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Free from the threat of Huntington's disease, our 'miracle baby' turns 18

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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, MAY 21, 2018

Free from the threat of Huntington's disease, our 'miracle baby' turns 18

I dedicate this article to my daughter Bianca Serbin.

In June, our “miracle baby,” who [tested negative in the womb](#) for Huntington's disease in 2000, will graduate from high school and turn 18. In August, she will enter the [University of Pennsylvania](#), to study in its College of Arts and Sciences.

It is a watershed moment, a milestone I once feared I would not reach, and a sign—though hardly a final one—that our daughter is on the road to adulthood with her family intact.

Because I inherited the HD gene from my mother, who died of the disease in 2006 at age 68, I will inevitably develop symptoms. At 58, I'm well beyond my mother's age of onset. Each day of health is a blessing and a privilege, as I witness so many of my affected “HD brothers and sisters” struggle with the disabling symptoms.

Scientists strive to understand why people like my mother and me, with the same degree of genetic defect, become symptomatic at different ages. Although there is no scientific proof, doctors and scientists have told me that leading an enriching life – and treating my health carefully – has helped me stay healthy.

I agree. Watching HD rob my mother's ability to walk, talk, and care for herself, I could not imagine reaching this point free of the disease's classic symptoms. Joining my wife Regina in guiding Bianca to adulthood has provided me with a deep sense of purpose, enjoyment, and pride.

With Bianca, we have also faced crises: being HD-free is no guarantee of perfect health or a worry-free life for her. As a result, we have become closer as a family, and Bianca has matured.

Now, as Bianca prepares to enter the next stage of life, I am deeply relieved.

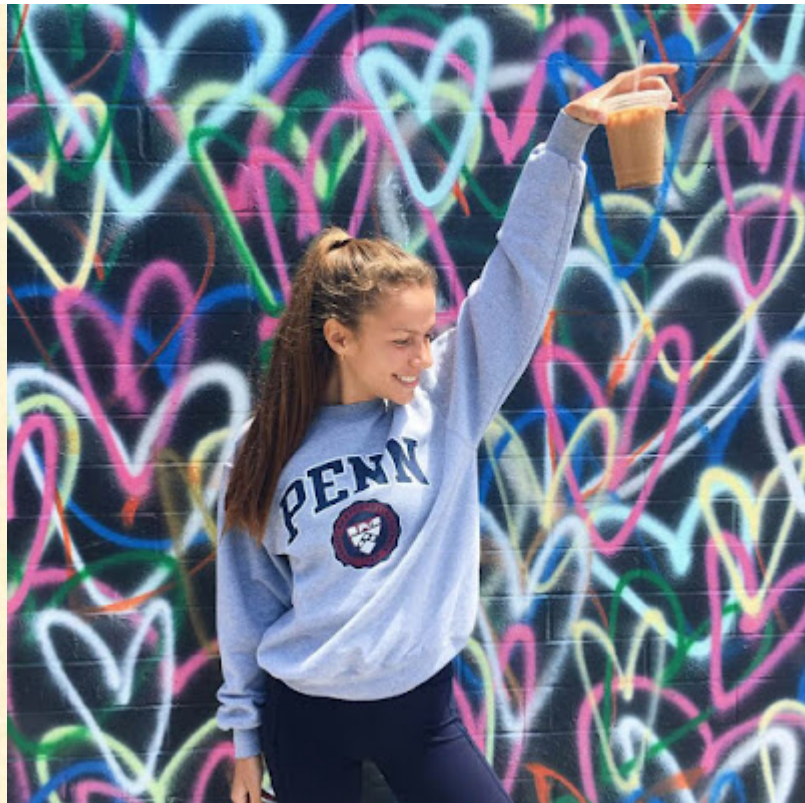
I had feared not being able to watch her graduate from high school. As educator parents valuing quality schooling, [we sacrificed financially](#) to put her in a top private high school to give her the best chance to succeed in life. I had worried that, if disabled by HD, I could not help pay the bills and save for college.

I also feel a deep sense of pride, satisfaction, and accomplishment: I have fulfilled some key responsibilities as a father, handing Bianca the baton of life.

