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At Risk for Huntington's Disease

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## 'None of us are free until we are all free': science and solidarity at the 10th Annual Huntington's Disease Therapeutic Conference

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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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## About Me

 GENE VERITAS

[View my complete profile](#)

THURSDAY, FEBRUARY 26, 2015

## 'None of us are free until we are all free': science and solidarity at the 10th Annual Huntington's Disease Therapeutics Conference

Riding the emotion of a keynote speech by a young scientist at risk for Huntington's disease, and seeking treatments with the immense help of a non-profit foundation, the participants at a historic research conference this week witnessed the fusion of science and human solidarity ultimately necessary for defeating HD.

On the evening of February 23, I and the approximately 300 attendees at the 10th Annual HD Therapeutics Conference, sponsored by the [CHDI Foundation, Inc.](#), listened as Jeff Carroll, Ph.D., recounted his mother's demise from HD, his positive test for the HD genetic mutation, and his decision to pursue a career in science to save himself and others from HD.

"He's an interesting combination of things in terms of being an advocate in the community, in terms of being someone from an HD family, in terms of being a top-flight researcher in the HD community, in terms of being a great communicator – he and his partner Ed Wild – in establishing [HDBuzz](#), which is just a tremendously useful model of how to communicate results out to the rest of the community," Robert Pacifici, Ph.D., CHDI's chief scientific officer, said in introducing Dr. Carroll at the conference in Palm Springs, CA.

As an HD researcher-advocate who has attended all ten therapeutics conferences since 2006, Dr. Carroll offered a uniquely qualified, candid assessment of the progress towards treatments and CHDI's role in the process.

"Every year, I come home revitalized and energized by the site of so many smart people working so hard on this problem," Dr. Carroll, 37, told the audience in the main ballroom at the [Parker Palm Springs](#) hotel. He expressed his profound gratitude to CHDI, which has funded his and numerous other scientists' research.

### Painful progress toward success

However, success depends on the "efficient and timely completion of well-designed Phase III trials with HD drugs," Dr. Carroll continued.

"A few weeks ago I attended a meeting at the Princeton CHDI office that included attendees from major pharmaceutical companies currently running HD clinical trials," he said. "They are deeply concerned about something that would never have occurred to me to worry about, which is poor recruitment for trials of Huntington's disease drugs.

"On reflection, it makes sense that the HD community may be wary of the way we have been speaking to them. Participating in the first clinical trial

## 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](#)

of a new molecule might be exciting, but participants of the third could be excused for having some questions.”

Trial administrators put participants through a daunting number of tests, he observed, which may discourage people from participating in more than one trial. Because trials are extremely expensive, sponsors often try to maximize the findings in Phase II, but not enough trials are reaching Phase III, he added.

“It must be said the scale of what is possible here must be unique in human history,” Dr. Carroll said of the efforts by CHDI, which has put more than \$700 million towards treatments. “Resources on the scale being deployed by CHDI have been spent on common diseases, but never before have they been spent on such a focused attempt to ameliorate a rare disease.”

The HD community will achieve “something never done before” or “fail majestically,” he quipped with irony.

He added: “We might actually be watching the painful progress toward success.”

You can watch Dr. Carroll’s speech in the video below.



### None of Us Are Free Until We Are All Free: A Keynote Speech on Huntington's Disease by Dr. Jeff Carroll

from [Gene Veritas](#)

1:02:28 |

[None of Us Are Free Until We Are All Free: A Keynote Speech on Huntington's Disease by Dr. Jeff Carroll](#) from [Gene Veritas](#) on [Vimeo](#).

### Our brothers and sisters

After Dr. Carroll and his wife Meghan had HD-free twins, thanks to [preimplantation genetic diagnosis](#) (PGD), he believed that “HD is done killing people in my family until I am gone,” he recalled.

However, recently two at-risk babies were born in his extended family.

“For a brief window, my family was the last that had to face this awful threat,” Dr. Carroll said. “But the arrival of these children has reminded me that none of us are free until we are all free.”

We must “raise up those of our brothers and sisters still suffering,” he concluded.

Like me, Dr. Carroll is racing against the genetic clock.

### Crying for our community

This conference, my fifth, has proved especially poignant for me personally – even more so than the 2011 meeting, which I [keynoted](#). In terms of the quest for HD treatments, it has been a landmark event. (My next article will provide an overview of the conference's scientific aspects.)

I was both deeply saddened and heartened by Dr. Carroll's story. I relived my own mother's death from HD in 2006, [my positive test](#) for the gene in 1999, and my daughter's negative test for HD in the womb (PGD was unavailable) in 2000.

It was one of the best speeches I have heard in two decades of observing the HD movement. Dr. Carroll tempered his enthusiasm and compassion for the HD community with hard-nosed, no-nonsense scientific analysis.

For the evening of February 25, the conference organizers arranged for a surprise outdoor screening of the 28-minute documentary *The Lion's Mouth Opens*, about actress, director, and producer Marianna Palka's positive test for HD. The film made the 2015 Academy Awards shortlist for Best Documentary Short.

