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At Risk for Huntington's Disease

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## My arduous, lucky, and enlightening journey since my mother's death from Huntington's disease 15 years ago

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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 08, 2021

## My arduous, lucky, and enlightening journey since my mother's death from Huntington's disease 15 years ago

February 13, 2021, will mark fifteen years since my mother Carol Serbin died in 2006 after a two-decade fight against Huntington's disease. She was 68.

Recalling her struggles and taking stock of my own predicament as an HD gene carrier have stirred me to reflect on my arduous, lucky, and enlightening journey since her death. Greater maturity and experience have also afforded me a deeper perspective on the HD cause as a whole.

My mother was diagnosed with HD in 1995, just two years after the discovery of the huntingtin gene. That breakthrough permitted the development of a genetic test confirming passage of the disease from one generation to the next. However, in retrospect, her symptoms probably had begun in the late 1980s, when she was in her late 40s.

### The arduous years

Given Carol's inexorable physical, cognitive, and emotional decline and the lack of treatments, in July 2005 my "HD warrior" caregiver father Paul Serbin sadly concluded that she needed 24/7 care in a [nursing home](#).

Her move to the nursing facility greatly eased the caregiving burden on my father, although he faithfully visited her daily, still spoon-feeding her as he had done at home.



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## HD Blogs and Individuals

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It also freed him to travel from their home state of Ohio to spend Thanksgiving of 2005 with my wife Regina, our five-year-old daughter Bianca, and me at our place in San Diego.

“I didn't know how much I loved your mother until these past few years, taking care of her and seeing how much she has lost,” my usually stoic father [confided in me](#).



*Paul Serbin pushing Carol Serbin in wheelchair (photo by Gene Veritas, aka Kenneth P. Serbin)*

From my standpoint, my mother was descending into an HD hell. Psychologically, this became the roughest period of my life. Not only was she was dying. I, too, had tested positive for the HD gene in 1999, so watching her decline was like “looking into the genetic mirror” that reflected my own future.

After my mother steadily lost the ability to swallow, in January 2006 I helped my father make the wrenching decision not to approve a [feeding tube](#), which would at best have prolonged her physical life but left her bedridden, unable to communicate.

On the weekend of January 28-29, 2006, with my mother in hospice care at the nursing home, I flew to Ohio to visit her for

what I knew could be the last time. With almost indescribable emotion, I said good-bye to my mother and, once again, gazed into the genetic mirror. This time it revealed a practically lifeless individual, barely able to move and unable to speak ([click here](#) to read more).

After that visit, and then learning that she had died in her sleep the morning of Monday, February 13, 2006, I felt utterly distraught about my gene-positive status.

In the months after her passing, I felt so terrified about getting HD that I began [to act out](#) some of the disease's physical symptoms in front of my wife and daughter. I could not write anything in this blog for eight months.

My father, suffering his own severe cognitive loss likely accelerated by the loss of his wife, [died](#) on September 25, 2009, with a broken heart.

### **Tons of luck, and some positive strategies**

I have now been without parents so long that memories of them feel like a distant past.

At 61, still without any apparent symptoms of HD, I feel extremely lucky. Each moment of good health is a blessing.

I have practiced personal and social enrichment, which scientists have recommended.

I have the benefit of a stable, good-paying job. Also, as the centrality of my parents faded, my roles as husband and father became paramount. Bianca became the center of our lives. Regina's and Bianca's love and support have proved crucial.

Also, because Bianca tested negative for HD in the womb, we have averted enormous health, financial, and psychological burdens ([click here](#) to read more).





*The Serbin Family Team of the 2014 HDSA-San Diego Team Hope Walk: from left to right, Dory Bertics, Bianca Serbin, Jane Rappoport, Gary Boggs, Yi Sun, Kenneth Serbin, Regina Serbin, and Allan Rappoport (photo by Bob Walker)*

I also exercise regularly, meditate daily, take medications to control depression and anxiety, and have a solid, long-term relationship with a psychotherapist.

I cannot be sure whether any of these things have staved off HD, but they generally bolster health.

Significantly, scientists have discovered very powerful explanations for why I am might have stayed asymptomatic so long: genetic factors, including modifier genes, that [delay disease onset](#).

### **Gaining enlightenment about HD**

Becoming enlightened about HD research and [building bonds](#) with scientists have reinforced both my advocacy and personal enrichment.

As a college professor, HD advocate, and explainer of the science – both in this blog and in [interviews](#) with researchers – I have had a privileged window on the quest for treatments. I have thoroughly enjoyed this work.

Moreover, I have gained great satisfaction in encouraging HD families to participate in research studies, platforms like [Enroll-](#)

[HD](#), and clinical trials.

Witnessing the progress towards treatments has also boosted my hope to participate someday in an HD clinical trial and, ultimately, enjoy the benefits of the first wave of effective treatments.

Overall, I believe that becoming enlightened about HD has helped me become a better person.

### **Pride**

My devout Catholic parents – when I was a child, my father especially had hoped that I would become a priest – would have been especially proud of my family's participation in [#HDdenmore](#), Pope Francis' special audience with the Huntington's community in Rome in May 2017.

The pope [declared](#) HD to be “hidden no more” from the world.

I presented Pope Francis with a framed photo of my parents, well-dressed and smiling in a formal pose, taken after my mother had already been diagnosed with HD.

“My mother died of Huntington's,” I told the Pope in his native tongue of Spanish. “My father cared for her for 20 years.”

In September 2017, I gave a [presentation](#) on [#HDdenmore](#) at my workplace, the University of San Diego. In February 2020, just before the COVID-19 crisis hit, I organized a [screening](#) of the poignant documentary on the papal audience, *Dancing at the Vatican*. It was well-attended by members of the local HD community.

Pope Francis displayed great love and mercy for our community.





*Photo of Paul and Carol Serbin presented to Pope Francis by Kenneth Serbin, May 18, 2017. Photo taken shortly after Carol's diagnosis for Huntington's disease in 1995 (family photo).*

### **Tributes, and imagining a world without HD**

In many ways, since its inception sixteen years ago in January 2005, this blog has paid tribute to my parents. I have also honored the lives of other HD-affected people who valiantly fought against the disease such as [Steve Topper](#) and [Harriet Hartl](#).

In these years since my mother's departure, I have often wondered what our lives would have been like without the scourge of HD. This April 30, my mother would have turned 84 – within a plausible lifespan nowadays.







How wonderful it would have been had my mother – who could not interact with Bianca as a baby and toddler – been able to see her granddaughter reach college and to see Regina and me next year mark 30 years of marriage.

I can forge the greatest of tributes to my parents by continuing to nurture my health and hopefully secure a longer life so that I can grow old with Regina and see Bianca go out into the world.

When we learned of my mother's diagnosis in 1995, there was no real hope of an HD treatment. However, since her death, research and the advent of clinical trials have brought unprecedented hope. As we've seen in response to the coronavirus pandemic, science can make great strides.

In unison with others, I can honor my parents by renewing the fight for Huntington's treatments so that thousands of families around the world can be freed from witnessing loved ones die early deaths.

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Posted by [Gene Veritas](#) at [12:03 AM](#)      

Labels: [#HDdenomore](#) , [Bianca Serbin](#) , [Carol Serbin](#) , [Catholic](#) , [death](#) , [enrichment](#) , [genetic test](#) , [HD gene carrier](#) , [HD warrior](#) , [huntingtin](#) , [Huntington's disease](#) , [nursing home](#) , [Paul Serbin](#) , [Pope Francis](#) , [symptoms](#) , [treatments](#)

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