

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

6-11-2012

The wholehearted embrace: my first HDSA convention

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 wholehearted embrace: my first HDSA convention" (2012). *At Risk for Huntington's Disease*. 131.

<https://digital.sandiego.edu/huntingtons/131>

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.

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)
 - ▶ December (2)
 - ▶ November (3)
 - ▶ October (1)
 - ▶ September (2)
 - ▶ August (2)
 - ▼ June (2)
 - [The wholehearted embrace: my first HDSA convention](#)
 - [Yale's partnership against Huntington's disease: a...](#)
- ▶ May (1)
- ▶ April (2)
- ▶ March (3)
- ▶ February (3)
- ▶ January (5)
- ▶ 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](#)

MONDAY, JUNE 11, 2012

The wholehearted embrace: my first HDSA convention

For the first time since learning in 1995 that I was at risk for Huntington's disease, I participated in the annual convention of the [Huntington's Disease Society of America](#) (HDSA).

Despite my heavy involvement in [HDSA-SanDiego](#), I hadn't previously attended a national convention, even when the event took place in my home city, because of annual research trips to Brazil, my focus as a historian.

Last year I strongly wished to attend the June convention in Minneapolis, where I was named the [2011 HDSA Person of the Year](#), only to cancel the trip at the last minute after falling ill. I was crestfallen.

This year I finally made it (!), driving with others from San Diego to Las Vegas for the 27th Annual Convention at the Red Rock Resort (June 8-10).

Though I flew back to San Diego the evening of the first day in order to watch my 11-year-old daughter sing in public for the first time and therefore missed the rest of the event, the trip meant a lot. I took my biggest step yet out of the "HD closet," took stock of my long years of struggle, and made important new connections for the future.

Reflecting on HD's tough reality

The convention atmosphere put me in a deeply reflective mood. After meeting Jenny Rogers of the host Las Vegas affiliate of HDSA, which operated an information table in the registration area during the day before the official opening, I returned in the evening, when nobody was around, to learn about her family's struggles with HD, as told in pictures, letters, and a newspaper article attached to a poster.

I was profoundly shocked to read that Jenny's mother had committed suicide in 2000 after Huntington's had begun to

[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](#)

rob her of her physical and cognitive capabilities. A teenager at the time, Jenny discovered her mother's body lying on the floor in the bedroom of her home.

"I'll be an angel watching over you," wrote Jenny's mother in her suicide note. "I did the best I could, but I just didn't have any strength to cope with life anymore."

Once again, a Huntington's story cast a pall of sadness over me. I pondered how this disease relentlessly assaults families and destroys dreams.

Like me, Jenny is gene-positive for HD. She faces the onset of symptoms in the next couple decades, the prime of life. (Learn more about Jenny's story by [clicking here](#).)

I returned to my room, turned off the lights, and gazed at the night skyline of the Las Vegas Strip. As I admired its magnificence, I recalled the shortness and fragility of life – a reality intensified a thousand times in the HD community.

An upbeat opening

For me, the morning was more upbeat.

During the opening ceremony, Jenny welcomed the convention-goers assembled in the main hall. HDSA Chairman of the Board Don Barr addressed the audience. Nora Guthrie, the daughter of HD-stricken folk singer Woody Guthrie and HDSA founder Marjorie Guthrie, greeted the convention via a recorded video, in which she reminded us that this year marks the 100th anniversary of Woody's birth.

Also via a recording, Social Security Administration (SSA) Commissioner Michael Astrue addressed the audience about the HD community's important victory, in the form of the SSA's announcement in April that juvenile HD benefits applications would be fast-tracked starting in August ([click here](#) to read more).

HDSA CEO Louise Vetter presented a measuredly optimistic "State of the Society" address, in which she outlined the organization's recently unveiled [five-year strategic plan](#).

The meaning of HDSA

At the end of the ceremony, I joined HD advocates Ted Krull and [Shana Martin](#) on a panel titled "We Are HDSA."