[Hereditary Disease Foundation Huntington's Disease Advocacy Center](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
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Bianca Serbin (family photo)

Because of the psychological trauma of testing Bianca in the womb, Regina and I decided against further children. Raised as an only child, Bianca needed to overcome shyness and social isolation. Her high school's strong emphasis on academics and leadership helped her blossom in these areas.

Bianca and her generation will face immense challenges beyond the first-order responsibilities of learning, growing, and finding their place in the world. They are bequeathed such daunting social problems as gun violence, inequality, anti-democratic political movements at home and abroad, global warming, and nuclear proliferation – challenges my generation has failed to adequately address. They will need to exercise great leadership and form new social movements.

I believe they will. I am impressed with, and proud of, young people such as the Parkland, Florida, shooting survivors who have organized politically, refusing to accept the tiresome and dangerous status quo on gun violence. Their movement has the potential to impact society the way the civil rights and anti-war movements of the 1960s did. Bianca and her schoolmates joined students around the country in the local-level protests against the violence.

Raising a daughter in the era of [#MeToo](#) produces great angst. Bianca will need to be strong and independent as she navigates new challenges and, as in the fight against HD, she will need to find allies.

I'm confident that, no matter what path she chooses, Bianca will help make the world a better place.



Gene Veritas (aka Kenneth P. Serbin) with daughter Bianca (family photo)

Previous generations did not have our options. After the discovery of the HD gene in 1993, Regina and I became part of the first wave of couples testing babies in the womb, and later using preimplantation genetic diagnosis, to safeguard our children from the disease.

Regina and I were especially adamant about testing because, in a cruel twist of HD, men can pass on an even greater level of genetic defect, leading some children to develop the juvenile form of the disease.

Our generation of HD families have also become more outspoken about HD, a disease so terribly hidden and stigmatized in the past. It's still that way for many families here and around the world.

I've always answered Bianca's questions about HD, wanting her to learn about the topic with full transparency, to prevent the harmful effects of denial. She was first exposed to HD at the age of two by learning that her grandmother was ill with a "boo-boo on her brain." At age nine, she learned that I carried the gene – but also that she did not.

Since childhood, Bianca has participated in HD fundraisers and other events. Recently, she has also volunteered for the local chapter of the Huntington's Disease Society of America.

Bianca reads this blog regularly, a way for her to deepen her understanding of HD and to tighten her bond with me. I know that she loves me and is deeply concerned about my risk for HD.



Bianca, San Diego Chargers tight end Antonio Gates, and Gene Veritas at an HDSA-San Diego fundraiser, 2008 (family photo)







Throughout Bianca's senior year, Regina and I have begun to brace ourselves for the empty nest syndrome.

At the same time, we're very excited for Bianca. I'm looking forward to our family trip to Philadelphia to install her at Penn and help her transition to this new phase in her life.

Meanwhile, on the HD front, much work remains to be done: along with thousands of other Americans, I still face the threat of HD. We need to realize the dream of effective treatments – perhaps even a cure – that would allow me to live to a ripe old age and, with Regina, continue to enjoy the next stages of Bianca's life.




Kenneth, Bianca, and Regina Serbin after Bianca's induction into the Cum Laude Society (family photo)

Posted by [Gene Veritas](#) at [12:09 PM](#)      


Labels: [advocacy](#) , [Bianca Serbin](#) , [education](#) , [genetic testing](#) , [HD-free](#) , [Huntington's disease](#) , [Kenneth P. Serbin](#) , [miracle baby](#) , [Penn](#) , [preimplantation genetic diagnosis](#) , [Regina Serbin](#) , [symptoms](#) , [tested negative](#) , [treatments](#)

3 comments:

 **Anonymous said...**

Congratulations!!!

[4:13 PM, May 21, 2018](#)

 **Anonymous said...**

Your one of the LUCKY ones so far.

I am watching my daughter who is 44 lose every piece of dignity one has due to this horrible disease.


I'm glad for you and your daughter.

I had no idea what HD was in my husband's family, never heard of it tell his mother was tested

for it when the second of my two girls was 2 yrs old.

[5:00 AM, May 22, 2018](#)



 **mary said...**

Felicidades! 😊

[5:59 AM, May 22, 2018](#)

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