

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

9-18-2010

More to lose than ever'

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., "More to lose than ever'" (2010). *At Risk for Huntington's Disease*. 74.
<https://digital.sandiego.edu/huntingtons/74>

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)
 - ▶ November (1)
 - ▶ October (2)
 - ▼ September (3)
 - [Out of the closet and on to the cure](#)
 - ['More to lose than ever'](#)
 - [Living in limbo](#)
 - ▶ 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

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

SATURDAY, SEPTEMBER 18, 2010

'More to lose than ever'

Living gene-positive for Huntington's disease frequently distresses me as I worry about the inevitable onset of its destructive symptoms and the impact my illness will have on my wife and daughter. I have struggled mightily to cope – a theme of so many entries in this blog.

But, as so many at-risk people have pointed out over the years, the threat of Huntington's also forces them to put life in perspective and live it more intensely.

In early 2005, as I was just starting this blog, an old friend best summed up my situation by contrasting it with his relatively care-free life: "I envy you. I feel immortal. I don't believe I'm going to die. But you know you're going to die, and so you can live your life more fully" ([click here](#) to read more).

Life's priorities

I especially struggled this past week with fear and anger about HD. On September 13, I published "[Living in limbo](#)," in which I described the harrowing "waiting game" that I and so many other people who have tested positive for genetic diseases face as we are forced to imagine a bleak future. (This is akin to what one gene-positive woman calls "[genetic roulette](#).")

I felt overwhelmed after writing that entry and reading the responses (posted comments, e-mails, and Facebook remarks) of other gene-positive individuals and their relatives.

Feeling a sudden urge to protect my family, life's priorities flashed through my mind.

I recorded these thoughts in my blog notes:

Our job is to pass down our culture/history/values to the next generation. I feel this acutely. Just as important now to do daughter's soccer practice as attend an HDSA-SD board meeting. Feel in my bones and my blood: our time here is limited and the prime directive is to guarantee the survival and success of the next generation. Nationally: get rid of debt. Locally: active in community. At home: prepare daughter [for life].

Personal growth

I awoke the next morning at 2:30. I was very agitated and couldn't get back to sleep. Somehow I got through the workday with the usual good game face, but I didn't get relief from the agitation and adrenalin rushes until returning from work in the afternoon. I turned off the ringer on the phone and took a long nap. I awoke feeling disoriented.

Luckily, on September 16, I had my bi-weekly session with my

[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](#)

psychotherapist, the person who understands my mind probably better than anybody, especially after my mother became ill with HD (and died in early 2006) and my father, the Huntington's warrior who cared for her for 15 years and died a year ago. Besides the usual worries about HD, I've become more anxious because of the approaching first anniversary of his death ([click here](#) to read more).

I told my therapist about the difficult feelings generated by the "Living in limbo" entry, including the huge transition I've begun as I become more public about my situation with HD. On September 24 I will make my first-ever public presentation about HD to an American audience. ([Click here](#) for an entry on the talk I gave in Brazil last June.)

As we worked together to sort out the painful feelings, we reflected on how I've evolved as an activist for HDSA, the Huntington's Disease Society of America. She also pointed out how much I've grown *because of* the need to confront HD.

A valuable insight

"You have more to lose than ever," she said.

I interrupted her and asked for a slip of paper to write down this phrase. Right then and there I decided that it would become the topic of my next blog entry.

"You're right!" I said about her insightful comment.

It's impossible to know how my life would be today if it weren't for the threat of HD.

But I believe that I'm a better person in many ways.

Gaining perspective

To begin with, I have indeed gained perspective. The preoccupations of the past now seem like mere details, and I've calmed my tightly-wound personality considerably.

The other day my daughter was late for an orthodontist's appointment. I patiently and quietly waited for her to get ready.

As we got into the car, she asked, "Dad, aren't you angry that we're late?" She was wondering why I wasn't upset with her.

"Will getting upset make the minutes on the clock go backwards?" I asked her. She thought a few seconds and responded, "No."

