I also felt relieved to know that medicine has found a way to reduce the risks for Jolie and myriads of others threatened with the possibility of breast cancer.

"My chances of developing breast cancer have dropped from 87 percent to under 5 percent," Jolie, whose mother died of the cancer at the age of 56, wrote. "I can tell my children that they don't need to fear that they will lose me to breast cancer."

For some, the option of the double mastectomy might seem extreme, and, as commentators on Jolie's situation noted, other approaches to combatting breast cancer do exist.

However, people should not judge Jolie. She made the best decision for *her*. Nobody can fully comprehend her decision until walking in her genetic shoes.

Likewise, nobody should judge HD families faced with the extremely difficult issues surrounding genetic testing and procreation.

### Hoping for prevention

The minute I heard the report on Jolie, I thought of my own test – and the fact that for the HD community no preventive procedure or treatment exists.

Sometimes, HD-affected individuals, gene-positive people like me, and caregivers feel like jumping at a radical solution. We do so because of hopelessness.

My chances of HD onset are 100%. To reduce that by even half would be fantastic. To reduce it to 5 percent would be a miracle.

With the rest of the HD community, I'm rooting for the current and upcoming clinical trials aimed at testing approaches such as gene therapy, which could potentially halt, reverse, and maybe even prevent symptoms.

*(May is HD Awareness Month! Learn more about the cause and donate by visiting the site of the [Huntington's Disease Society of America](#).)*

Posted by [Gene Veritas](#) at 10:43 PM      

Labels: [CAG repeats](#) , [coping skills](#) , [cure](#) , [DNA](#) , [emotions](#) , [family planning](#) , [genetic clock](#) , [genetic counseling](#) , [genetic testing](#) , [Huntington's disease](#) , [Lauren Dennis](#) , [preimplantation genetic diagnosis](#) , [suicide](#) , [untreatable](#)

3 comments:



**Unknown said...**

I'm so pleased to see that your "emergence" from the HD closet has allowed you to take a more active role in advocating for

disease awareness and ethics. Your efforts in your community and society at large are at least as important as those in the labs.

8:46 AM, May 17, 2013

**Anonymous said...**

Thanks for sharing your story. It truly helps people like me considering the HD test as well.

10:38 PM, May 17, 2013

**Ash said...**

Excellent article and video! I wonder how the decision is changed if you're considering testing a child who's already been born (but not yet an adult).

5:22 PM, July 25, 2013

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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

---