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At Risk for Huntington's Disease

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## Big decisions while facing the threat of Huntington's disease

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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.*

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## About Me

 [GENE VERITAS](#)

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## HD Links

WEDNESDAY, MARCH 20, 2013

## Big decisions while facing the threat of Huntington's disease

At every turn of life, we all make big decisions such as choosing a career, a mate, a home, and the number of children to conceive.

Living with the knowledge of a positive test for a devastating condition such as Huntington's disease radically complicates such decisions. Coupled with the deep stigma associated with HD, the fear of the onset of symptoms magnifies the stress and doubt that come with such turning points.

As I have frequently revealed in my writings and in speeches about HD, I have faced life-changing decisions about a [feeding tube](#) for my HD-stricken mother, my [genetic test](#), and the test of our daughter while still in the womb. (Thankfully, she tested negative!)

Planning for the inevitable symptoms of this currently untreatable disease has also [profoundly altered my career](#), leading me into a new field far different from my original focus on Brazilian history: the history of science, technology, and medicine.

With my definitive exit from the "HD closet" last fall, I have begun to integrate this new intellectual passion into my professional life.

### Professional excitement

Lately, however, I've relived the intensity of how the threat of HD affected my professional decisions.

With the surprise [resignation of Pope Benedict XVI](#) on February 11 and the emergence of several potential successors from among Latin America's cardinals, my expertise on the Roman Catholic Church's actions in the region and its [relations with the region's dictatorships](#) – topics usually of no interest to the media and the general public – suddenly were in demand.

The election of Pope Francis I created great excitement: his initial attitudes and actions indicated that he might very well attempt to clean up the corruption and abuses that have plagued the institution.

At the same time, it rapidly became apparent that the new pope had had his own complex and (to some) controversial relationship with the Argentine dictatorship, which carried out a "dirty war" against Argentines from 1976-1983.

In the period before and after the election of Pope Francis I, I gave eleven interviews and answered a number of other queries from newsmagazines and radio and TV outlets.

[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](#)

My personal excitement culminated with the publication on March 17 of an op-ed article, outlining the potential paths of the Church under Francis I, in one of Brazil's most prestigious newspapers, the *Folha de S. Paulo*, followed by a quotation from me about the Argentine branch of the Church in a front-page story in *The New York Times*.

As I told a number of friends, never before and probably never again will my scholarly work on the Catholic Church command so much attention in the United States.

Throughout all this, I began to relive the past thrills and satisfaction of researching the Church, publishing books on the topic, and discussing my work in the Brazilian media.

My wife seemed especially happy to see me enjoying, for the first time in a very long while, recognition for my original career path. For her, it was a relief from that dogged, sometimes seemingly one-dimensional aspect of my life involving the fight against HD.

### Second-guessing the past, but welcoming the future

As a result, I began second-guessing my decision in 2007 to turn down a job to help run a prestigious Latin American studies center in Florida in order to remain in biotech-rich San Diego to focus on the fight against HD. Staying put also helped safeguard my family's financial future by allowing my wife to keep her good job and better-than-average retirement plan – absolutely essential if HD were to leave me disabled.

I thought of the HD people I had recently read about who had roughly the same degree of genetic mutation as I did and managed to avoid symptoms until their sixties and even continued to work after onset.

However, in the process of second-guessing, I recalled how I made that decision when the memories of my mother's demise just a year and a half before still haunted me.

In hindsight, it's easy to argue that I should have taken the other job and not worried so much about HD.

However, hindsight also reminds me of how HD completely destroyed my mother's ability to work, to communicate, and to care for herself.

My wife and I made our big decision with the best information available to us at that moment.

I quickly reminded myself that rather than reliving the past, I must look to the future, value the intellectual flexibility of my university, and fulfill the plans I have mapped out for myself. I will be seeking connections with my university's neuroscience program and social outreach project in order to promote brain health as a national priority.

Indeed, my dean has fully supported me after my exit from the HD closet. I felt especially reaffirmed with the publication of [a feature article about my journey](#) with HD on the university's website.