As part of the surprise, Marianna, whom I had met earlier in the day, took questions from the audience. She appeared at the edge of the crowd, next to me, just as the film was ending.



*Gene Veritas (left, aka Kenneth P. Serbin), Marianna Palka, and Louise Vetter, CEO of the [Huntington's Disease Society of America](#) (photo by Jerry Turner, CHDI)*

It was a highly emotional experience for me. Filled with anger, frustration, and overwhelming sadness that a young person like Marianna should have to face HD, and once again reliving the trauma of my own HD test and the excruciating experience of testing our daughter, I hugged Marianna and cried uncontrollably for several minutes as she held and consoled me.

*It's so unjust that people have to face HD, I thought to myself.*

I hardly ever let myself think that, trying to be strong, but at that moment I allowed myself to do so, and also to let loose all of the powerful emotions of the conference.

I told Marianna I was so sorry for her.

Marianna, who is just 33, was strong, telling me that we would all work together against HD.

After the film finished, Marianna talked with the audience about her experience of genetic testing, her strategies for staying healthy, and her work in film. She observed that *The Lion's Mouth Opens* makes men cry.

You can watch Marianna's exchange with the audience in the video below.



## 'The Lion's Mouth Opens' and Marianna Palka on Huntington's disease

from [Gene Veritas](#)

22:46



'The Lion's Mouth Opens' and Marianna Palka on Huntington's disease from [Gene Veritas](#) on [Vimeo](#).

### Enrolling families in the fight

At the start of the conference, I had lunched with Joe Giuliano, the CHDI director of clinical operations in Princeton, N.J., HD advocate [Jimmy Pollard](#), and Chris Brown, a scientist from Evotec, a drug discovery company headquartered in Germany.

We pondered the same critical issue raised by Dr. Carroll, and that brave advocates like Marianna impel us to consider: how to inspire more families in the HD community to become involved in research studies and clinical trials.

I recalled my own speeches and blog articles about the terrible barriers to greater involvement: ignorance, fear, denial, stigma, and family tensions.

Giuliano is also the chief CHDI administrator for the [Enroll-HD](#) program, a global platform, research project, and HD patient and family registry aimed at facilitating clinical trials and the discovery of treatments. As Giuliano and others have noted, it is not scientists who cure diseases, but the patients who participate in clinical trials.

That observation provides a fitting coda to Dr. Carroll's speech.

And it underscores the absolute necessity to fuse science and solidarity in the fight against not just HD, but all diseases.

For an update on Enroll-HD, watch my interview with Giuliano below.



## An Update on Enroll-HD

from [Gene Veritas](#)

09:57

[An Update on Enroll-HD](#) from [Gene Veritas](#) on [Vimeo](#).

### A personal landmark, and gratitude

With this article I have completed my own HD milestone: it is the 200th post in this blog.

I am grateful to so many: God, my wife and daughter, my HD-victimized mother Carol Serbin, my HD-warrior father Paul Serbin, who died with a broken heart in 2009, CHDI, and the entire HD community.

Although I worry that my overly emotional response to the conference could signal the mood swings characteristic of early HD onset, I am also grateful that I remain, according to my last neurological checkup, asymptomatic.

As I prepared to depart the conference, I pondered how the HD movement can reinforce human solidarity and our bond with the researchers.

Posted by [Gene Veritas](#) at [11:24 AM](#)     

Labels: [CHDI Foundation](#) , [clinical trials](#) , [Enroll-HD](#) , [HD genetic mutation](#) , [HD Therapeutics Conference](#) , [Huntington's disease](#) , [Into the Lion's Mouth](#) , [Jeff Carroll](#) , [Marianna Palka](#) , [research](#) , [science](#) , [solidarity](#) , [treatments](#)

### 3 comments:

#### Alice said...

There is a clinical trial in Massachusetts General Hospital that can help those has the mutated gene. They have a a high dose treatment with nutritional supplement creatine. I am not eligible for the study last year.

<http://www.massgeneral.org/about/pressrelease.aspx?id=1674>

[8:18 AM, February 27, 2015](#)

#### Jimmy Pollard said...

Ken!!!

I finally got to meet you in person!!!

I just want to pass on one observation about YOU to some other longtime readers of your work who may not have had the opportunity to see themselves. I have never seen anyone work harder and longer at a conference than you did in Palm Springs, and that includes professional career science withers covering them. Interviewing, recording, writing, tracking folks down, encouraging participants, lugging equipment around...you give a new meaning to "covering a meeting." I know it's a "labor of love," but, man, to the depth you do it, it's a lot of labor!!! The word "indefatigable" came to mind every time I saw you!!! A tip of the cap to you, Ken! Hope our paths cross again...but grateful this blog introduced us long ago!!!

7:28 PM, March 01, 2015

**Anonymous said...**

Thank you so much for the work you do on behalf of HD! Coming from a community with only a couple of doctors who have specific knowledge about the disease, this blog, along with HD Buzz and a few other sites, have proven invaluable for providing information and hope! I do think it's imperative those families affected with HD get the information necessary to enroll in clinical trials. This is something missing in my family's struggle with HD.

1:43 AM, March 09, 2015

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