

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

4-2-2011

The faceless faces 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., "The faceless faces of Huntington's disease" (2011). *At Risk for Huntington's Disease*. 91.

<https://digital.sandiego.edu/huntingtons/91>

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)
- ▼ 2011 (33)
 - ▶ December (2)
 - ▶ November (4)
 - ▶ October (4)
 - ▶ September (2)
 - ▶ August (1)
 - ▶ July (2)
 - ▶ June (2)
 - ▶ May (4)
 - ▼ April (4)
 - [The diary of a Huntington's disease activist](#)
 - [The shadow career](#)
 - [Let's fix the law to help Huntington's families](#)
 - [The faceless faces of Huntington's disease](#)
 - ▶ March (3)
 - ▶ February (3)
 - ▶ January (2)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me

 **GENE VERITAS**

[View my complete profile](#)

SATURDAY, APRIL 02, 2011

The faceless faces of Huntington's disease

Huntington's disease is an orphan disease with an estimated 30,000 patients and 250,000 individuals at risk for inheriting the genetic defect that causes the disorder. HD is largely unknown to the populace, or even within the medical community. When people do learn about HD, they are shocked by the way this genetic brain disorder robs its victims of their humanity, leaving them twitching nervously, emaciated, and unable to walk, talk, and eat. The result is a slow and ugly death.

For these and many other reasons, HD families face a terrible stigma.

As a pre-symptomatic, gene-positive individual who has just recently begun exiting the "HD closet" ([click here](#) to read more), I can attest to the great discrimination, ignorance, and denial that we regularly encounter. Still, I can't reveal many of the stories, because of the risk of damaging people's livelihoods.

We hide. We change our names. We cut ourselves off from family and friends.

We live in constant fear.

In the words of HD patient James Valvano, we are "the faceless faces of Huntington's disease."

Time for an HD coming-out ritual

The HD community must unite and speak with a common voice to the world: we *will* be heard, and we will *no longer* tolerate discrimination.

We will *erase* forever the stigma of Huntington's disease. And, by joining hands with the millions of other brothers and sisters victimized by other neurological conditions, end *their* stigma, too.

As so many other disease communities have done, we must create a ritual for speaking out in public so that people can instantly identify with our plight, our cause for treatments and a cure, and our connection to the chain of social justice and human solidarity.

The Valvano family's fight

James has thought hard about these issues.

In 2009, James' 47-year-old brother John was diagnosed with HD after experiencing symptoms first thought to be Parkinson's and/or the results of a stroke. Soon thereafter, James, who turns 40 this July, also tested positive for HD. He now had an explanation for his own health problems, which stretched back at least five years: shaking legs and occasional twitching in his right arm.

HD Links

[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](#)



James Valvano (photo from his Facebook page)

“At the time I was not in the best of health and decided to change my eating habits and exercise, alongside a medication regimen,” James wrote me. “I lost upwards of 60 pounds and learned to focus my energy and meditate. I can no longer drive (my eyes flutter/move abnormally), and I sometimes have a hard time with my speech.

“I had to forfeit my small business (Marine Aquarium Shop), so I am home working on advocacy most of the day....

“Since I learned meditation techniques and decided to live more positively, I am able to function a bit less symptomatic....

“Just recently, my niece in Denver was diagnosed with HD (27) and my Dad (79) here in Saint Cloud (Florida). There are seven total (brothers and sisters) at risk. I am the second youngest of the seven, with thirteen nieces and nephews at risk.”

A film about the ‘monster’

James might have devised a successful formula for a neurological coming-out ritual.

As part of his growing advocacy, James decided to produce an allegorical film depicting HD symptoms and the fear felt by its victims. He titled it *The Faceless Faces of Huntington's Disease*.

In the film's captions. James calls Huntington's disease a “monster” and a “living nightmare.” The main character wears a black, hooded robe and a silver, ominously expressionless mask. Afflicted by HD, this person lives a lonely life as symptoms intensify.

Police officers, also wearing masks, lock up the HD person in a small cubicle. The HD person then visits a cemetery.

“Without a cure, Huntington's disease will win,” the film's captioning continues. “We are not monsters.”

