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A holiday message: hope for the forsaken of Huntington's

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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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SATURDAY, APRIL 11, 2009

A holiday message: hope for the forsaken of Huntington's

Growing up Catholic, I was always both bewildered and impressed by Jesus's words on the cross on Good Friday: "My God, my God, why have you forsaken me?"

I wondered: why would God the Father – Jesus's own father! – abandon his son? At that moment, dying for all of humankind, Jesus hung on the cross in utter loneliness.

As I have contemplated Passover, Holy Week, and Easter in light of my gene-positive status for Huntington's, it struck me that HD patients and their caregivers must often feel just as forsaken in their daily struggles against this condition that destroys the brain.

Bearing burdens

After writing about my family's decision to borrow money for us to build and enjoy a swimming pool while I am still healthy (click [here](#) to read the entry), I received an e-mail from a caregiver. Her husband died young of HD, and her adult daughter now has the disease.

"I am wide awake at 3:26 a.m.," she wrote in telling me of her many burdens and reminding me of the many nights my wife has lost sleep in worrying about my health. She continued, "I don't think there is anything as ugly as HD. Satan did a good job creating this one! If I could only stop, for just a day." But she didn't give up and has started a Huntington's disease support group.

This past week I also met a brave woman, Missy, through [WeAreHD.org](#) (the Social Support Network of Huntington's Disease). Her late husband had been diagnosed with HD when she was eight weeks pregnant with their second child.

Men usually pass on HD in a far worse form than women, and this also results in their children getting the disease much earlier. The father died in November 2007. Only two months later, the couple's oldest child, Jordan, was diagnosed with juvenile Huntington's disease. Now 13, Jordan already experiences the involuntary movements, known as chorea, that ultimately stop HD people from working and walking.

I was shocked to read that Jordan has 73 CAG repeats. (Everybody has the huntingtin gene, but the repeats of the CAG trinucleotide are normally no higher than 30.) I have 40 and am on the cusp of what is defined as HD. The number 73 is phenomenally high. In general, the higher the number of repeats, the earlier onset will occur and the more severe the disease will become. That's why Jordan is already so deeply affected.

Here is how Missy describes her daughter's symptoms on her page at [WeAreHD.org](#): "twitching, choking, decline in school work, abnormal gait,

[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](#)

decline in speech, some falling, mild depression, some memory loss. Dementia is starting to come into play.”

Missy urged us to get our pool and enjoy our time together. She told me how Jordan had an easier time with mobility when she entered a pool in Florida during a trip away from the family's home state of Wyoming.

I was deeply moved by the image of a young person being struck down by HD just as she was beginning the transition to full awareness about her body, her surroundings, and her life. I thought of her enjoying the warm water of the pool despite the curse of Huntington's.

Feeling abandoned

And I wondered how forsaken she must sometimes feel. Where was the God of the Passover who spared the first-born of the Israelites while ravaging the households of the sinful Egyptians?

On Good Friday I listened to one friend tell of another's struggle to deal with a recent and rapid onset of multiple sclerosis. Like HD, MS is a disease of the central nervous system. Our friend is having spasticity (impairment of the muscles). She is only in her forties but could be relying on a wheelchair in as few as seven years.

Thinking of my own mother's death because of HD three years ago, I could not bear to listen to our friend's plight and had to turn away. How long will it be before I start to show symptoms and lose the ability to walk, talk, swallow, and think?

I too felt forsaken.

But, according to the Bible, God delivered the Israelites to the Promised Land.

And less than three days after Christ died on the cross, He rose from the dead.

Finding hope

The Passover and Christ's Resurrection are two of the most unbelievable stories ever told. Through the centuries, these stories have motivated billions of believers in numerous religious traditions. Today many people still believe in the literal intervention of God on behalf of the Israelites and in the Resurrection. Others are indifferent or discount these stories as superstition.

They are undeniably stories of salvation that all people can relate to. An overburdened caregiver's attention to the sick is akin to the men carrying the dead Jesus to the tomb. The yearning for a cure for a girl with juvenile Huntington's is like the hope of the Israelites in Egypt.

What human being has not struggled with the inevitability of death? Families struck with Huntington's feel it all too soon and all too poignantly. But, as Jesus exhorted people to do, Huntington's families take up their cross and move on with life.

The Promised Land and the Resurrection are their hope – a land and an existence enjoyed with the fullness of life and without twitching, choking, depression, or dementia.

The prophets and Jesus asked their followers to believe in the possibility of such a life. In effect, they asked people to believe in the seemingly impossible. Today, scientists are making immense strides in finding treatments and perhaps even a cure for a disease that not so long ago seemed incurable. Like the faithful of the past, Huntington's disease

families can persevere if they're willing to believe in the possibility of the cure and dedicate themselves – no matter how modestly – to the cause.

Posted by [Gene Veritas](#) at [11:27 PM](#)      

2 comments:

 **Anonymous said...**

Gene,

This entry just made me smile! Although it's so hard to read about these things, I also have hope. I KNOW, I FEEL, that there WILL be a cure for this! Everyday bigger things are happening! Thank you for sharing your story, and Jordan's. You totally inspire me, and put a huge smile on my face each and everytime you contact me! AMAZING! Today is a day to rejoice, and be happy! And I plan to do JUST that. Jordan and Sara are sitting with me, and it's a GOOD day! Thank you my friend for opening your heart, sharing your feelings, and just being who you are! You've truly blessed me in the short time we've been talking. May God Bless You, today and ALWAYS!

In his name,

Missy

[6:37 AM, April 12, 2009](#)

 **Anonymous said...**

WOW! You are amazing. My brother Danny has HD and I will never give up hope! Thank you for inspiring me.

Amy

[10:16 AM, April 13, 2009](#)

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