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At Risk for Huntington's Disease

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## Six cool L.A. ladies 'bare the truth' about Huntington's disease, highlighting an exceptionally creative year for advocacy

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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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[Huntington's Disease Society of America](#)

TUESDAY, DECEMBER 23, 2014

## Six cool L.A. ladies 'bare the truth' about Huntington's disease, highlighting an exceptionally creative year for advocacy

From a pie-in-the-face challenge to documentaries to a plan to light up Chicago in blue, Huntington's disease activists rose to new creativity in 2014 in their quest to raise awareness.

One of the most ingenious initiatives, [#BareYourTruth](#), materialized as a photograph of six naked women advocates from the Los Angeles area, their bodies partially shielded by placards with the letters C-U-R-E-H-D.

Tastefully sexy but haunting, [#BareYourTruth](#) captures an essential issue for the HD community: ill and at-risk individuals like me and our families have struggled to [exit the terrible and lonely HD closet](#), tell the world of our plight, and focus society's energies on improved care and the search for remedies for this untreatable neurological disorder.



*From left to right, Rachel Giacomuzzi-Brown, Angelica Randall, DeAnna DeNaro, Adriana Venegas, Taryn Renau, and Amy Morris O'Keefe (photo by #BareYourTruth)*

The goal of [#BareYourTruth](#) is to "share the truth about HD," explained DeAnna DeNaro, 49, a participant in the project. She lost her half-sister Denise DeNaro to HD on February 26.

"There isn't anything fun about Huntington's – it's raw and it's bare," said Deanna in a phone interview on December 21. "When you're naked, it's a rawness, and you're showing everything. If you can do that – to talk about something so raw and painful – 'bare' means you're showing everything. We didn't want to say 'bare your soul.' We wanted to do 'bare your truth.' Each one of us has a truth about Huntington's. When you talk about the truth, being naked is showing everything."

Denise was 59 and had two children, now young adults. In 2001 DeAnna's half-brother Donald DeNaro died at 52. He was believed to have HD. He

[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](#)

had three children, today also young adults. DeAnna, Denise, and Donald shared the same father, but Denise and Donald had a different mother, who had HD. Of DeAnna's five nieces and nephews, only one has tested for the disease. The result was negative. The other four remain untested and at risk.

### Cross-country trips to offer care

For more than a decade, DeAnna traveled an average of five times per year from her home in Redondo Beach, CA, to Miami to help care for Denise. During that time, she has served on the board of the resurgent [Los Angeles chapter](#) of the Huntington's Disease Society of America (HDSA), the last three years as president.

"I would go there a month at a time," DeAnna said. "Each stage that she would enter into, we as a family had to collaborate to evaluate her care and what was the best for her, including her doctors and caregivers."

As a result of her experience with HD, three years ago Deanna left her career as a manager in the construction business and opened a caregiving business. She will continue in that field when she moves next year to Germany, her husband's homeland.



*DeAnna DeNaro (photo by #BareYourTruth)*

### The birth of #BareYourTruth

Denise's death spurred DeAnna to create #BareYourTruth and to recruit other women advocates.

"I am not at risk for HD," Deanna said. "It does affect me personally. Those are my siblings, regardless of the fact that we are half-siblings. We were very close."

The photo shoot (with services donated anonymously by a professional photographer) took place in September. On September 28, a copy of the

photograph was auctioned for \$200 at the HDSA-LA Team Hope Walk, which netted \$76,000 for the organization.

DeAnna witnessed HD for the first time in 1990 when she was 24 and visited Denise and Donald's mother and an HD-affected cousin in a nursing home.

"It was the most horrific thing I have ever seen," DeAnna said. "I was in shock. I learned very quickly that I wouldn't be able to help my sister. It was obvious. I would be watching my sister suffer and die from this disease, which she did. Taking care of my sister was extremely challenging. I feel compelled to do this, now that my sister is gone."

### **Reactions to nudity**

DeAnna at first worried whether the photograph was an appropriate form of advocacy.

"I wasn't sure of how that was going to be perceived," she confided. However, she quickly adopted a "don't care" approach because of the urgency of the HD cause.

"We kind of threw this picture around to a lot of people to see what they would say," DeAnna said. "Not one man said anything sexual about the photograph. And I think they were being honest."

So far, Deanna has gotten only positive feedback: "If you look at the faces, it's so gratifying to see the combination of the pain of HD and our determination to do something about it. I think people are seeing that. They are reacting to what they see in the photograph, not that we're naked. Talking about Huntington's disease can be very difficult for many people. That's how #BareYourTruth came out."

DeAnna's and fellow advocate #BareYourTruth advocate Rachel Giacopuzzi-Brown's husbands at first balked at the idea but, after seeing the photo, "totally loved" it, DeAnna said.

