University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

2-24-2020

Striving to overcome the doom of 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., "Striving to overcome the doom of Huntington's disease" (2020). At Risk for Huntington's Disease. 284.

https://digital.sandiego.edu/huntingtons/284

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)**
- **V** 2020 (16)
 - December (1)
 - November (3)
 - October (1)
 - ► August (1)
 - ▶ July (1)
 - ► May (1)
 - ► April (1)
 - ► March (3)
 - ▼ February (3)

At Therapeutics

Conference,

landmark study of

youn...

Striving to overcome the doom of

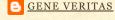
Huntington's disease

I'm a Huntington's

disease gene carrier at age 60,...

- ▶ 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



View my complete profile

HD Links

MONDAY, FEBRUARY 24, 2020

Striving to overcome the doom of Huntington's disease

Usually, I experience a <u>whirlwind of emotions</u> during and especially immediately after the annual Huntington's Disease Therapeutics Conference, held in Palm Springs, CA.

This year, however, intensifying my advocacy in what I call the "HD movement," I feel that I've reached another level of engagement. Paradoxically, at the same time, I feel that I've attained greater calm and insight regarding the disease and its impact on the community.

After my <u>last article</u> – on the pathbreaking scientific evidence suggesting how and why the HD age of onset varies widely and how I've reached 60 healthy – I've read stories in Facebook HD groups confirming that variability.

Some pointed to extremely early, very tragic onset, but others resonated with my (very fortunate) situation of having gone more than a decade beyond the point of my mother's first symptoms. Significantly, scientists are seeking ways to use the biological mechanisms behind delayed onset to produce treatments.

As I pondered those more optimistic scenarios, I thought: "Does HD have to be only a story of doom?"

Clearly, in many instances, it still is.

On February 19, at the packed, moving <u>screening</u> of the HD documentary *Dancing at the Vatican* at my university, one HD family member recalled how, out of ignorance, both a parent and a grandparent had been kept in a straightjacket.

However, the collective celebration of the film's portrayal of Pope Francis' historic audience with HD families in Rome also demonstrated how far the HD cause has come. Thanks to Francis – but also to thousands of family members and advocates around the world – HD is "hidden no more."

Huntington's Disease Society of America International Huntington Association **Huntington's Disease Drug** Works **Huntington's Disease Lighthouse** <u>Hereditary Disease</u> 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



A life-size stand-up poster of Pope Francis at the February 19 screening of Dancing at the Vatican at the University of San Diego (photo by Gene Veritas)

How far we've come

An illuminating panel discussion at the screening illustrated how awareness has grown on all fronts. The presence of representatives from four biotech sponsors underscored the growing commitment to discover effective treatments.

The evening of February 21, the mother of a young man who died of juvenile HD left me a voicemail. She spoke of how the near-20-year struggle to care for her son led her to develop bipolar disorder and PTSD.

That sounds devastating. However, she also reminded me of an important trend in the HD community, in which the affected are no longer referred to as "HD people" but as "people with HD."

"You're not Huntington's disease," she said. "How could I ever look at my son and think, 'disease?"

At this evening's opening of the 15th Annual HD Therapeutics Conference, sponsored by <u>CHDI Foundation</u>, <u>Inc.</u>, I will have renewed hope for the development of effective treatments. As understanding of the disease has evolved, so have the approaches to achieving those treatments.

On February 27, conference attendees will hear a report on a clinical study investigating RG6042, the gene-silencing drug also currently under evaluation in a Phase 3 clinical trial run by Roche.

If successful, that trial will have produced the first treatment to slow, halt, and perhaps even reverse HD.

That could signal the end of doom for tens of thousands of HD-affected families around the world.

	Posted by <u>Gene Veritas</u> at <u>10:40 AM</u> Labels: <u>advocacy</u> , <u>biotech</u> , <u>CHDI Fou Vatican</u> , <u>emotions</u> , <u>gene silencing</u> , <u>Huntington's disease</u> , <u>onset</u> , <u>Pope Fr</u>	indation , clinical trials , Dancing a HD Therapeutics Conference , Hidd	<u>it the</u> en No More ,
	No comments: Post a Comment		
	Newer Post	<u>Home</u>	Older Post
	Subscribe to: Post Comments (At	<u>om)</u>	
一种人们的一种人们的一种人们		上面 4 人口面	4 年 / 自由