

University of San Diego

Digital USD

---

At Risk for Huntington's Disease

Department of History

---

9-23-2009

## The unending 'thank you'

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 unending 'thank you'" (2009). *At Risk for Huntington's Disease*. 50.  
<https://digital.sandiego.edu/huntingtons/50>

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)
- ▶ 2010 (26)
- ▼ 2009 (21)
  - ▶ December (1)
  - ▶ November (2)
  - ▶ October (3)
  - ▼ September (2)
    - [The unending 'thank you'](#)
    - [In the midst of the hurricane](#)
  - ▶ August (3)
  - ▶ July (3)
  - ▶ June (1)
  - ▶ May (2)
  - ▶ April (4)
- ▶ 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](#)  
[Huntington's Disease Drug Works](#)

WEDNESDAY, SEPTEMBER 23, 2009

## The unending 'thank you'

Make no mistake about it, living at risk for a debilitating brain disorder like Huntington's disease is a harrowing experience. During the past fourteen years, I learned of my mother's diagnosis, tested positive for the disease, awaited the results from the testing of our daughter while still in the womb (she was negative), experienced rejection from relatives, saw my mother decline and die at a relatively early age (68), and wondered almost daily about when my own symptoms will start.

I often feel alone and hopeless.

But along the way some remarkable individuals from all walks of life have supported the fight to alleviate Huntington's disease.

And that's when I gain the strength and confidence to keep up my own individual fight to delay the onset of my symptoms and step up my activism for the Huntington's Disease Society of America (HDSA).

Many of the people most devoted to the cause have no HD in their family. Some had never heard of Huntington's disease before coming into contact with the HDSA through a fundraising event.

## Support in times of tragedy

In the eleven and a half years that I have volunteered for HDSA, I have seen thousands of different individuals attend the dozens of fundraisers that our local chapter has put on, from go-kart races to sumptuous galas.

A couple of these events took place right after September 11, 2001. Despite the fear and anger gripping our nation, people still attended those events and made generous donations.

A year ago, when the national financial meltdown was leading many to speak of another Great Depression, our local chapter raised a record amount of money at our annual Celebration of Hope Gala.

I am always moved by such outpourings of solidarity and the human spirit.

Huntington's disease shocks people when they learn of the devastating, dehumanizing symptoms that in the end leave people unable to walk, talk, and swallow. I am highly impressed that our supporters do not shy away from HD's horrors.

It's impossible to meet most of these people personally. Our chapter offers its thanks by publicly recognizing these individuals and their organizations on our website, in our newsletters, and in our event materials.

"Thank you" is a universal term uttered countless times each day, yet nobody grows tired of it. It's a basic part of our humanity, of our mutual dependence.

[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](#)

In the struggle against HD – an orphan disease still unknown to most people and a huge stigma for many of those who have it – we know how much we depend on our supporters.

### A personal thanks

Last Friday evening my wife and I did our small part in thanking one very special group of supporters: the HDSA-San Diego Board of Directors. We invited the board over to our house to enjoy snacks, drinks, and conversation around our brand new swimming pool. In part we built the pool so that I can keep in shape and perhaps delay the onset of symptoms or at least alleviate them ([click here to read more](#)). But we also wanted to share it with people like the dedicated and caring members of the board.

I have been a non-public member of this board since 1998 and have served on it longer than any current member.

In scores of meetings over the years, we have challenged one another to be more effective fundraisers, advocates, and supporters of the local HD support group and [HDSA Center of Excellence for Family Services and Research at the University of California, San Diego](#). These meetings are among the most demanding, most important brainstorming sessions in which I have ever taken part.

We constantly ask ourselves the question: how do we bring greater attention to our cause?

The board members – most of them without HD in their families – attend some of the support group meetings to gain firsthand knowledge of the disease. They work many evenings and weekends planning our fundraising events and seeking sponsors and auction items. Their networking skills are superb. They visit the county hospital during the holidays to take gifts to HD patients. They tirelessly advocate for greater public awareness of HD, public investment in HD-related stem-cell research, and the passage of federal legislation to bring disability benefits more quickly to those stricken with the disease. They donate large sums, and they run in marathons and other races to bring in yet more money.

Not surprisingly, HDSA-San Diego has twice been named HDSA's Chapter of the Year.

### Working against time

Because board members know how desperately HD families need treatments and a cure, they waste no time.

In fact, the board works so fast and so consistently that it rarely has the opportunity to give itself credit for its many accomplishments.

In contrast with the board and support group meetings, our party provided some fun and relaxation, an opportunity for us to share more of our lives and thoughts without the relentless deadlines and the depressing realities of Huntington's as our central focus.

It's those awful realities that make the need for care of patients and the cure of the disease such an urgent task. With this board and our many supporters, as well as the many scientists whose research their efforts help fund, we have a team that can reach this goal.

And for that I write these words again: thank you.

Posted by [Gene Veritas](#) at 8:40 AM



No comments:

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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

---