

University of San Diego

Digital USD

---

At Risk for Huntington's Disease

Department of History

---

4-15-2016

## From sheepish to self-assured in the fight against Huntington's disease

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., "From sheepish to self-assured in the fight against Huntington's disease" (2016). *At Risk for Huntington's Disease*. 226.

<https://digital.sandiego.edu/huntingtons/226>

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)
  - ▶ November (2)
  - ▶ October (1)
  - ▶ September (1)
  - ▶ May (2)
  - ▼ April (2)
    - [From sheepish to self-assured in the fight against...](#)
    - [Just living life: a focus on what matters most in ...](#)
- ▶ March (1)
- ▶ February (2)
- ▶ January (2)
- ▶ 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](#)

FRIDAY, APRIL 15, 2016

## From sheepish to self-assured in the fight against Huntington's disease

Occasionally some readers of this blog have told me that, in comparison with their own travails, it seems that I cope well with living at risk for Huntington's disease.

With two decades of experience in the HD fight, a loving family, and a support system that includes a helpful psychotherapist and other health professionals, I've become more self-assured.

However, the hard truth is that I have struggled a lot.

Each act of advocacy, including the articles I post here, represents a challenge.

Driven by fear of the illness, I've constantly strived to improve my advocacy.

I've also been inspired by the dedication and ingenuity of HD researchers as they've advanced [towards the first treatments](#) for this complex, incurable disorder. I believe that the hope of effective treatments has boosted the overall morale of the HD community.

Scientists, physicians, drug companies, and advocates all unite forces in this historic quest. Ultimately, HD-affected families hold the key to success. Without our participation in research studies and clinical trials, we won't defeat HD.

### The 'HD closet'

I first heard about HD when I learned of my mother's diagnosis, the day after Christmas 1995. I was about to turn 36.

I immediately started educating myself about the disorder, including the fact that, as the child of an affected parent, I had a 50-50 chance of having inherited the defective gene.

I started attending a monthly HD support group. A few years later I became very active in the local chapter of the [Huntington's Disease Society of America](#) (HDSA).

However, for many years I hid in the "terrible and lonely HD closet," telling nobody but close relatives and friends about my family's plight.

I quickly learned to feel comfortable around other HD advocates and support group members, but, when first attending public events, I acted sheepishly.

### Thanking my geneticist



[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](#)

Last week, I wrote a thank-you e-mail to Dr. O.W. Jones, who made a very generous donation to my family's team in the HDSA-San Diego Team Hope Walk, held April 10.

Dr. Jones was the geneticist who delivered fateful news to me in 1999: I carried the HD gene.

In early 2000, he brought the best of news: our daughter-to-be had tested negative for HD in the womb.

Every year I send Dr. Jones, now retired, our family Christmas photo. It's my way of thanking him again for his assistance, and also a way for us to both recall his sage observation after I received my test results: "a positive test is not a diagnosis of the disease." I've lived with that knowledge for nearly 17 years without developing classic symptoms.

"Hi Ken: Keep it going!" Dr. Jones wrote on our donation page.

### Summoning up courage

As I sent my latest note to Dr. Jones, my mind hurtled back the first HDSA-San Diego fundraising gala in October 2001. HDSA presented Dr. Jones with its Distinguished Leadership Award for, as I later wrote in an anonymous article in the chapter newsletter, "his informed and compassionate assistance to the many families faced with the traumatic difficulties of genetic testing for the disease."

It was my first high-profile HDSA event, with community leaders such as San Diego Chargers President Dean Spanos present. Dr. Jones's family also attended.

I had never ventured to bring up HD with anybody outside my inner circle, yet I wanted to personally express my appreciation for Dr. Jones. With great trepidation, I approached one of Dr. Jones's relatives, an adult daughter. In general terms, but with great emotion, I told her how her father had played a very important role for my family.

I had to summon up great courage to say those words. In a very tentative way, I had "come out" about HD.

### Small steps are okay!

Like life, advocacy is a process. Many of my early blog articles reveal how long and difficult the path to greater self-assurance has been.

Indeed, only in late 2012 did I fully exit the HD closet.

It's still not totally comfortable for me to address HD with people outside my inner circle.

Indeed, who could *ever* be completely self-assured when facing a disease like Huntington's?

