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At Risk for Huntington's Disease

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## Blog article No. 300: who exactly is Gene Veritas?

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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.*

## Blog Archive

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- ▶ [2006](#) (4)
- ▶ [2005](#) (17)

## About Me

 [GENE VERITAS](#)

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## HD Links

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

SUNDAY, MARCH 14, 2021

## Blog article No. 300: who exactly is Gene Veritas?

On January 10, 2005, I began the first [post](#) in this blog with a simple but consequential sentence: “My name is Gene Veritas and I am at risk for Huntington’s disease.”

Today, 16 years and two months later, after my mother’s death from Huntington’s at age 68 in 2006 and my own long struggle to avoid disease onset, I am writing my 300th post.

Now 61, I never expected to get this far. Starting in her late 40s, my mother’s symptoms left her progressively unable to care for herself and ultimately bedridden. And I inherited from her the same degree of mutation in the huntingtin gene – which I long thought portended the same fate.

As I have noted often in recent years, I feel extremely lucky to remain asymptomatic. Although there is (as yet) no genetic test available to individuals to pinpoint the reason, researchers have discovered key modifier genes that slow or hasten onset among people with identical mutations ([click here](#) to read more). Also, as doctors and researchers have observed, my efforts to lead a healthy lifestyle likely have also helped.

In the early years of the blog, writing under the protection of my Gene Veritas pseudonym, I focused mainly on my family’s struggles with the many medical and psychosocial ramifications of HD. More recently, with the tremendous advances in HD research of the past decade, I have emphasized the science and the advent of crucial clinical trials. Those trials have brought unprecedented hope for the HD community.

[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](#)

However, in the [whirlwind](#) of HD advocacy and writing, I have not paused to reflect on the deeper meaning of my alias. Even after I went fully public as Kenneth P. Serbin nine years ago in an article in [The Chronicle of Higher Education](#), I am still widely known in the HD community as Gene Veritas.

I have relished explaining a pen name that has become my trademark. In my HD work, I actually prefer the pseudonym, which not only intrigues people but also instantly focuses our interaction on the profound implications of Huntington's.

To mark my blogging milestone, I thus want to clarify two things: who exactly is Gene Veritas? And what does that name mean?

### A college professor and family man

Huntington's, as a 100-percent genetic disorder, always involves stories about families.

After the news of my mother's diagnosis blindsided my wife Regina and me in late 1995, our life plans changed dramatically. A future as my potential caregiver has loomed over Regina ever since. She is ever thankful about my delayed onset.

We forged ahead as best we could. Over the past two decades, we have brought our HD-free daughter Bianca to the [threshold of adulthood](#). Bianca expects to graduate from college in 2022.

I am in my 28th year as a [history professor](#) at the University of San Diego, and Regina works as an instructional coordinator for the San Diego Unified School District.

As a family, we have been active in the local chapter of the Huntington's Disease Society of America. In 2017, we traveled to Rome for one of the most extraordinary moments in our journey with HD, "[HDdenomore](#): Pope Francis' Special Audience with the Huntington's Disease Community in Solidarity with South America."

In the doctor-recommended [enrichment and exercise](#) that I practice, I have included the canine member of our family, our cockapoo Lenny, with long walks on diverse routes through our neighborhood.



*Gene Veritas (aka Kenneth P. Serbin) with wife Regina, daughter Bianca, and dog Lenny (family photo)*

### **Representing our common struggles**

I began this blog under “Gene Veritas” because I lived in the [“terrible and lonely HD closet,”](#) fearing discrimination on the job and in healthcare and insurance matters. I built what I have described as an “absolute firewall” between my HD reality and the rest of my life.

In February 2011, I took a major step out of that closet by delivering the keynote speech at the “Super Bowl” of HD research, the Sixth Annual Huntington’s Disease Therapeutics Conference, sponsored by [CHDI Foundation, Inc.](#), the nonprofit virtual biotech solely dedicated to finding HD treatments. It was held in Palm Springs, CA.

About 250 prominent scientists, physicians, drug company representatives, and others listened to my speech, which was titled “*Blog Entry 85 ... Unmasking the World of Gene Veritas: An Activist Copes with the Threat of Huntington’s Disease.*” (I referred to an “entry” instead of “post,” because of the diary-like nature of the blog in the early, anonymous years. Now I use the term “article,” because the posts have become more in-depth and sometimes run several thousand words or more.)