"Being late once in a while is okay," I continued. "Ideally, we should be early for things, so that we're not late. There are many things we have to be on time for, like school. But it's not the end of the world if we're late once in a while."

In her words, a lot of times I "freak out" about things. But it's happening less.

It was a small but valuable lesson.

With ever greater appreciation for the gift of life, I've become more sensitive to my family's needs.

A multi-dimensional life

I also feel that I'm a more tolerant person. This helps in my professional relationships and in working with the HD community.

Indeed, my HD activism has built many more layers onto my life: blogging, website development, volunteer recruitment, advocacy, fundraising, the translation of research advances into terms understandable to the HD community, and the building of mutual support within the community. I sometimes feel as if I'm living in several dimensions at the same time.

I've definitely improved as a writer, because living at risk for HD has led me to explore the depths of human emotions about life and death. I've felt the impact of the worst kind of denial, but also the utmost of courage and compassion.

As I've written on several occasions, confronting HD has led me to a clearer understanding of my religious faith. I now see faith as going hand in hand with the movement to stop HD.

I feel inspired to help others. I've pledged that when and if the cure for HD comes and I finally break free of its destructive shackles, I will channel my energy into another volunteer cause.

The secrets of life

In sum, I feel more mature and more aware.

I think I'm beginning to understand some of the precious secrets of life. Possessions, power, and fame in the end are irrelevant. Love, sharing, and dedication are what count.

Clearly I am far from perfect. Nobody is. I stand only near the starting line of this process.

But in reaching this point, I now have a clearer view of the great potential of my life yet to be unlocked.

The threat of Huntington's disease has brought me a load of worries. But it's also given me so much more to feel good about in my life.

I indeed have more to lose than ever, and that's why I'm ever more anxious to prevent HD from cutting me off in my prime.

Posted by [Gene Veritas](#) at [10:28 PM](#)     

Labels: [at-risk](#) , [Brazil](#) , [daughter](#) , [death](#) , [denial](#) , [faith](#) , [father](#) , [fundraising](#) , [gene-positive](#) , [HDSA](#) , [Huntington's](#) , [love](#) , [mother](#) , [research](#) , [support](#) , [symptoms](#) , [warrior](#)

4 comments:

Michelle said...

Disease makes the present so much more precious. It leaves me with little control and much confusion, but my appreciation for people and my amount of happiness is increased. You do have more than every to lose, and are blessed to know it.

[2:12 AM, September 19, 2010](#)

Anonymous said...

Thank you for this blog. I don't have HD, but my mom does. I went through a period of waiting and testing to find out that I am negative. That period of waiting left me questioning all that I was living for. Through that experience I realized that many things in life are fleeting, but what matters is loving others and

reaching out to help those in need. It has definitely helped strengthen my faith and even though I tested positive I still pray for a cure and for all those who have tested positive. Thanks again for this post!

~Eunice

8:05 AM, September 19, 2010

⊗ **Lauren said...**

As always, Gene, I can relate so well to your blogs. Feeling more mature and aware, being more tolerant, etc.

You mentioned that your daughter says a lot of times you "freak out" about things, but it's happening less. My husband says the same about me, and it seems to happen less often as I realize what's important--Is it really necessary to get angry at this or worry so much about this? Will it make a difference? It's not worth spending the time arguing over something so silly when you can't change it. Things like that. I would rather spend the time I have happy and enjoying life and doing things that DO make a difference than worrying and "freaking out" as my husband, and apparently as your daughter, put it.

As always, thank you for your blog and providing me someone to relate to :)

8:29 AM, September 19, 2010

⊗ **Ian Hibbert said...**

I can definaly relate to your blogs.My Mum also had this horrible disease and to watch her suffer for years was just disturbing to watch.She passed on Oct 08 which was a blessing because she couldnt do anything what so ever.Im going to be tested as well and have my 1st appointment with the genetic nurse Oct 1st.I just think its better all round if i know either way then ill know what to expect.How long is the testing process from the 1st appointment?Thanks and god bless you

10:22 AM, September 20, 2010

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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