Ted recalled the life of his deceased daughter Emily, whose battle against juvenile HD inspired Ted and his wife Carla to push for passage of [The Huntington's Disease Parity Act](#), a pending bill in Congress that would more quickly bring Social Security and Medicare benefits to affected individuals.



Emily Krull (family photo)

Shana, a model, lumberjack athlete, and fitness competitor, told the story of her mother's ongoing struggle against HD, her involvement in HDSA's National Youth Alliance, and the use of her athletic prowess to raise awareness of HD.

To the audience of several hundred people – the largest HD crowd to which I've spoken – I told my story, revealing the true identity of Gene Veritas. My family was the reason for my involvement with HDSA, I said. And while my mother died of HD and I tested positive for the genetic mutation, my daughter, our gene-negative "miracle baby," thrives as she prepares to enter the seventh grade in the fall.

She and I are both "addicted to writing," I said. For a class project, and using my at-risk status as an example, my daughter recently sent letters to 35 U.S. Senators urging them to reverse their opposition to health care reform. Using my writing talent, I said, I've produced the HDSA-San Diego newsletter and more than 130 articles for this blog.

However, not one of my newsletter or blog articles has carried my real name as the author, I pointed out.

Now, more than ever, I'm taking off the mask of Gene Veritas and exiting the terrible and lonely HD closet – a closet in which so many families remain hidden because of fear of genetic discrimination.

Explaining that HDSA has provided me with the necessary support to carry out my struggle against HD, I highlighted the organization's meaning for me by summing up its mission in words beginning with the four letters of its acronym: *Hope* (through its support services), *Determination* (to find treatments), *Solidarity* (togetherness as the key to beating the disease), and *Awareness* (about the need for public advocacy and of the HD community's key role in the larger battle against neurodegenerative disorders that will afflict millions in the coming decades).

You can watch a recording of our three presentations by [clicking here](#).



Ted Krull (left), Shana Martin, and Gene Veritas

New allies

After the opening ceremony, I sought to meet online friends in person for the first time, as well as connect with new allies in the movement.

I spoke to one young brave man, a regular reader of this blog, who bears a double hardship: years ago a traffic accident left him paralyzed from the waist down, and later he tested positive for HD. "We are brothers," he told me after an intense conversation about many aspects of HD.

Meeting him helped me put my own situation in perspective: compared to some, my burden is light.

I ran into another online acquaintance with an HD-stricken wife and daughter whose symptoms began much earlier than her mother's.

In the exhibit hall, I signed and photographed the banner filled with messages of thanks to Congressman Bob Filner of San Diego, the original sponsor of the *HD Parity Act*.



Volunteers hold "thank you" banner to be presented to Representative Bob Filner (photo by Gene Veritas).

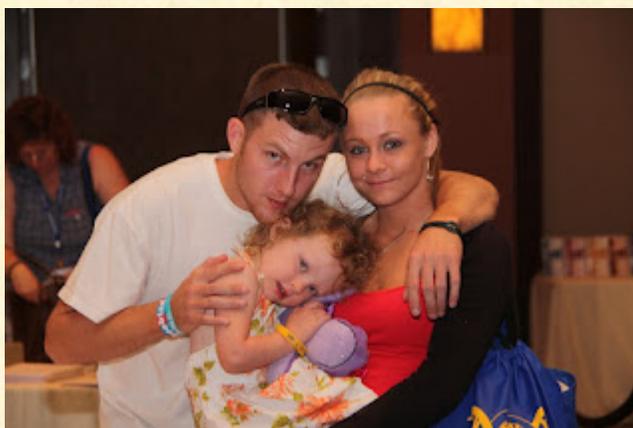
Three-year-old Kayden Bujnowski scrawled her own message on the banner, then posed for me.

When I heard that Kayden's mother Heather Lewis has HD, and that Kayden has a 50-50 chance of inheriting the mutation, I gasped and thought, "No, not another family!"

To contribute further to awareness, Heather and her husband Jason Bujnowski graciously allowed me to take a family photo.