At the very end, James appears onscreen: “My name is James Valvano. I have Huntington's disease. I am no longer a faceless face.”

You can watch the film below.



Scare tactics?

The Faceless Faces is not an easy film to watch. I believe it will especially shock people who have not heard of HD before or ever seen an HD patient.

In fact, the film has generated controversy among some members of the HD community. One viewer accused James of using “scare tactics.”

James addressed that criticism in a comment in an HD discussion group on Facebook.

“Let me say that I searched high and low prior to creating the film, for another interpretation similar to mine – to no avail,” James wrote in the February discussion. “Did I have another format? Yes. Why did I change the portrayal to its current state? I believed that HD needed to be exposed for exactly what it is – what I experience on a daily basis – what thousands experience (whether they have HD, [are] not yet sure, or if they are a caregiver).

“At the end of the film, it was key (in my expression) to ‘transform’ the ‘monster’ into human form – the person who lives with this horrific disease, the thousands of wonderful and loving people in our community who are not given the level of awareness which is so desperately needed.”

I contributed to the discussion with my own comment on the film:

“Someone once criticized me for saying HD was ‘dehumanizing.’ I did not apologize for my description, because it IS dehumanizing. The individual thought I was calling HD people unhuman. But it's not the people – it's the disease.

“And that is James' point. HD is a shocking disease. And unknown. So it's difficult to explain.

“I thought James packed in a lot of info into a very short time. Yes, many people will find it shocking. We need different approaches for different audiences. Some people find it difficult to look at HD people. I found it difficult to look at my own mom, because the disease had stolen her humanity and because I was looking at my own future.”

The Neuro Film Festival

The Faceless Faces has also created a stir in the community of neurologists.

James entered the film in the 2011 Neuro Film Festival, sponsored by the

American Academy of Neurology Foundation. Among the more than 100 entries, it received the third highest number votes from the online viewing public. (A film about multiple sclerosis came in first, followed by one about arachnoid cysts.)

According to [the festival's website](#), the goal is to “help raise awareness through video about brain disorders and the need to support research into preventions, treatments and cures.”

The official first- and second-place winners of the competition, judged by a panel of academy members and film experts, will be announced at the festival in Honolulu on April 10.

‘I am No Longer Faceless’

To build awareness even further, James is preparing part two of the film, titled *The Faces of Huntington's Disease: I am No Longer a Faceless Face*.

For this phase of the project, James is collecting short video clips of people taking off a mask and stating this sentence: “My name is (state name) and (I have Huntington's disease) (someone I love has Huntington's disease) (I am at risk for Huntington's disease), etc., and I am no longer a faceless face.”

In a [teaser clip for part two](#), James calls for everybody in the HD community tell his or her story: “You are special. You are a fighter. Our story must be told. Let's put the stigma to rest. The mask is off. We are no longer faceless. It's a new day for awareness. We will let the world know – together.”

James plans to travel across America to visit participants in the film. He also hopes to fly overseas

“I believe it is time for us to unite as a worldwide community and bring about a wave of awareness unlike any other!” James [wrote on his website](#).

Combating discrimination

The task of ending the facelessness of Huntington's disease is urgent. Despite the passage of the Genetic Information Nondiscrimination Act of 2008, people in the HD must still confront harsh discrimination and ignorance about the condition. (In a future article I plan to explore the enforcement of this act.)

HD people continue to land in jail because police officers think they are drunk or because of aggressive behavior caused by the disease.

Amanda K. Titus-Meadows of Marquette, MI, recently told me and others in an HD group on Facebook that her mother Teresa, a licensed practical nurse, was laid off from her job at a hospital late last year because she'd been diagnosed with early-stage Huntington's. Amanda gave me permission to tell this story.

Suffering mainly from short-term memory loss, Teresa, 50, was nevertheless told “by both of her doctors, her neurologist, and her memory specialist that she is perfectly capable of still working. They were the ones who encouraged her to speak to a lawyer, because they believe that her rights have been violated and her employer is breaking the law.”

The doctors also pointed out that the hospital had asked for Teresa's “medical records without a release.” Amanda added that Teresa's boss filed disability and unemployment papers without Teresa's consent.

The family has retained an attorney.