Ultimately, overcoming the insecurity resulting from the threat of HD starts with joining the cause.

Small steps are okay! With time, they will lead to bigger ones.

The accumulation of small steps by many people is powerful. As I always tell people in online discussions or e-mails, "together we will beat this disease!"

### Becoming more assertive



At the first HDSA-San Diego Team Hope Walk in early 2012, my family had a small team and raised very little money.

Since going public later that year, I have grown more assertive.

The exhortation of one leading local advocate at our support group has often guided me: if we don't tell our stories, why should anybody care about us?

I have shared my family's story with as many people as possible: relatives, friends, co-workers, high school and college classmates, and new acquaintances.

In the last three walks we have entered, my family's team has raised more than \$30,000 for HDSA, thanks to our generous donors.

In addition to raising funds, we've educated scores of people about Huntington's disease and the need for treatments.

This year's San Diego Team Hope Walk was especially poignant. After the several hundred participants finished the course, we held a minute of silence for Terry Leach, the brave 18-year-old San Diegan who lost his life-long fight against HD on January 2. Terry's mother Angela took part in the walk.

It's time to stop the suffering caused by HD, help point the way to cures for other neurological and rare diseases, and make brain health a national priority.

*(In the spirit of assertive advocacy, I dedicate this article to the members of the Serbin Family Team and the many donors who supported our participation in the 2016 Team Hope Walk. Thanks to their generosity, we garnered \$9,400 for HDSA, making us the top local walk fundraiser for the third time! Scroll down for photo highlights of the walk.)*



*The Serbin Family Team at the 2016 HDSA-San Diego Team Hope Walk: from left to right, Gary Boggs, Yi Sun, Regina Serbin, Dory Bertics, Isabelle Wisco, Bianca Serbin, Allan Rappoport, and Kenneth P. Serbin (aka Gene Veritas) (photo by Randy Oto). Not pictured: Jayne Millum and Cindy Stempien.*





*Serbin Family Team members Gary (left), Ken (Gene Veritas), Regina, and Yi with downtown San Diego skyline in background (personal photo)*



*Advocate Sharon Shaffer, affected by HD, greets former HDSA-San Diego president Bill Johnston, public relations director of the San Diego Chargers and recognized during the event along with daughter Hayley for their leadership in the HD cause (photo by Gene Veritas)*





*HDSA-San Diego vice president Misty Daniel (left) recognizes Tim Schroeder, one of the top Team Hope Walk fundraisers, for his steadfast, exemplary fight against Huntington's disease (photo by Randy Oto).*



*Misty and Angela Leach, mother of deceased juvenile HD patient Terry Leach, at the start of the minute of silence for Terry (photo by Randy Oto)*





*Participants in the 2016 HDSA-San Diego Team Hope Walk (photo by Randy Oto)*



*Fanny & the Attaboys provided live entertainment (photo by Randy Oto).*





*Gene Veritas (left) with HDSA-San Diego president Burt Brigida (personal photo)*



*Paul Negulescu (left), vice president of research at Vertex Pharmaceuticals, a sponsor of the Team Hope Walk that conducts HD research, with Gene Veritas, Debbie Negulescu, and Heather Farr of Vertex (photo by Bianca Serbin)*









*Team Hope medals awarded to all participants in the Team Hope Walk (photo by Randy Oto)*





*The path to the cure of Huntington's disease (photo by Randy Oto)*

Posted by [Gene Veritas](#) at [10:51 PM](#)      

Labels: [advocacy](#) , [clinical trials](#) , [cure](#) , [genetic testing](#) , [geneticist](#) , [HD closet](#) , [HD gene carrier](#) , [HDSA](#) , [HDSA-San Diego](#) , [Huntington's disease](#) , [psychotherapist](#) , [research](#) , [scientists](#) , [support group](#) , [Team Hope Walk](#) , [treatments](#)

2 comments:



**Bev said...**

Thank you for raising so much money and for your tireless advocacy! Your blog reminds me that I am part of a larger community.

[4:12 PM, April 16, 2016](#)

**Anonymous said...**

For the ten years since my mother's diagnosis, I've read your blog. Thanks so much for keeping us informed and hopeful!

[11:24 PM, April 18, 2016](#)

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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