

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

4-18-2011

The shadow career

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 shadow career" (2011). *At Risk for Huntington's Disease*. 93.

<https://digital.sandiego.edu/huntingtons/93>

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)
 - ▶ December (2)
 - ▶ November (4)
 - ▶ October (4)
 - ▶ September (2)
 - ▶ August (1)
 - ▶ July (2)
 - ▶ June (2)
 - ▶ May (4)
 - ▼ April (4)
 - [The diary of a
Huntington's disease
activist](#)
 - [The shadow career](#)
 - [Let's fix the law to help
Huntington's
families](#)
 - [The faceless faces of
Huntington's disease](#)
- ▶ March (3)
- ▶ February (3)
- ▶ January (2)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me

 GENE VERITAS

[View my complete profile](#)

MONDAY, APRIL 18, 2011

The shadow career

After my mother was diagnosed with Huntington's disease in 1995, I joined the local support group of the [Huntington's Disease Society of America](#) (HDSA). In 1998, I became a member of the HDSA-San Diego Board of Directors in the cause to raise awareness about HD and the need for treatments and a cure. After testing positive for HD in 1999, I intensified my efforts even further.

As I watched HD destroy Mom's brain and worried about the inevitable onset of my own symptoms, my activism developed into a second career.

This was a *secret* career – one that I hid from everybody outside the HD community because of the very real possibility of genetic discrimination in the workplace, and in my field as a college professor and specialist in Brazilian history.

This has been my “shadow career.”

A bombshell

At the start of my first career, I had to keep HD in the back of my mind. I was striving to obtain tenure at my university job. This required complete dedication, with many 12-hour days, lost weekends, and weeks of forfeited vacation dedicated to research and publications, the gold standard of scholarly distinction and advancement.

In the first couple years, I felt completely exhausted, physically and emotionally. Getting tenure is like making partner at a law firm. The institution virtually owns you for the first six or seven years.

Then, just as things were starting to look a little brighter during my third year, I received a bombshell: my mother had HD, and I had a 50-50 chance of inheriting the condition. I could pass it on to the potential children my wife and I were contemplating.

That news transformed my life forever. Since that moment, the threat of HD and its many social implications (for marriage, family, insurance, health care, and income) severely impacted my career.

Focusing on the essentials

I first reacted to the emotional jolt by working even harder for professional success. I was 36, and I knew that I could start getting symptoms in my 40s. So I wanted to squeeze in as much life as possible – even to the point of neglecting my wife.

In June 1999 I tested positive. That was another huge blow. In January 2000, our daughter tested negative in the womb, a huge relief to my wife and me. She was born healthy in June 2000. ([Click here](#) to read more about these two genetic tests.)

HD Links

[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](#)

Along with my decision to join the HDSA-San Diego board, those new, life-changing experiences forced me to change perspective about my career.

The birth of a first child brings most couples a deeper understanding of life's meaning and responsibilities. The birth of our "miracle baby" especially moved me to focus on the essentials of life.

Sadly, Mom had already lost the ability to talk, and she couldn't even properly hold our baby on her lap during my parents' trips from Ohio to our home in San Diego.

As Huntington's disease attacked Mom, I felt an urgency to get my own psyche in order to become a better father and husband in the potentially very short window of time of good health that remained. I worked extremely hard with my psychotherapist, my "mind coach," to clear my mind of as much emotional clutter as possible.

Racing against time, I also wanted to multiply my efforts in the HD cause.

Hiding my activism

Juggling a new baby, household, job, and HD activism, I stopped going the extra mile at work.

Even with tenure in hand, this was highly risky. Office politics can often trump competence, as I learned in 2005 during my [attempt to obtain a promotion](#).

So, while genetic discrimination remained my primary concern, I also hid my HD activism from my professional colleagues because I feared some might not sympathize with my predicament.

I have noticed, for instance, that as a man I am not expected to act as the primary caregiver for my daughter, whereas it's considered perfectly natural for a woman to take on such a role.