### **A terrifying reality**

In early October the women set up a [#BareYourTruth Facebook page](#), where each has explained her connection to HD. Each has added a phrase to the hashtag #BareYourTruth that reflects each's personal story and its broader meaning for the HD community.

"I think there is still the part of me that is terrified to know the truth for fear that I wouldn't be strong enough to handle it," Adriana Venegas wrote about her decision to test for the HD gene. "#BareYourTruth, even if it terrifies you."

On November 3, Adriana received her result: she tested positive for the gene. In an e-mail, she told me that she is still mentally processing the result.

"You are my sister in HD," I wrote her. "I am gene-positive, too. I am here for whatever you need."



*Adriana Venegas (photo by #BareYourTruth)*

### **Seeking media attention**

"I am now in my early 40s, with two young children and I am at risk for Huntington's disease," wrote Amy Morris O'Keefe. "#BareYourTruth for those at risk."

"Every day I watch my former Marine husband struggle with memory issues, myoclonic seizures, emotional instability, cognitive function, etc.," wrote Rachel, who used the phrase "BareYourTruth for your children." "As these symptoms became harder to hide, we struggled with how to break the news to our three children. In the end we decided that because of the behaviors he was exhibiting it was better to tell them the truth than to have them think that Daddy didn't love them. Ever since that day they have been amazing with him."

Other women have shared their stories and photos. DeAnna and her collaborators have stimulated further discussion with a series of "truths," or brief commentaries, about HD. So far, they have published nearly 60, posting several times a week.

Deanna calculated that through the page her story has reached more than 14,000 people.

#BareYourTruth hopes to attract more media attention. The group is producing a two-minute public service announcement that will include a message from HDSA CEO Louise Vetter, DeAnna said. They plan to post the video on Videolicious.com, with the hope that it will go viral.

### **Catchy initiatives**

"Six very cool L.A. ladies," I texted a friend about the #BareYourTruth initiative.

#BareYourTruth echoes past HD awareness-building efforts such as the "[faceless faces of HD](#)" project created by James Valvano, one of the seeds

in the creation of the advocacy organization [Help for HD International](#).

In 2014, other thought-provoking and catchy initiatives emerged.

At mid-year, HD-affected writer and blogger [Sarah Foster Parker](#) produced an interesting twist on the famous [ALS Ice Bucket Challenge](#) – which raised \$115 million in a matter of weeks – with the creation of the [HD Pie in the Face Challenge](#). This effort increased HD awareness on Twitter and other social media as well as donations to the HD cause.

HDSA's Illinois Chapter has started a petition drive to have several of Chicago's major buildings lit up in blue, the organization's official color, during HD Awareness Month in May 2015 ([click here](#) to read more).

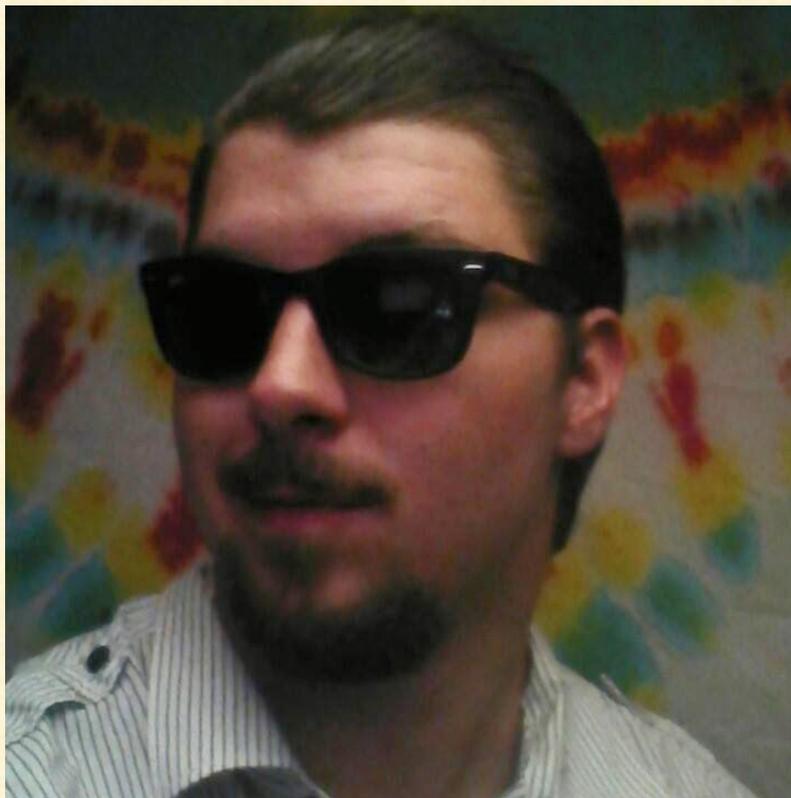
Many other ideas abounded in 2014, too numerous to detail here.

