

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

11-1-2021

A proud Huntington's disease gene carrier's message to his 'miracle baby' daughter on her senior year in college

Kenneth P. Serbin
University of San Diego

Follow this and additional works at: <https://digital.sandiego.edu/huntingtons>



Part of the [Nervous System Diseases Commons](#)

Digital USD Citation

Serbin, Kenneth P., "A proud Huntington's disease gene carrier's message to his 'miracle baby' daughter on her senior year in college" (2021). *At Risk for Huntington's Disease*. 309.

<https://digital.sandiego.edu/huntingtons/309>

This Blog Post is brought to you for free and open access by the Department of History at Digital USD. It has been accepted for inclusion in At Risk for Huntington's Disease by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.

More[Create Blog](#) [Sign In](#)

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.

Blog Archive

▼ 2021 (12)

▼ November (1)

[A proud Huntington's disease gene carrier's messag...](#)

▶ September (1)

▶ July (1)

▶ May (2)

▶ April (3)

▶ March (2)

▶ February (2)

▶ 2020 (16)

▶ 2019 (19)

▶ 2018 (16)

▶ 2017 (14)

▶ 2016 (13)

▶ 2015 (24)

▶ 2014 (24)

▶ 2013 (30)

▶ 2012 (26)

▶ 2011 (33)

▶ 2010 (26)

▶ 2009 (21)

▶ 2008 (7)

▶ 2007 (7)

▶ 2006 (4)

▶ 2005 (17)

About Me

 [GENE VERITAS](#)

[View my complete profile](#)

HD Links

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

[International Huntington Association](#)

[Huntington's Disease Drug Works](#)

[Huntington's Disease](#)

[Lighthouse](#)

[Hereditary Disease](#)

[Foundation](#)

MONDAY, NOVEMBER 01, 2021

A proud Huntington's disease gene carrier's message to his 'miracle baby' daughter on her senior year in college

When I tested positive for the Huntington's disease genetic mutation in 1999, at 39, I was convinced I was doomed to repeat my HD-stricken mother's onset of symptoms in her late 40s.

I had tested because my wife Regina and I wanted to plan for children, who, if I had the mutation, would also have a 50-50 chance of inheriting it.

We decided to have a child before the availability of [preimplantation genetic diagnosis](#) (PGD), which involves in vitro fertilization of embryos without the mutation. So, we had our daughter Bianca tested in the womb. Her *negative* result in early 2000 was one of the happiest moments of our life. She was our "[miracle baby.](#)"

Now, 21 years later, Bianca has started her senior year at the [University of Pennsylvania](#), where she is finishing a U.S. history honors thesis. She has flourished in her classes and successfully taken on several leadership roles.

Bianca understood from about the age of two that her [grandmother was ill](#) with a genetic disease. HD transformed my mother into a mere physical and mental shadow of herself, taking her life at 68 in 2006. Four years later, when Bianca was 9, she learned that I, too, was at risk but that [she was not](#).

I have been extremely lucky. I am almost 62 and was found to have no HD symptoms at my recent annual neurological checkup.

[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](#)

I have perhaps benefited from the positive action of [modifier genes](#) and a far greater opportunity than my mother had – we had never heard of HD prior to her diagnosis – to prepare for the disease.

As Bianca navigates the challenges of senior year and prepares for post-college life, I want to provide her with a message of hope, challenge, and some of the wisdom I have picked up along my own life's journey, including our family's struggle against Huntington's. My letter to Bianca follows after the photo below.



Regina Serbin (left), Gene Veritas (aka Kenneth P. Serbin), and Bianca Serbin at the Edge sky deck during a visit to New York City in August 2021 to celebrate Bianca's 21st birthday (photo by Devon Riley)

Dearest Bianca,

When you graduate next May, you and your classmates will come of age at a time of immense challenges.

I am impressed with how you (and so many other students of all levels) have shown great fortitude and flexibility when forced into the new reality of online learning and social distancing during the monumental disruptions of the COVID-19 crisis.