In such an environment, I felt it would be extremely difficult for some co-workers to understand my commitment to the Huntington's disease cause.

Until recently, I've kept a near-perfect firewall between my activism and my job. In that respect, the pen name "Gene Veritas" has lent me great protection.

Doubts and guilt

My shadow career looms large.

The extra hours I once spent on my paid job I now dedicate to the HD cause. I maintain professionalism in the workplace, but I no longer strive for the academic glory that can be achieved only with intense, ongoing dedication to intellectual matters.

Lately my secret career has cast a great shadow of guilt and doubt over my life.

In 2007, I had received an excellent job offer at another university, but I turned it down because of the very likely possibility that we will need to depend on my wife's income when my HD symptoms begin. ([Click here](#) to read more.) She teaches in the public school system and, barring a fiscal meltdown, will receive a generous pension. So my wife and I have decided to make a stand in San Diego.

But the question rankles in my mind: what would my career have been like without HD? What new opportunities might our family have encountered

had I been able to advance on a regular basis?

We are financial prisoners of HD. Long ago we abandoned our goal of a summer (and eventually retirement) home in Brazil, my wife's country and where she could fully enjoy her home family and culture without having to rent as a short-term visitor or rely on relatives for lodging.

As my wife and I are constantly reminded, HD has robbed us of many dreams.

Public appearances

Recently I started taking my activism to an even higher level – and in public.

On February 7, I delivered the [keynote address](#) to the 6th Annual HD Therapeutics Conference, sponsored by the CHDI Foundation, Inc., the so-called “cure Huntington's disease initiative.”

On May 7, I will speak at the convention of HDSA's Northern California Chapter. And on May 17, I will make a presentation in Cambridge, MA, at [Alylam Pharmaceuticals](#), which hopes to bring a potentially revolutionary treatment into human clinical trials within the next year or so. At both events I will speak on the topic of my activism and coping with HD.

I will visit HDSA national headquarters a couple days later, and in June I am tentatively scheduled to appear as an HD community representative at a Huntington's disease meeting at the National Institute of Neurological Disorders and Stroke (NINDS) in Washington, D.C.

Crashing in the fog

As I come out of the shadows, this second career could completely overshadow my regular job.

This huge transformation in my activism has preoccupied me now for more than a year.

The other day it left me so emotionally foggy that I became distracted while driving and accidentally crashed my brand new car (!) into a wall. I was okay, but the mishap caused \$1,600 in damage to the vehicle.

Just a couple days later, I almost rear-ended another car as I drove down a familiar street.

In the case of several HD people I know, frequent, seemingly inexplicable car accidents or other driving difficulties were one of the first signs of symptoms.

Are my symptoms starting?

Or, as a friend pointed out, am I a “multi-processor” with much on my mind? (After all, I crashed a previous new car into a wall shortly after I received my HD test results. That was long before any symptoms were expected to occur, but I was unnerved.)

Part of the fog comes from the deep sadness I feel as my first career becomes less and less significant. And that causes the guilt about that career to increase.

No time for wavering

In Palm Springs, I spoke on the topic of “unmasking Gene Veritas” and reintegrating the two, until now separate parts of my life.

Since then, I have also have begun thinking of possible ways to integrate my two careers.

So much is on the line: my life, the lives of my wife and daughter, the lives of tens of thousands of HD-affected and at-risk individuals and their families.

As I completely abandon the shadows, I must resolutely overcome doubt and guilt. It is not a time for wavering. It is a time for conquering Huntington's disease.

Posted by [Gene Veritas](#) at 5:59 PM      

Labels: [activism](#) , [activist](#) , [Alnylam](#) , [at-risk](#) , [caregiver](#) , [CHDI](#) , [CHDI Foundation](#) , [cure](#) , [daughter](#) , [diagnosis](#) , [discrimination](#) , [genetic](#) , [genetic test](#) , [Huntington's](#) , [mother](#) , [NINDS](#) , [psychotherapist](#) , [symptoms](#)

3 comments:



 **Mike Anthony said...**

Dear Friends

Do you know anything about entitlements and who those entitlements belong to ? Do they belong to the state ? do they belong to DHHS, do they belong to Elder indapendance of maine? do they belong to Home care agencies? or do they belong to the sick and severely disabled families ? Millions of Tax \$\$ go though all these people and only about 10% goes to the disabled families.