Sickening treatment

In the discussion, other HD-affected people revealed that co-workers harassed them or pushed them out of their jobs.

“I'm sickened that things like this happen to people,” Amanda wrote. “How upsetting that we be counted out just for carrying a disease. This should be handled with kid gloves and no different than a case with somebody who has diabetes, lupus, or any other disability.

“I hope that for the future of our potentially afflicted children that we are able to make the disease clear to those who don't understand and protect them from suffering the same discrimination.”

I added my own feelings about this situation: “I am deeply saddened, disturbed, and angered.... NOW WE KNOW why so many people in the HD community are FACELESS! We've all got to fight for our rights! Many people have asked why I use a pseudonym on my blog. It's experiences like Amanda's mom's that have kept me anonymous for fear of losing my own job.”

Removing the mask (again)

To those in the HD community who would still hesitate to end their facelessness, James says: “If not now, when?”

After remaining anonymous for 15 years after my mother's diagnosis with HD in 1995 (she died in 2006), I began to exit the HD closet last year.

On February 7 of this year I came out to some 250 prominent HD scientists and other attendees by giving the [keynote address](#) to “Super Bowl” of Huntington's disease research, the 6th Annual HD Therapeutics Conference, held in Palm Springs, CA, and sponsored by the CHDI Foundation, Inc., the so-called “cure Huntington's disease initiative.”

My speech was titled “*Blog Entry No. 85 ... Unmasking the World of Gene Veritas: An Activist Copes with the Threat of Huntington's Disease.*”

On March 31, I spoke about HD to the very first time to a trusted co-worker, although I'm still deeply fearful of potential discrimination if more colleagues find out.

Like tens of thousands of affected, gene-positive, and at-risk individuals, I'm in a race against time. We are all awaiting treatments for HD.

For me, the time to speak out is truly *now*. I will submit my own short video clip for inclusion in *The Faces of Huntington's Disease: I am No Longer a Faceless Face*. Please watch below.

This video is my way of bidding farewell until my next article – and of asking everybody to help make HD, and other devastating neurological disorders, diseases with real faces.



Gene Veritas: No Longer a Faceless Face of Huntington's Disease

from [Gene Veritas](#)

00:22



[Gene Veritas: No Longer a Faceless Face of Huntington's Disease](#) from [Gene Veritas](#) on [Vimeo](#).

Posted by [Gene Veritas](#) at 1:27 PM



Labels: [advocacy](#) , [at risk](#) , [awareness](#) , [brain](#) , [closet](#) , [cure](#) , [death](#) , [faceless](#) , [gene-positive](#) , [genetic](#) , [genetic defect](#) , [Huntington's](#) , [ignorance](#) , [orphan disease](#) , [stigma](#) , [symptoms](#) , [treatments](#)

4 comments:

James Valvano said...

Ken, I wish to thank you from the bottom of my heart for writing this article! I am honored that you featured my story, and my (film) mission. I am blessed to be a part of this amazing and loving HD family!! I am touched by your personal story and your own strengths! I look forward to meeting you!! For those who are unaware- I am currently visiting my friend in Tennessee (I have not seen her in 19 years), and phone / Internet connectivity is poor...so I am glad to be able to have this short moment to express my gratitude! Thank you again, and you are loved - James Valvano

11:37 AM, April 03, 2011



Timeout Group "Share" said...

Hi Ken great to read your Blog and meet you even tho not in person.

I am so pleased to have so many people like you who want to bring HD into every day talking rather than hiding behind the faces we are born with ...thank you to our HD family xx

june Brown

Carer for my husband suffering HD

3:11 PM, April 03, 2011

Amanda Meadows said...

Wow, that is fantastic. I'm speechless and that does'nt happen very often. Until joining the HD group I had no idea that there were so many people whos lives have been affected by HD. It's

because of you all that we felt strong enough to stand up for ourselves. And I truly hope that anybody else experiencing the same stories experience the same strength to get them through.

Amanda Meadows

[10:57 AM, April 04, 2011](#)



Kate's Kronies said...

Ken,

once again your gift for writing is amazing! thank you... your blog is truly wonderful...

thank you so much

[6:23 AM, April 22, 2012](#)

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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