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At Risk for Huntington's Disease

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Striving to overcome the doom of Huntington's disease

Kenneth P. Serbin
University of San Diego

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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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MONDAY, FEBRUARY 24, 2020

Striving to overcome the doom of Huntington's disease

Usually, I experience a [whirlwind of emotions](#) during and especially immediately after the annual Huntington's Disease Therapeutics Conference, held in Palm Springs, CA.

This year, however, intensifying my advocacy in what I call the "HD movement," I feel that I've reached another level of engagement. Paradoxically, at the same time, I feel that I've attained greater calm and insight regarding the disease and its impact on the community.

After my [last article](#) – on the pathbreaking scientific evidence suggesting how and why the HD age of onset varies widely and how I've reached 60 healthy – I've read stories in Facebook HD groups confirming that variability.

Some pointed to extremely early, very tragic onset, but others resonated with my (very fortunate) situation of having gone more than a decade beyond the point of my mother's first symptoms. Significantly, scientists are seeking ways to use the biological mechanisms behind delayed onset to produce treatments.

As I pondered those more optimistic scenarios, I thought: "Does HD have to be only a story of doom?"

Clearly, in many instances, it still *is*.

On February 19, at the packed, moving [screening](#) of the HD documentary *Dancing at the Vatican* at my university, one HD family member recalled how, out of ignorance, both a parent and a grandparent had been kept in a straightjacket.

However, the collective celebration of the film's portrayal of Pope Francis' historic audience with HD families in Rome also demonstrated how far the HD cause has come. Thanks to Francis – but also to thousands of family members and advocates around the world – HD is ["hidden no more."](#)

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
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HD Blogs and Individuals

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A life-size stand-up poster of Pope Francis at the February 19 screening of Dancing at the Vatican at the University of San Diego (photo by Gene Veritas)

How far we've come

An illuminating panel discussion at the screening illustrated how awareness has grown on all fronts. The presence of representatives from four biotech sponsors underscored the growing commitment to discover effective treatments.

The evening of February 21, the mother of a young man who died of juvenile HD left me a voicemail. She spoke of how the near-20-year struggle to care for her son led her to develop bipolar disorder and PTSD.

That sounds devastating. However, she also reminded me of an important trend in the HD community, in which the affected are no longer referred to as “HD people” but as “people with HD.”







“You’re not Huntington’s disease,” she said. “How could I ever look at my son and think, ‘disease?’”

At this evening’s opening of the 15th Annual HD Therapeutics Conference, sponsored by [CHDI Foundation, Inc.](#), I will have renewed hope for the development of effective treatments. As understanding of the disease has evolved, so have the approaches to achieving those treatments.

On February 27, conference attendees will hear a report on a clinical study investigating RG6042, the gene-silencing drug also currently under evaluation in a [Phase 3 clinical trial](#) run by [Roche](#).

If successful, that trial will have produced the first treatment to slow, halt, and perhaps even reverse HD.

That could signal the end of doom for tens of thousands of HD-affected families around the world.

Posted by [Gene Veritas](#) at [10:40 AM](#)      

Labels: [advocacy](#) , [biotech](#) , [CHDI Foundation](#) , [clinical trials](#) , [Dancing at the Vatican](#) , [emotions](#) , [gene silencing](#) , [HD Therapeutics Conference](#) , [Hidden No More](#) , [Huntington's disease](#) , [onset](#) , [Pope Francis](#) , [RG6042](#) , [Roche](#)

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