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At Risk for Huntington's Disease

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10-21-2012

## Hope of clinical trials creates new, proactive outlook on Huntington's disease

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Serbin, Kenneth P., "Hope of clinical trials creates new, proactive outlook on Huntington's disease" (2012).  
*At Risk for Huntington's Disease*. 136.  
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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.*

## Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▼ 2012 (26)
  - ▶ December (2)
  - ▶ November (3)
  - ▼ October (1)
    - [Hope of clinical trials creates new, proactive out...](#)
  - ▶ September (2)
  - ▶ August (2)
  - ▶ June (2)
  - ▶ May (1)
  - ▶ April (2)
  - ▶ March (3)
  - ▶ February (3)
  - ▶ January (5)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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## HD Links

[Huntington's Disease Society of America](#)  
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SUNDAY, OCTOBER 21, 2012

## Hope of clinical trials creates new, proactive outlook on Huntington's disease

A diagnosis or positive genetic test for Huntington's disease has always meant a terrible, prolonged death sentence. However, the vast, growing body of knowledge about the disease and the genuine hope of clinical trials have opened the door to a more optimistic, proactive outlook on HD.

That's the message I've transmitted in recent speeches, including one titled "Genuine Hope for Huntington's Disease Treatments: New Ways of Thinking about HD," the keynote for the event "Living with Huntington's: An HD Education Day," held by the [North Carolina Chapter](#) of the Huntington's Disease Society of America (HDSA) on May 12.

"It was a very, very hopeless situation," I told the audience in describing my mother's diagnosis with HD in 1995 and my positive test for the condition in 1999. We in the HD community kept hearing that there was no "effective way of stopping Huntington's."

In recent years, however, the increase in research and the promise of potential treatments have brought about "the transition from hopelessness to hope."

Read on for a summary of the speech's main points. You can also watch it in the video below.



## Genuine Hope for Huntington's Disease Treatments: New Ways of Thinking about HD

from [Gene Veritas](#)

34:25 |

[2012 North Carolina HD Talk from Gene Veritas on Vimeo.](#)

**Our lives are not lost**

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[Heather's Huntington's Disease Page](#)

I drove home the idea of hope by discussing the worldwide effort to end HD and the imminence of potential trials, including the one aimed by Isis Pharmaceuticals, Inc., [to silence the HD gene](#) and expected to begin by late 2013 or early 2014, and, if successful, to result in a drug perhaps by 2020.

“These are real people in the labs,” I emphasized, showing a photo of Isis scientists at the company’s Carlsbad, CA, facility. “We think of scientists as people in these white coats, maybe wearing really thick glasses, or having really pointy heads, sitting in a lab. But they’re everyday people just like all of us, and they want to see the treatments.”

“It’s time for a new outlook,” I continued, recalling the HDSA slogan “let’s make this the last generation with HD.” “That seemed like a dream ten or 15 years ago, but now I think we’re closer to that becoming a reality.”

Rather than slip into the old, depressing notion that HD is untreatable, we now must embrace a new phrase: “HD will be treatable.”

“It’s more and more a question of not if, but when this is going to happen,” I said, noting that scientists are now [“genuinely optimistic”](#) about potential treatments. “We need to tell ourselves everyday: there is hope, and my life is not lost.”

### **A more proactive view of genetic testing, self-care**

Because of the hope provided by research, fear of genetic testing “can and should diminish,” I observed. Gene-positive people can plan for the future by maximizing their physical, emotional, and spiritual health and putting in order matters related to insurance coverage, career, finances, and family planning.

They can and should also participate in current or future trials requiring gene-positive, asymptomatic participants, I said.

“You can give back to the community at large by participating in the search for treatments,” I added.

“So yes, testing is scary, there’s no doubt about it,” I said. “But I think now testing is ultimately proactive. I think we need to turn around the way that people think of testing as something so intimidating and scary, a life-ending experience.”

### **Overcoming denial, spurring participation**

I began and ended the presentation with a reflection on the roadblocks to our success.

“We know that there are a lot of HD families that could not make it here or didn’t want to be here today,” I said. “Part of the reason there aren’t more people in the room is because we struggle in Huntington’s with a terrible stigma, and along with that stigma comes shame, fear, and one of my worst enemies of all, denial.”





Denial affects *all* of us because it discourages the participation in clinical trials and therefore hinders scientists from effectively testing potential treatments.

To engage others in the process, we cannot preach or harass, but must pursue a gentle approach. Most importantly, we need to live by example, to keep telling our personal stories, “opening your heart to others” and educating them about the trials.

“We need to live optimistically, on a daily basis,” I concluded. “Yes, HD is a terrible cross to bear. But I think that knowing we can be part of the solution, that we can help the scientists, help the doctors find a treatment, this is something that gives us a sense of purpose, gives us a sense of being part of something larger

than ourselves. It's not just me, it's not just my family. It's people around the world who are affected by Huntington's, and other conditions."

(For additional thoughts about the new outlook on HD, please [click here.](#))

Posted by [Gene Veritas](#) at [1:05 PM](#)    

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