

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

3-15-2020

In times of crisis, Huntington's and other chronic disease communities provide examples of fortitude

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., "In times of crisis, Huntington's and other chronic disease communities provide examples of fortitude" (2020). *At Risk for Huntington's Disease*. 287.
<https://digital.sandiego.edu/huntingtons/287>

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.

More

Create Blog Sign In

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)
 - ▶ December (1)
 - ▶ November (3)
 - ▶ October (1)
 - ▶ August (1)
 - ▶ July (1)
 - ▶ May (1)
 - ▶ April (1)
 - ▼ March (3)
 - [Giving back during the COVID-19 pandemic](#)
 - [In times of crisis, Huntington's and other chronic...](#)
 - [CHDI head scientist Pacifici: 'hang on in the lear...](#)
 - ▶ February (3)
 - ▶ January (1)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 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

SUNDAY, MARCH 15, 2020

In times of crisis, Huntington's and other chronic disease communities provide examples of fortitude

For individuals and families facing Huntington's and other chronic diseases, daily living often seems like nonstop crisis. These communities, including selfless caregivers, have demonstrated great fortitude.

The current coronavirus pandemic adds another giant, unknown layer to the kind of challenges and suffering many in these communities are already accustomed to.

The country's reaction to the pandemic and the shutdown of daily routines starkly reminded me of the national climate in the months following the [September 11, 2001, terrorist attacks](#) on New York City and Washington, D.C. Resulting in 3,000 deaths, 9/11 led to a temporary grounding of all domestic flights, the fear of subsequent attacks (including nuclear), and panic regarding other, unrelated terrorist threats such as the deliberate spread of highly dangerous anthrax bacteria. The economy also suffered serious long-term effects.

Members of the San Diego Chapter of the [Huntington's Disease Society of America](#) (HDSA), in the bewildering days after 9/11, held a previously planned fundraiser and got ready to hold its first Celebration of Hope Gala.

With so many other, urgent demands on potential donors, we feared people might not remember our needs.

Later that fall, in an editorial in *Conquest*, our chapter newsletter, I wrote the following:

On September 20, less than two weeks after the crisis, members of the public and local organizations participated in the Third Annual Indy Go-Kart Challenge to raise funds for the cure of HD. Then, on October 11, the one-month anniversary of the attack, several hundred San Diegans took part in the Celebration of Hope Dinner to assist the Center of Excellence for Family Services and Research at the University of California, San Diego. We raised tens of thousands of dollars at these events. Elsewhere in the country other HDSA events went on as planned.

In this manner HDSA and its supporters have sent a resounding message that generosity and compassion are far stronger than the hateful politics of terror. We will move ahead, no matter what the odds are against us. This is the American spirit.

Unprecedented impact on daily life

So far, the coronavirus pandemic has had an unprecedented impact on the United States, with schools, universities, and many other institutions closing or switching to remote, online operations. As of March 15, at least [65 people had died](#) in the U.S., with worst-case scenarios projecting [200,000 to 1.7 million deaths](#).

[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](#)

The pandemic has changed my workplace unlike any earlier tragedy. After 9/11, no classes were cancelled by my employer, the [University of San Diego \(USD\)](#). In 2003, the devastating [Cedar Fire](#) in San Diego County left 15 dead, destroyed 2,820 buildings, and charred more than 280,000 acres. In response, USD shut down for just two weeks and finished the semester normally, with everybody back on campus.

Now, because of the virus, USD has cancelled classes this week and will finish the semester (eight more weeks, plus final exams) [online](#). The University of Pennsylvania, where my HD-free daughter Bianca studies, will do the same. My wife and I are worried that Bianca will not be able to make it home in time before potential travel restrictions.

Each hour, we learn of more victims of the virus and further curtailment of life as we know it.

Impact on the HD community

The global crisis has also impacted the mission of HDSA and individual HD families.

On March 13, HDSA CEO Louise Vetter sent an e-mail to “friends of HDSA” announcing that the organization “holds the well-being of our families, volunteers and staff as our top priority” and will therefore postpone “ALL local HDSA events (educational & fundraising) nationwide” until April 30. That complies with public health recommendations to curtail public gatherings to slow the spread of the coronavirus.

According to Vetter, HDSA still plans to hold its 35th Annual Convention in New Orleans, June 4-6, but will continue to follow the guidance from the Centers for Disease Control, World Health Organization, and state and local health agencies.

HDSA’s national headquarters in New York City is closed. However, the entire staff is working remotely and has the resources “to continue the uninterrupted support of our mission during this time,” Vetter assured.

The Huntington’s Disease Youth Organization [postponed its May 2020 international congress](#) in Glasgow, Scotland, to March 2021.

I have accepted an invitation to deliver the keynote address at the 37th National Conference of the [Huntington Society of Canada](#) in November, but have been told to hold off on reserving flights until the pandemic’s long-term effects become clear.

Visiting the afflicted

For one [HD community member and blogger, Mandi](#), 33, the pandemic meant that on March 12 she could not visit her 58-year-old HD-stricken father, Danny, at the Missouri nursing home where he resides.

“They are locking all doors for the safety of people there,” wrote Mandi, a dedicated caregiver and herself at risk, but untested, for HD. “Was my first reaction sad I couldn’t see my dad? Sure, but I immediately checked myself. I realized my own selfish want to see my dad was tiny in comparison to keeping the people in the nursing home safe because who knew if I was a carrier since you can have it for over a week and not show symptoms.”

Mandi pointed out how the nursing home’s restriction is “terrifying for those of us with possibilities of losing family.” She wants “to do everything in my power to protect him as I always have.”

However, she concluded: "Until we really know what we are dealing with let's just take the precautions seriously."



Danny (left) and Mandi (family photo)

Especially resilient

With the coronavirus pandemic, the world can learn from the example of the HD community and our generous supporters.

We in the HD community, and other neurological disease groups, face relentless adversity. HD grinds down the brain, leaving the affected like my late mother unable to walk, talk, or care for themselves. Caregivers like Mandi and my late father are true "["HD warriors."](#)"

However, because of this, we have developed a very realistic view of life.

"We are all in a race to death, but people at risk for life-shortening diseases know that their time to the finish line is painfully fast and troubled," I wrote in 2009 in an article titled "["HD: hurtling towards death."](#)"

At the same time, we also have a special appreciation for the "["preciousness of life."](#)"

Confronting HD makes us especially resilient. I am hopeful that the HD community will successfully meet the challenges of the coronavirus pandemic and, as in facing past challenges, become even stronger.

Posted by [Gene Veritas](#) at [11:39 PM](#)     

Labels: [9/11](#) , [caregiver](#) , [chronic diseases](#) , [coronavirus](#) , [fortitude](#) , [HD warrior](#) , [HDSA](#) , [HDSA-San Diego](#) , [Huntington Society of Canada](#) , [Huntington's disease](#) , [nursing home](#) , [pandemic](#) , [resilience](#) , [University of San Diego](#)

No comments:

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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

