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At Risk for Huntington's Disease

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## New film unmaskes the raw reality of Huntington's disease

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# 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.*

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FRIDAY, SEPTEMBER 04, 2015

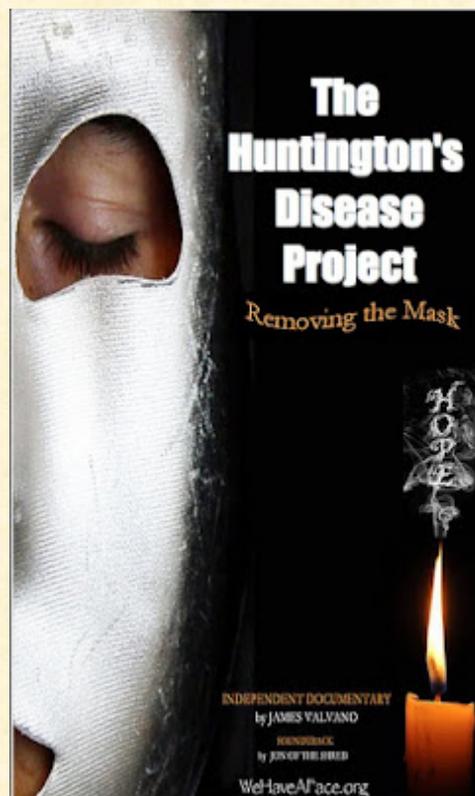
## New film unmask the raw reality of Huntington's disease

A new, award-winning documentary film, *The Huntington's Disease Project: Removing the Mask*, reveals the raw reality of HD so thoroughly and authentically that it should become required viewing for health care professionals and trainees in the neurological field.

This 100-minute film, not yet released widely, is also a must-see for the HD community and the general public, although it will likely cause many to recoil from what it calls the "monster" tormenting HD-affected individuals and their families.

As an HD gene carrier and long-time grassroots advocate who saw his mother succumb to the disease, I consider myself a hardened observer.

Even so, *Removing the Mask* shocked me with its exploration of the lives of HD-affected individuals and caregivers, including producer and narrator James Torrington Valvano, diagnosed with HD in 2009 yet still able to function sufficiently to make the film.



With an anthropologist's eye, James probes the many layers of HD reality – and the hearts of its victims.

## 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](#)

*Removing the Mask* delves into the wide range of issues HD families face, including medical challenges and social disruption.

The HD community will recognize many of them, although they are rarely discussed so openly in a medium such as film: ignorance about the disease, misdiagnosis, denial, family tensions, rage and aggression, genetic testing, financial devastation, caregiving, and loss of the affected individual's independence, to name just a few.

*Removing the Mask* does not shy away from the most difficult themes: inaccurate racial interpretations of HD by physicians, associated sexual disorders, suicide, the exclusion from clinical trials of HD people with suicidal tendencies, and mercy killing. It also pays close attention to juvenile HD, often omitted in the overall conversation about HD.

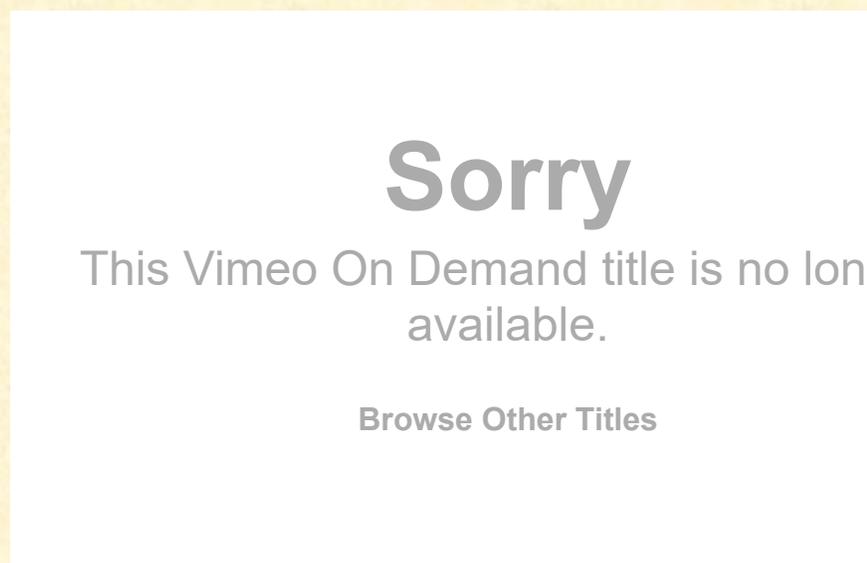
In striving for a comprehensive view of HD, *Removing the Mask* adamantly advocates for a broad understanding of the disease by medical and psychiatric professionals, relevant government agencies, and the public. This includes recognition of HD as not just a movement disorder, but also one involving cognitive, emotional, and behavioral difficulties.