Above, Kayden Bujnowski blows a kiss from the HD Parity Act banner. Below, Kayden with mom Heather Lewis and dad Jason Bujnowski. (Photos by Gene Veritas)



A new HD sister

After my morning presentation, I had only a few hours before catching the shuttle to the airport. I felt bad explaining that I needed to leave early, but everybody immediately supported my decision when they heard about my daughter's performance.

After spending much of the past month on the road (North Carolina, Ohio, New York City, and New Haven) advocating for HD, I did not want the fight against HD to rob me of this precious moment. At 52, now in the range of years when my

mother's symptoms hit, I *must* strike a healthy balance between advocacy and the rest of my life.

I decided to spend my last half hour at the convention sitting next to a woman with HD. She was about my age. She had pronounced chorea (the dance-like movements caused by HD), and, like so many other HD people, was emaciated.

I struck up a conversation with her and the HD social worker sitting next to her. To my relief, the HD woman could take part in the dialogue – an ability my mother lost almost completely as the disease progressed.

The woman's husband appeared and sat with us.

The three of us talked about HD.

The woman asked for her pills, about a half dozen, which she took one by one with drinks of water from a sipping cup. She dropped one of the pills, but her husband rescued it from the floor.

To my great satisfaction, the woman told me that she read my blog. She thanked me for it.

"Keep writing," she said.

"Keep reading," I responded.

It was time to catch the shuttle.

Summoning up her strength, my new sister rose to hug me.

We embraced for a few moments. Our bodies seemed to fuse into one sensation of fear, but also of love and hope.

I had never embraced an HD person so wholeheartedly – perhaps not even my own mother.

Back in San Diego, I realized that this was a symbol: I also had wholeheartedly embraced my role in the HD cause in a new way.

Posted by [Gene Veritas](#) at 9:43 AM



Labels: [daughter](#) , [discrimination](#) , [gene-positive](#) , [genetic](#) , [Guthrie](#) , [HD closet](#) , [HD Parity Act](#) , [Huntington's](#) , [juvenile HD](#) , [Louise Vetter](#) , [mother](#) , [mutation](#) , [onset](#) , [sister](#) , [Social Security](#) , [suicide](#) , [symptoms](#) , [tested positive](#)

4 comments:

 **Jimmy Pollard said...**

As always, "Gene," well done and inspiring!!! Thanks, Jimmy Pollard

[11:24 AM, June 11, 2012](#)

 **chriswick said...**

Was good to chat briefly with you as you...you are truly inspiring!

Hope your daughter's recital was wonderful!!

5:17 PM, June 11, 2012

 **Ashby said...**

I'm sorry I missed meeting you at the convention. Maybe next year! Great presentation by the way. Keep up the good fight!

11:47 PM, June 12, 2012



 **heartsandhumor said...**

Gene

I heard you speak at the conference in Veags. Both my wife's children married into families with Huntington's. My stepdaughter is married to a man who has it. His father, brother and sister have it. Two more siblings are at risk and haven't tested yet.

My stepson married a girl who tested negative, but her mother died from HD and her sister has it.

I write inspirational stories. A few samples are below. I'm working on a story about Huntington's now. The conference inspired me to make people aware of the disease.

This morning, I spoke to Jason Gromley of Strategic Health Care in DC and Mackenzie Platten - VP of HDSA Southeast Ohio. They were a wealth of information.

Would you be willing to speak to me? I want to get your story too.

I can be contacted at heartsandhumor@gmail.com.

Here's a couple samples of what I write. Tissues may be required in some parts.

This first one is my life story in a few pages.

<http://www.ourecho.com/story-7296-The-Tattered-Bookmark.shtml>

This next one was written in 1999. Since then it has circled the world. I was the fool in the window. 15 years after the event took place, the story was printed in the local paper of the city the story played out in. The editor called me the next day in amazement. "Michael, you will not believe this. I've had three calls today from people who said, 'I was on that bus.'" <http://www.thinthreads.com/samples/happiest.html>

Hoping we can speak.

Mike.

12:33 PM, June 16, 2012

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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