The decision to pursue the history of science, technology, and medicine has exposed me to new vistas of the human story. HD is a challenge – but also a gift that has led to profound intellectual and personal growth.

### The real successes and challenges

I savored my public moment as a Latin America scholar.

However, it stood in sharp contrast to the intensity and immensity of the challenge to avoid HD symptoms and contribute to the defeat of the

disease.

While friends and colleagues were impressed with the recognition of my expertise, I quietly pondered the truly significant accomplishment for me during the week of Francis I's election: the successful arrangement of a meeting between Paulo Vannuchi, Brazil's former Minister of Human Rights, and Taíse Cadore, the president of the Associação Brasil Huntington. They discussed the crucial need to involve Brazil's Ministry of Health in the fight against HD in Brazil, which will host the 2013 World Congress on Huntington's Disease from September 15-18.

Ultimately, scientists' work will go for naught unless events such as the World Congress can draw more people into the HD cause and involve them in the all-crucial research studies and clinical trials.

### **Participating in a study**

On March 13, as I monitored the Internet for news of the papal conclave, I spoke to a researcher at the Huntington's Disease Society of America Center for Excellence at Iowa Hospitals and Clinics, one of the sites for a key study known as PREDICT-HD, an observational study of the earliest signs of HD that needs asymptomatic, gene-positive volunteers.

PREDICT-HD will help establish ways to measure the efficacy of potential treatments.

Participating in PREDICT-HD represents another big decision for my family and me. The study requires the presence of a spouse or partner, who must answer a questionnaire about the gene-positive individual. All three of us must spend two days traveling and at least two days in Iowa.

The PREDICT-HD also involves a voluntary spinal tap so that cerebral spinal fluid from gene-positive people can be studied for the effects of HD and ways to measure the efficacy of potential treatments.

Spinal taps are routine but, like any procedure, involve risks such as a debilitating headache that could require emergency room treatment. In my case, it means that I will probably notify my health insurance plan for the very first time of my gene-positive status. I want to make sure I can safely undergo the tap, and I want to have my plan doctors on standby in the event of complications.

In and of itself, informing my health plan about HD represents yet another significant shift in my medical, psychological, and emotional approach to the disease.

### **Channeling the positive energy**

As the HD researcher and I finished our discussion about PREDICT-HD, I saw the announcement of breaking news about white smoke from the Sistine Chapel: a new pope had been chosen.

Minutes later, my daughter and I watched as Francis I appeared on the balcony of St. Peter's Basilica in Rome and humbly prayed the Our Father and Hail Mary with the crowd gathered below – the same prayers she and I say together each night, alternating in English and Portuguese, before she goes to sleep.

I felt a new beginning for the Church.

In the days since then, I have frequently asked myself how I can channel the deep fulfillment and positive energy from my study of this troubled but nevertheless key institution into the effort to relieve the suffering caused by Huntington's and so many other devastating diseases.

As I wrote in my op-ed piece on the pope, Francis I “seems to be saying that believers, and the rest of the world, must rediscover the fundamentals of human existence.”

In his [inauguration homily](#) on March 19, Francis I stated that “authentic power is service.” As pope he must protect “the hungry, the thirsty, the stranger, the naked, the sick and those in prison.”

For me, this means protecting my family from the consequences of HD and striving to do my small part to help others.

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Posted by [Gene Veritas](#) at [11:32 AM](#)      

Labels: [brain](#) , [Brazil](#) , [career](#) , [cerebral spinal fluid](#) , [daughter](#) , [genetic test](#) , [HD closet](#) , [health insurance](#) , [Huntington's disease](#) , [mother](#) , [mutation](#) , [neuroscience](#) , [Pope Francis I](#) , [PREDICT-HD](#) , [science](#) , [stigma](#) , [symptoms](#)

1 comment:

 **Anonymous said...**

I love the fact you are getting involved in research! I have been going for 8 years! I have 6 children at risk I wanna do anything I can to help!!

[6:44 PM, March 20, 2013](#)

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