### **Informing the police about HD**

Josh Bane, the nephew of Jeffrey Bane, a West Virginia HD-afflicted man roughly handled by the police as he begged for help, started a [Justice for Jeffrey Bane page](#) on Facebook.

Disturbed by the online video of Jeffrey Bane's mistreatment and the ongoing mishandling of HD patients by police officers, a group of HD advocates set up an information booth at the 121<sup>st</sup> Annual International Association of Chiefs of Police Conference in Orlando, FL, October 26-28.

Some 250 individuals, most with no prior knowledge of HD, obtained information at the booth. ([Click here](#) to read more).



*Josh Bane (personal photo)*

### **A dance, a twitch, and a lion's mouth**

The year brought the release of *three* documentary films about HD. In January, HD patient and activist Chris Furbee's 85-minute *Huntington's*

*Dance* premiered at the Slamdance Festival in Park City, UT, winning a jury special mention for "most compelling personal journey."

Stanford University student and HD advocate Kristen Powers launched her short film *Twitch*, which chronicles her journey to testing for HD. Kristen is currently holding private screenings of the film for the HD community. (I will review the film.)

Director Lucy Walker recently released her short documentary, *The Lion's Mouth Opens*, about filmmaker Marianna Palka's decision to test for HD. The film, which will appear on HBO in spring 2015, has been short-listed for an Academy Award in the short-subject documentary category ([click here](#) to read more).



*Kristen Powers discussing Twitch in San Diego on October 9 (photo by Gene Veritas)*

### **Scientific progress, but urgency for a cure**

Scientists made immense progress on the search for treatments, including the announcement by [Isis Pharmaceuticals, Inc.](#), that it will commence a [gene-silencing clinical trial](#) in the first half of 2015.

The [CHDI Foundation, Inc.](#), the non-profit virtual biotech focused solely on the development of HD treatments, is preparing to sponsor the landmark Tenth Annual HD Therapeutics Conference in Palm Springs, CA, in February.

Noting the legal existence of assisted suicide in some jurisdictions and also the use of non-approved, still experimental drugs in the race to stave off a worldwide Ebola epidemic, HD advocate Andy Meinen wondered why HD patients could not receive potential drugs still undergoing testing.

"Allow the dying to determine which risks they will choose for themselves," Andy wrote on his [Facebook site](#). "Ebola is hell, so is HD, give us our treatments now."

He added in a Facebook message to me: "Once adequately informed of the risks inherent to experimental treatments, patients should have access to

those drugs without interference from regulators.”

That's a controversial idea. (I will explore the context and implications of Andy's ideas in a future article.) Nevertheless, Andy made a valuable observation about how clinical protocols might need adjustment as both the challenges of disease and the potential of science evolve.

In 2015, the HD community will once again need creative, sharp-thinking advocates to drive home the demand for better care and a cure.

As I enter my eleventh year as an HD blogger, I'll do my best to report on new initiatives.

Posted by [Gene Veritas](#) at [12:36 AM](#)      

Labels: [#BareYourTruth](#) , [advocacy](#) , [awareness](#) , [caregiving](#) , [clinical trial](#) , [DeAnna DeNaro](#) , [gene-positive](#) , [HD closet](#) , [HDSA](#) , [Huntington's Dance](#) , [Huntington's disease](#) , [tested positive](#) , [The Lion's Mouth Opens](#) , [truth](#) , [Twitch](#)

## 2 comments:

### **Anonymous said...**

Enjoyed your blog post, as always. Thanks for raising awareness and, more significantly, thanks for supporting the HD community.

Best,  
Allie

[3:50 AM, December 30, 2014](#)



### **Unknown said...**

I want to post something before I decide not to out of shyness. I read your blog and emphasize in many ways. I have a sclerosing neurological illness with intractable neurological pain. I was diagnosed with Lupus and MS a few years later. I can't remember where I first read about HD, but it captured something for me, the incredible strength of humanity fighting against inhumanity maybe. I was in a coma last year and run up against some serious discrimination in my school (if i have to go to the hospital and withdraw from a semester they're going to ask me to leave, I was told not to talk about continuing to struggle on my application back, etc). In a way I suppose I've been more effected than you if you haven't had symptoms yet, but knowing my reality as can be seen by progressions on MRIs...i know what the future looks like. I still plan for a future, though. I am getting my genetics class to watch a film or documentary on HD (probably in 3 weeks around) and was wondering if you had any recommendations? You can email me at [Adreamofform@gmail.com](mailto:Adreamofform@gmail.com) if you want--id like it, although you certainly don't have to! Oh--Im a female, 30, if you were wondering!

Best,  
J

[7:23 PM, February 11, 2017](#)

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