Although *Removing the Mask* mirrors the detailed information about HD known to specialists, many non-specialist health professionals don't understand the disease.

*Removing the Mask* is not a textbook-like film but a genuine illustration of the disease. Rather than a medical or scientific authority explaining HD for us, in the film we feel the pain as the affected and their loved ones tell us what it's really like to have the disease.

James brings it all to life with testimonies that are brutally honest.

You can watch the *Removing the Mask* trailer in the video below.



### Shaving seven hours a day

At James's invitation, I recently watched the film by myself in a private online session on my home computer.

One of many poignant segments concerns John and Sue Wright of Kent, England. John, who liked to work with computers before he fell ill, was diagnosed with HD in 1992, and soon thereafter Sue became his caregiver. In the film, she describes his mental decline.

“He was waking every morning threatening to kill me and throw me out the window,” Sue recalls. “He was sharpening knives in the kitchen constantly, and he was assaulting me. I always reported the assaults, for my own safety, to the police, but never wanted him prosecuted. I knew it was the disease making him behave this way, and not his intention.”

To avoid harm, Sue moved out, although she returned home up to seven times each day to care for John.

John developed a condition experienced by a number of HD-affected individuals: obsessive-compulsive disorder (OCD).

“He was obsessed with any paper towels, tissues, etc.,” Sue remembers. “He would pile them up and keep them. If I attempted to throw them away, he would retrieve them from the rubbish bin and put them back in their piles.

“He was also obsessed that any facial hair would suffocate him. So he started shaving for up to seven hours a day, making his face red raw.”

### **Starving himself to death**

Sue had to have John legally committed to a mental health facility.

“This was a horrific experience, as the police were brought into the house in riot gear, and he was dragged out of the house still trying to eat his lunch,” she explains. “My twin Sheila was wonderful. She stepped into the house when [it] happened so that John would blame her rather than me for what happened. This gave her nightmares for quite a considerable period but thankfully did preserve John’s and my relationship.”

Over the next several years, John lost his ability to walk and speak. Eating also became extremely difficult. When asked if he wanted a feeding tube, Sue says in the film, John violently shook his head no.

“John indicated that he’d had enough when he started refusing to eat and drink,” she says. “His quality of life was non-existent, and I knew he wanted it to be over.”

Mercy killing is illegal in the United Kingdom. “My only option was to help him as he starved himself to death,” Sue says plaintively.

John died in 2006. He was 56.

### **‘We have a face’**

At the film’s outset, James declares that the HD monster “caused so many people across the world to hide behind masks, masks of silence.[...] It was time to destroy the monster. Our goal was very simple: to remove the mask of Huntington’s disease.”

He adds: “It was time to show the world that we have a face.”

A former mental health care professional and small business owner forced to quit after his diagnosis, James began work on the film in 2011, with a powerful short showing people taking off masks and saying “I am no longer a faceless face” ([click here](#) to read more).

Before the short, he had never made a film, although he had studied communications, film, and psychology at St. John’s University in Jamaica, NY, for a while in the early 1990s.

James decided a film was the best way to get out the word about the disease.

“It frustrated me and so many people that no one was telling or showing the real truth behind the disease,” he said. “Advocacy is more than walking, fundraising, wine-tasting, and dinners. All of those ways to advocate are important, but they alone were not working. How can we expect the world to know about HD if we are not willing to get outside the box?”

In addition to his work as an advocate, James cares at home for his older brother John, now in the advanced stages of HD, with the assistance of his spouse, Ian V. Torrington. James's father died of HD and cancer. Five other siblings and numerous other relatives are at risk for HD. Ian also cares for James.



*Ian V. Torrington (left) and James Torrington Valvano (personal photo)*

To support the project but also to network globally to raise the profile of HD, James and other advocates from HD families formed [WeHaveAFace.org](http://WeHaveAFace.org).

Recently granted nonprofit status, the organization provides online and mobile support to the HD community. Activities include fundraising for HD research and family assistance, online support groups, the production of a quick reference guide about HD for police and rescue workers, and a mobile application with ample information about HD.

A number of WeHaveAFace.org's U.S.-based regional advocates tell of their struggles with HD in *Removing the Mask*.

According to James, he spent less than \$7,000 on the film, with funds coming from a t-shirt campaign, other small donations, and “heavy hitting on my credit cards.”

