

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

12-24-2010

The best Christmas gift of all

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., "The best Christmas gift of all" (2010). *At Risk for Huntington's Disease*. 82.
<https://digital.sandiego.edu/huntingtons/82>

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.


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)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▼ 2010 (26)
 - ▼ December (4)
 - [The best Christmas gift of all](#)
 - [The mission of a lifetime](#)
 - [Vertex and the new wave of Huntington's research](#)
 - [Globalizing the fight against Huntington's](#)
 - ▶ November (1)
 - ▶ October (2)
 - ▶ September (3)
 - ▶ August (2)
 - ▶ June (2)
 - ▶ May (3)
 - ▶ April (2)
 - ▶ March (2)
 - ▶ February (2)
 - ▶ January (3)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me

 [GENE VERITAS](#)

[View my complete profile](#)

HD Links

FRIDAY, DECEMBER 24, 2010

The best Christmas gift of all

This week I received the best Christmas gift of all: a clean bill of health during my annual visit to the local Huntington's disease clinic.

I tested positive for the HD gene in 1999, and my mother died of the disease in early 2006 at the age of 68. I don't know exactly when her symptoms began, but, as I look back, it seems that classic early signs such as mood swings and depression began in her late 40s.

I turn 51 on December 31, and I'm getting closer to the point at which my mother started having chorea, or the trembling of the limbs, one of the major symptoms of Huntington's.

In order to monitor my health and strategize on ways to avoid onset of the disease, each year I undergo an examination at the Huntington's Disease Society of America's [Center of Excellence](#) for Family Services and Research at the University of California, San Diego. On December 14, I went through an intensive, two-hour battery of cognitive testing at the center. This past Tuesday, December 21, I was examined by one of the center's physicians.

He found no evidence of chorea, and he informed me that my 2010 cognitive results matched the 2009 tests.

So I remain stable!

Bonus time

I felt enormously relieved.

The visits are extremely stressful, because there are no treatments for the root causes of HD. Symptoms eventually appear in *all* gene-positive individuals.

Onset would mean that I would begin a steady decline towards death. My mother's symptoms got steadily worse. During the 15 years (or more) of the disease, she lost the ability to walk, talk, think, and swallow. She was only a faint shadow of herself when she died in a nursing home.

So I realized once again that every extra moment of good health is a bonus.

A winning team

The doctor recommended that I maintain my routine.

Since 2004 I have taken the main supplements recommended by the [Huntington's Disease Drug Works](#) (HDDW) program: trehalose, creatine, coenzyme Q-10, omega-3 fish oil pills, and blueberry concentrate pills. Although there is some evidence suggesting these substances could affect HD, at this point there's no way to prove that they have actually helped me.

[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](#)

But, the doctor said, they might be helping me to remain stable.

HDDW used to cover the cost of the supplements but is no longer doing so. I will have to shell out two or three thousand dollars annually to pay for them. Because they're not officially approved remedies, insurance won't cover them.

Nevertheless, the doctor said the cost is justified.

I agree. There's a saying I learned in following Brazilian soccer: you don't mess with a winning team.

In my case, the team includes far more than the supplements: pills to avoid depression and anxiety, psychotherapy, exercise, dedication to my family, the nurturing of my faith and spirituality, and sharing my journey as an HD-positive person through this blog.

The need for hope

In writing this, I must admit that part of me feels enormously guilty.

So many others in the HD community already experience terrible symptoms. Young, at-risk people struggle with the news of their parents' diagnoses and decisions about genetic testing, and newly tested individuals who are gene-positive suddenly fear a dark future.

Will my desire to celebrate a symptom-free Christmas and New Year's Eve make others in the community feel even more frustrated with their helpless predicaments?

Probably not. People in our community are generally very understanding and sympathetic with a whole range of situations. But I feel so badly for others – and want even more badly for a cure to come *soon*.

We in the HD community we *all* need hope – especially at this time of year.

I may never know why in the year 2010 I did not have symptoms. In 2011 they very well could start.

But my lack of symptoms could very well serve as a piece of evidence in the mystery of HD and the search for treatments and a cure. That, after all, is a big reason why the results of my cognitive testing go to the researchers.

And I want to help others.





A gift of health and time

On the brighter side, my current state of stable health will permit me to continue the fight for greater awareness about Huntington's disease and the quest to end it.

As I noted in [my previous entry](#), on February 7, 2011, I will represent the HD community as I give the keynote speech before scores of scientists at the "Super Bowl" of Huntington's research.

More than ever before, I'll be putting myself in the public eye and calling fervently for a cure.

Thanks to this year's best Christmas present of all, I can carry out that mission with a strong and clear voice.

Posted by [Gene Veritas](#) at [12:25 PM](#)    

Labels: [at-risk](#) , [blueberry](#) , [Center of Excellence](#) , [chorea](#) , [coenzyme Q-10](#) , [cognitive](#) , [creatine](#) , [depression](#) , [gene-positive](#) , [genetic testing](#) , [Huntington's](#) ,

[mood](#) , [mother](#) , [omega-3](#) , [spirituality](#) , [symptoms](#) , [trehalose](#)

6 comments:



marissa said...

Where is this "superbowl" of Huntingtons taking place...I'd be interested in attending.

1:35 PM, December 24, 2010

Anonymous said...

Merry Christmas and congrats on your speaking engagements. Perhaps I'll be able to hear you in person some day. I think it's wonderful how you're putting yourself out there to raise awareness about HD. Also, your blog helps me to understand a first-person perspective of HD. My 2 stepsisters have HD and already have symptoms. One of them has received the Greatest Gift of all--Jesus Christ. He promised abundant life while on earth, and better still, eternal life without disease or infirmity for those who choose to accept His sacrifice and love He displayed while on earth. I pray the hope and future God promises in Jeremiah 29 and John 3:16 will be your present to unwrap this Christmas. Cordially, Shauna

9:37 PM, December 24, 2010

Anonymous said...

i feel that any one individual that receives good news is worth celebration, and ur work towards awareness of hd benefits all. keep up the good work and good health xxxx

12:20 PM, December 26, 2010

maura said...

Again thank you for your heartfelt blog. I have not been tested but end up wondering if everytime I forget a name or find I am in a dream, the beginning of a journey I do not want to begin! Being tested may be the confirmation of the path I do not want to tread and the knowledge that I may have passed this horror to my children and grandchildren. Thank you for your bravery in sharing your path.X

12:32 PM, December 26, 2010

Anonymous said...

Congratulations and Happy New Year. Enjoy that lovely daughter.

She'll be all grown up before you know it. God bless you and your work.

2:19 PM, December 26, 2010

Anonymous said...

The best Christmas gift indeed!! Thank you for all that you do for the HD community. God Bless you!

11:00 AM, December 29, 2010

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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