I was happy to see that this semester Penn has moved students back into the classroom, allowing you to recover some of the lost joy of the college years.

With the rapid development of highly effective RNA-based vaccines, many of us are reaping the fruits of the biotechnological breakthroughs of our era. Researchers are also exploring a variety of such genetics-based approaches as potential Huntington's

treatments. Because many of these advances promise to change our very nature, they will pose ethical dilemmas.

Our family has lived this in the flesh. The biomedical revolution made it possible for you to know your life will be free of Huntington's. However, as you have learned, being HD-free does not mean being challenge-free. Far from it!

But the freedom from HD has enabled you to plan a life in which you can strive for academic and professional excellence, and to develop your personal qualities.

As you venture forth, remember always that you're not going it alone. You can rely on others, just as you should be available to support others. Life is a collective endeavor, as our family has learned so well from the fight against HD. As I always tell people dealing with the initial shock of discovering Huntington's in their families, "together we will beat this disease!"

In your drive for personal success, cherish the preciousness of time, as I have learned to do in confronting the fears of HD. Use ambition to push ahead, but don't let it dominate your inner good. Always make time for family and friends.

Take time to meditate and cultivate your spirituality, because I believe that we all have such a dimension, independent of any belief system or organized religion. As you have done at Penn, find ways in your life to connect to something larger than you.

Bianca, I'm elated with how we have come to share many passions: for writing, the study of history, historical movies (especially war films), music, our dog Lenny, and our family.

Because of HD, your grandmother could barely hold you as a baby. Your "HD warrior" caregiver grandfather loved you deeply. I wish they could have shared your college years.

I have not wanted you to worry about me getting HD, which is a major reason that I have strived so hard to maintain good health –

and to support the search for treatments that could save me from HD's inevitable though often unpredictable symptoms.

You and Mom have joined me at Hope Walks and other fundraisers, and in 2017 you gave up the chance to attend your junior prom to take part in Pope Francis' special audience with the HD community in Rome. I so deeply appreciated having you by my side during that breathtaking moment.

I am thrilled and thankful to have the clarity of mind to enjoy your progress towards graduation. You have made me deeply proud.

Because of our and so many other families' dedication to the HD cause, and also thanks to the researchers, I remain ever hopeful for an HD treatment in my lifetime. If that moment comes, I know that no matter where you are geographically and professionally, we will celebrate with tears of joy.

I hope HD strikes me minimally and very late in life, as I have seen in some cases. Together our family has seen many people with HD fight tremendously to overcome the disease, and their caregivers devote every ounce of strength. As it has throughout our journey, the hope for both my good health and the arrival of treatments will continue to sustain us – even beyond the start of any symptoms that might occur.

No matter what difficulty, please remember that I have always treasured our great moments together and watching you grow as a person.

No one knows what tomorrow will bring. In this moment, let's cherish the positive, including the fact that you, Mom, and I are healthy. As your senior year progresses, I want to celebrate our joy together as you prepare to graduate.

Raising you has brought Mom and me greater meaning and purpose – and, above all, lots of love to share.

Healthy and ambitious, you are poised, with your generation, to leave your mark on the world.






Congratulations on your senior year! Enjoy the ride!

Love,

Dad



The Serbin Family Team of the Huntington's Disease Society of America San Diego Chapter's 2014 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)

Posted by [Gene Veritas](#) at [3:36 PM](#)     

Labels: [Bianca Serbin](#) , [biomedical revolution](#) , [COVID-19](#) , [HD warrior](#) , [HD-free history](#) , [Huntington's disease](#) , [miracle baby](#) , [modifier gene](#) , [mutation](#) , [PGD](#) , [symptoms](#) , [tested negative](#) , [treatments](#) , [University of Pennsylvania](#)

No comments:

[Post a Comment](#)

[Home](#)

[Older Post](#)

Subscribe to: [Post Comments \(Atom\)](#)