#### **‘We need the world to watch’**

According to my conversations with James via Facebook, he and his film team held “dozens upon dozens” of Skype calls and exchanged thousands of e-mails in the background research for the *Removing the Mask*.

Not everybody agreed with James' direct approach. According to him, one advocate broke off from the project “because I was tackling suicide.”

James himself admitted experiencing powerful emotions during the project.

“Filming the topic of suicide was one of the most difficult and painful experiences in my life,” he wrote in a digital journal kept during the production. “As a filmmaker you want to get the rawness of the topic, but as a person with Huntington's disease, my heart and soul ached through every second.”

In the film *Cindy Dupree*, an HD-stricken woman from Alva, Oklahoma, and her husband Ron speak hauntingly about suicide.

“I am not ashamed or afraid to talk openly about suicide, because it affects so many people within the Huntington's community,” says Cindy.

“I know that she battles thoughts of suicide each day, and I fear that I will receive that call that ‘your wife has just taken her life,’” says Ron. “I can only imagine how other caregivers feel. I know they are fighting the same battles we are. I am angry a lot of the time and do my best to realize and understand that it is the disease and not my wife.”

Cindy says that knowing Ron and their three daughters rely on her keeps her “grounded.”

“The documentary was never created for the Huntington's community,” James added. “We had to get outside the box and set our aim on the general public. Although I believe and hope that the film will resonate within our own community, we need the world to watch exactly what we go through.”

#### **How to see the film**

WeHaveAFace.org celebrated the official launching of *Removing the Mask* on June 20 in James's hometown of St. Cloud, FL. He has entered it in about a dozen film festivals in the U.S. and abroad.

It won in the category of best feature documentary in the July 2015 monthly competition of the [Miami Independent Film Festival](#).

James hopes to make the film available to the general public in early 2016 via DVD, Blu-ray, and Vimeo.com. He is also hoping to include it on Netflix and iTunes.

For now, organizations and support groups interested in showing the film as part of an HD awareness-building or fundraising event can do so by [registering at this link](#).

#### **The dilemma of illness**

*The Huntington's Disease Project: Removing the Mask* joins a group of high-quality documentaries about HD launched in recent years, including [The Lion's Mouth Opens](#), a courageous HBO film about filmmaker-actress Marianna Palka's decision to test for the genetic defect.

With its unapologetic presentation of HD, *Removing the Mask* will stir controversy not just about Huntington's, but also the way in which people and institutions deal with the terrible challenges of neurological disorders in general.

After watching the film, I kept remembering the dilemma I faced six years ago when I was directing the construction of an independent website for the [Huntington's Disease Society of America's](#) (HDSA) San Diego chapter, whose board I served on.

Should the homepage use positive, “feel good” images to advance our cause? Or should it show the harsh realities of HD? One of my fellow board members, a public relations specialist not from an HD family, cringed when I showed him some of the photos of gaunt HD-affected individuals I

was proposing for the site. I indeed used some of those photos on the site (which is no longer operative).

I don't know if I did the right thing.

I believe that *Removing the Mask* faces the same dilemma. It's raw, but will it ultimately be effective?

I believe that it *can* be in the health care community. *Removing the Mask* would make a fine multimedia companion to HDSA's *A Physician's Guide to the Management of Huntington's Disease*.

Professionals and students in the medical professions *must* see this film. So must public officials like the administrators at the Social Security Administration and doctors who evaluate HD-affected individuals for disability. And so must general medical practitioners, neurologists, psychiatrists, and others who potentially come into contact with HD patients.

I'm hoping that the Miami festival award indicates that the general public is also ready to help destroy the monster of HD.

*(Note: I have a very small part in the film, where I take off my own mask, but otherwise had nothing to do with the content.)*

Posted by [Gene Veritas](#) at [9:40 PM](#)      

Labels: [advocacy](#) , [behavioral](#) , [clinical trials](#) , [cognitive](#) , [denial](#) , [emotional](#) , [euthanasia](#) , [Huntington's disease](#) , [ignorance](#) , [James Valvano](#) , [misdiagnosis](#) , [suicide](#) , [symptoms](#) , [The Huntington's Disease Project: Removing the Mask](#)

## 2 comments:



**WeHaveAFace.org said...**

Dear Gene,

Thank you so very much for your honest and open review of our documentary! The entire endeavor was very difficult to produce, but worth every second. I am blessed to be part of this international community!

Sincerely,

James Valvano

[5:55 AM, September 05, 2015](#)

**Anonymous said...**

Hi

I have just been told that mum and aunt have H.D. and I am currently being checked. we are in the UK. It has knocked us and I would love to know where we can watch the film and where were talk to people.

Simon

[8:25 AM, September 15, 2015](#)

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