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At Risk for Huntington's Disease

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The gifts

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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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HD Links

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

FRIDAY, DECEMBER 21, 2012

The gifts

Christmas brings the profoundly sad reminder of receiving the news of my mother's diagnosis of Huntington's disease on December 26, 1995. She died of HD in 2006 at the age of 68. Remembering her struggle also reminds me that I tested positive for HD in 1999.

This year, however, I've been preparing for Christmas differently by reflecting on the wonderful gifts I've received.

Life itself is a precious gift. I was born because of my parents' love for each other and their desire to raise a family.

My life is also a gift from God.

I am extremely lucky to have the gift of health. Each day, I am pained by the suffering endured by families afflicted with the disease. However, as I look forward to my 53rd birthday on December 31, I am deeply thankful to have remained asymptomatic past the age of my mother's probable onset, her late forties.

The gift of health allows me to continue my work as an HD advocate, fighting for those who cannot fight for themselves and promoting the search for effective treatments.

Just last month [I exited the terrible and lonely "Huntington's closet"](#) by revealing my story and using my real name, Kenneth P. Serbin, in a mainstream publication. On December 16, [I repeated the experience in Brazil](#), where I am a recognized scholar and regular guest writer in the press; I received a tremendously moving response from friends and even former leading government officials.

For the first time in the 17 years of my journey with HD, I can advocate for the cause freely and openly, thus multiplying the impact of my efforts and honoring the memory of my "HD warrior" parents.

More than ever, I feel the need to help others. This desire and responsibility form the basis of all the great religious traditions.

In my Catholic faith, the advent of Baby Jesus, who came to save the world from imperfection and death, culminated in one of the greatest commandments to humankind: to love our neighbors as ourselves.

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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)



My family's miniature nativity scene, made by an artist in Latin America

In the wake of my exit from the HD closet, I have achieved an incredible sense of lightness and greater closeness to others. Friends have seen it in my face and felt my passion for the cause.

“The truth will set you free,” Jesus said. In recent days, I have also felt closer to God than I have in a long time. Thinking of the drive to defeat HD, I have recalled His mission: “I have come that they might have life, and have it more abundantly.”

My greatest gift is my family.

In January 2000, my wife Regina and I received the gift of our daughter Bianca's negative test for Huntington's while in the womb.

Together Regina and I nurtured her, and now we must help her navigate the challenging and rewarding teenage years.

In this very difficult past week, as we Americans have struggled to comprehend the senseless Newtown school massacre, I have frequently recalled President Barack Obama's beautiful description of parenting: “Someone once described the joy and anxiety of parenthood as the equivalent of having your heart outside of your body all the time, walking around.”







Faced with so many extraordinary demands and risks, HD families especially feel that anxiety. Yet we also have great gifts – including an immense capacity to appreciate the gift of life and the impact that a disease like HD can have on children.

My challenge is to preserve my gift of health so that I can love and support Regina and Bianca for many years to come.

To you and yours, Merry Christmas, Happy Holidays, and a 2013 filled with the gifts of hope and good health!

Our 2012 holiday greetings photo, taken at Yosemite National Park



Posted by [Gene Veritas](#) at 4:11 PM      

Labels: [advocate](#) , [anxiety](#) , [asymptomatic](#) , [Brazil](#) , [Catholic](#) , [closet](#) , [diagnosis](#) , [faith](#) , [family](#) , [God](#) , [HD warrior](#) , [health](#) , [Huntington's](#) , [Jesus](#) , [love](#) , [mother](#) , [onset](#) , [tested positive](#) , [treatment](#)

2 comments:




 **[Deshalamar](#) said...**

Hope you and your family have a wonderful Holiday Gene!

[5:35 PM, December 21, 2012](#)



 **[Thumper!](#) said...**

Thank you for those healing words. God bless you and your family, may you all have a holy, peaceful and happy Christmas time.

[2:50 AM, December 22, 2012](#)

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