Do you think Maine Tax Payers need to know where their Tax \$ are being wasted?

Support Letter from Hospice for them:

Office of the Governor

#1 State House Station

Augusta,
Maine 04333-0001

April 8, 2011

Dear Governor LePage:

This letter is in support of Raima and Mike Fernald's request for consideration to increase funding for the care that they provide in their home for their sons, John and Christopher Irving, as well as other

families caring for family members with significant disabilities or medical conditions.

I first met these men (John is 38 years of age, and Chris is 36 years of age) when John was admitted to hospice services in late January of this year. At the time, due to the demanding care needs of Huntington's Disease, they were both living in a group home with the support of Lutheran Social Services. While each of the staff members I had the opportunity to meet was pleasant and helpful, the "home" had more of a "Frat House" feeling than a home.

Most concerning to me during those visits was John's privacy and dignity as he embarked on this journey toward the end of life. John's hospital bed was in the living room, and during those visits he was clothed only in a t-shirt and adult diaper. Meanwhile, the staff, college aged men and women, went about their routine of preparing meals, keeping house, watching TV, and listening to music. If John had personal care needs, they were attended to for any and all to witness. Since John and Chris' ability to clearly communicate their needs and preferences is severely limited, I am not sure the staff at the group home ever considered that this might be uncomfortable for either or both.

John and Chris moved into their parents' home at the end of February, and Raima and Mike have been providing around the clock care with limited support of MAS Home Health services, and our agency. They have done a fabulous job, and this is evident from the look of comfort and calm that John and Chris now wear. No one can care for a loved one like the family who loves them. However, caring for one family member on hospice is taxing enough, but caring for two grown men with such significant needs for assistance for their every activity is unfathomable to me.

Additionally, Chris was also admitted to hospice at the beginning of April. I can see the toll this is taking on Raima though she does this all willingly and lovingly— what mother would not if given appropriate support?

I urge you to listen carefully to what the Fernalds have to say. They are the “experts” when it comes to providing cost effective, compassionate home based care for a family member whose needs are so great.

Respectfully,

Wendy Weise, MS/LMSW-cc

Social Worker

[2:13 AM, April 19, 2011](#)



⊗ **Mike Anthony said...**

Now is the Time tax payers :O}
They need our Help.

[3:26 AM, April 19, 2011](#)

⊗ **Anonymous said...**

Hi Gene,

I take heart from your blog! I was CMO at CHDI since July 2007 but retired a few months ago.

Your comments to the young woman and her boyfriend at risk about being open and straight forward were right on. In my experience lack of openness is not a sign of sensitivity. I have heard too many patients say I wish I had known earlier so I would have understood that my father, mother, grandparent's behavior was not my fault or that they were not nasty people, but were suffering from HD. Or that I could have done something so my kids would not have to go through the same. I was early in my career a family therapist. Family secrets can be very destructive to relationships. The loneliness, the fear and the struggle with the at-risk-status can be dealt with as you well know. People should know that they are not alone. But there is so much misunderstanding about what it means in and outside the HD community, including physicians. However, testing remains a very personal decision, that outsiders not always appreciate. When clinicians or genetic counselors promote their opinions, rather than helping people to make the right decision for them, I think we lose our supportive role. I very

much like your approach in your blog. From the literature it is clear that not all people who test negative live happily ever after, while others who test positive turn this specter into something positive and show great resilience. Including participation in research as a way of working towards a better tomorrow. Knowing that you could find out what was ahead for your child allowed you to make the right decision.

I wish you all strength in your efforts to break the silence.

Warm regards,

Dan

10:34 AM, April 25, 2011

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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