As I wrote in an [article](#) about that key moment, despite revealing my real name to the audience, my penname “Gene Veritas’ will still live on in cyberspace.[...] Through its anonymity and universality, it symbolizes the common struggles of families threatened by HD and numerous other neurological and genetic diseases.”

Indeed, in many talks since then I have introduced myself with both my real name and pseudonym.

### **‘The truth in my genes’**

I explain to people that “Gene Veritas” means “the truth in my genes.”

A “gene” is a sequence of DNA, the code that programs our development as humans and gives us particular characteristics. “Veritas” is Latin for “truth.”

The truth of my future lies in the mutant huntingtin gene that I inherited from my mother.

I also have a personal connection to “veritas”: it forms part of the motto “lux et veritas” (light and truth) on the seal of my alma mater, Yale University.

The connection to Yale bubbled up from my subconscious while I was searching for a pseudonym. Surely Yale also came to mind because of the solidarity, advice, and assistance I have received from fellow alumni (click [here](#), [here](#), and [here](#) to read more).

As one observed, because of the devastation caused by HD, the pseudonym can also represent a [grim pun](#) on the school motto.

### **We are all Gene Veritas**

On March 8, I participated in an online interview conducted by HD global advocate [Charles Sabine](#) and [Simon Noble, Ph.D.](#), CHDI's communications director. They wanted to learn more about the Gene Veritas facet of my life.

Dr. Noble asked me whether I had an alter ego and other identities, in line with the ideas of 2010 keynoter and graphic novelist Steven Seagle, who has addressed his family's way of confronting Huntington's by juxtaposing the reality of disabling HD with the [fantasy of Superman](#).

"Gene Veritas" *is* my alter ego, I said.

So, Dr. Noble wanted to know, how did the Gene Veritas alter ego protect me? Did it allow me to do other things? Did I become a different person in some respect? Were there positives to being Gene Veritas?

"Absolutely," I responded. "Being anonymous for so many years allowed me to be completely honest about Huntington's disease. Those first years of the blog were a complete explosion of HD honesty – talking about the feelings, talking about the discrimination, talking about the anger, the hurt, the pain, worrying about my mother, seeing my mother die from the disease. Those early years were really, really hard."

This blog and "Gene Veritas" have also served as coping mechanisms, I added, and they allowed me to build awareness about HD.

"But how to build awareness anonymously?" I continued. "It's like a contradiction in terms. That's why 'Gene Veritas' became so important, because I was somebody. I couldn't be Ken Serbin, but I could be Gene Veritas."

Pondering further the universality of my pseudonym, I observed: “It’s my story, but it’s really the story of the HD community. Anybody could be Gene Veritas in the HD community. Because I think we’ve all been at one point or another a kind of Gene Veritas, at least when we first find out about Huntington’s. It’s representative. It’s something that has a broad meaning to it.”

### **Writing the history of the HD movement**

In this blog, my CHDI [keynote](#), and other speeches, I have documented the new and harrowing human experience of living in the gray zone between a genetic test result and onset of a disease.

In my CHDI speech, I showed a slide with a simple breakdown of main blog topics to that point. Information about the disease and research was the leading topic, followed by articles on my mother, fear of onset, and coping.

I will do a more fine-grained content analysis of posts for an academic article on the blog as a coping mechanism, fount of information for the HD community, and source of insight into the fight against HD and the search for therapies. I will submit the article to a scientific or medical journal.

I am also planning a book on the history of the Huntington’s disease cause, tentatively titled “Racing Against the Genetic Clock: A History of the Huntington’s Disease Movement and the Biomedical Revolution.” The blog will serve as a considerable primary source (a document or other material produced by a participant in a historical event) for my research and/or future historians of the HD cause.

In academic year 2021-2022, I will dedicate an expected sabbatical (a leave from teaching and other on-campus duties) to the book project. I will consult researchers, physicians, and members of the HD community about the key themes.

I earnestly hope to recount in this blog and my book the achievement of effective treatments for HD.

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Posted by [Gene Veritas](#) at [12:54 AM](#)      

Labels: [advocacy](#) , [asymptomatic](#) , [blog](#) , [CHDI](#) , [coping](#) , [discrimination](#) , [DNA](#) , [Gene Veritas](#) , [HD closet](#) , [HD Therapeutics Conference](#) , [huntingtin](#) , [Huntington's disease](#) , [mother](#) , [pseudonym](#) , [research](#) , [symptoms](#) , [treatments](#) , [Yale](#)

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