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Reinforcing the global fight against Huntington's disease: a visit to Brazil and a reminder of our common struggles

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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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 [GENE VERITAS](#)

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HD Links

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

SATURDAY, AUGUST 15, 2015

Reinforcing the global fight against Huntington's disease: a visit to Brazil and a reminder of our common struggles

The global cooperation necessary to defeat Huntington's disease requires the bridging of cultural divides. It entails recognition of each country's unique needs and contributions – but also of the common struggles involved.

With this in mind, last month I embarked on another phase of my own international advocacy by traveling to Brazil, the country I have studied since 1986, to deliver a speech on HD and build new connections for the cause.

The world's fifth most populous country, with over 190 million people, Brazil occupies a significant place on the world's HD map. Perhaps 19,000-plus Brazilians suffer from the disease, and tens of thousands are at risk.

Thus, once the global HD clinical trial and research study platform known as [Enroll-HD](#) gets under way in Brazil, the country's potential contributions to the search for effective treatments will increase substantially (click [here](#) to read more).

A 'bi-cultural' perspective

As I have done almost every year over the past three decades, I visited Brazil primarily to work on my ongoing [research in Brazilian history](#). In all, I have spent nearly seven years there. In 1991, during my Ph.D. research in Rio de Janeiro, I met my wife Regina.

Brazil is my second home. I refer to myself as "bi-cultural."

Even before I joined the board of the [San Diego chapter](#) of the Huntington's Disease Society of America in 1998, I established contact with Brazilian HD activists who founded the [Associação Brasil Huntington \(ABH\)](#) in 1997.

As a carrier of the HD genetic defect, I spoke in 2013 about my personal strategies for avoiding onset of symptoms at the sixth World Congress on Huntington's Disease, held in Rio (click [here](#) and [here](#) to read more).

[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](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)



Gene Veritas (aka Kenneth Serbin) at Ipanema beach in Rio de Janeiro (photo by Regina Serbin)

Combating genetic discrimination

During this most recent trip, I advocated for HD-related issues in my meetings with political leaders.

In 2005, the Brazilian Senate passed a bill protecting citizens against genetic discrimination. However, the Câmara dos Deputados (the House of Representatives), has yet to take up the matter. Until then, the bill cannot become law.

Senator Aloysio Nunes Ferreira Filho, who ran for vice president in the 2014 election on the losing ticket of the opposition Brazilian Social Democracy Party, supports the legislation. During my visit to his office in Brasília, the capital, he phoned a colleague in the Câmara to urge action on the bill.



Senator Aloysio Nunes Ferreira Filho (above, photo by Gene Veritas) and Gene Veritas in the chamber of the Senado Federal in Brasília (below, photo by Lucas Souza)



Defending the rights of the disabled

Later, in São Paulo, South America's largest industrial and financial hub, I attended a presentation by the famous liberation theologian Leonardo Boff about the geopolitical state of the world, the threat to the global environment, and the current political crisis in Brazil.

The event was moderated by Paulo de Tarso Vannuchi, who served as Minister of the Special Secretariat for Human Rights from 2005-2011 in the government of the ruling Workers' Party.

Vannuchi briefly introduced me to leaders of the National Council for the Rights of the Disabled. I committed to furnish them with information about HD and put them in touch with the ABH.

Vannuchi told the audience of 60, which included clergy and grassroots social activists, of my HD advocacy and suggested that the reporters present interview me.



Paulo Vannuchi, former Minister of the Special Secretariat for Human Rights (photo by Gene Veritas)

That same day I gave an interview to the TVT television outlet commenting on the importance of Boff's speech. (You can see the report on the event, including my commentary, by clicking [here](#)).

Shortly after my return from Brazil on July 22, one of the reporters present at the event, São Paulo-based radio broadcaster Marilu Cabañas, interviewed me via phone about HD for her program. Shocked to hear of [police detentions of HD-affected individuals](#) in both Brazil and the U.S. because of ignorance about the disease, she [headlined her report](#) with that fact.

Bioethical challenges

I gave my speech, "Huntington's Disease, Bioethics, and the Promise of Biotechnology," on July 20 at the [Universidade Candido Mendes \(UCAM\)](#) in downtown Rio de Janeiro.

I have known the rector, Candido Mendes, for more than 20 years. My friends and colleagues, UCAM Professor Luiz Alberto Gómez de Souza and his wife Lúcia Ribeiro, both leading scholars and grassroots activists of the

Catholic Church, organized the event. (Brazil is the world's largest Catholic country.)

During my hour-long presentation in Portuguese, I recalled my family's long fight against HD, beginning with my mother's diagnosis in 1995, followed by positive test for the genetic defect in 1999 and the wrenching experience of testing our daughter Bianca in the womb in early 2000.

I felt deep relief after showing the audience pictures of our HD-free "miracle baby" in action as a youth soccer player. I spoke of the "double luck" we currently savor: Bianca will never face the terrible threat of juvenile HD, and I remain symptom-free despite having long passed my mother's age of onset.

"At 55, my mother [...] could no longer drive, she couldn't work, she couldn't talk," I said. "By a huge stroke of luck, I am healthy. Each day is a blessing."

However, I also pointed to the many other bioethical challenges faced by HD families, including discrimination, family and caregiver stress, financial burden, and the lack of adequate facilities and caregiving personnel for late-stage patients.

The room became very quiet as I related how Carol Carr (of Georgia) in 2002 took a gun to the nursing home where her two HD-stricken sons lay helpless in bed and shot them dead to prevent further suffering. Carr spent nearly two years in prison.

"That was extremely sad for our community," I recalled. "Huntington's disease is not something easy to speak about."

With no effective treatments, such was the degree of hopelessness that has plagued the HD community, I had pointed out earlier.

The hope of clinical trials

"But I came to Brazil not to speak just about sadness," I continued. "I also came to speak about hope and the promise of biotechnological research."

The scenario for the HD community has changing radically in recent years with major advances in research and the advent of clinical trials to test potential remedies, I said.

I spoke of the immense potential revealed in the announcement last year of the gene-silencing clinical trial by Isis Pharmaceuticals, Inc. Citing an e-mail from Isis executive Frank Bennett, Ph.D., received the day before the presentation, I confirmed that the trial would start by year's end.

(Indeed, the morning *after* my talk, Isis officially announced that it had commenced the trial.)

You can view my talk in the video below.



A Doença de Huntington, a Bioética e a Promessa da Biotecnologia

from [Gene Veritas](#)

1:06:05

[A Doença de Huntington, a Bioética e a Promessa da Biotecnologia](#) from [Gene Veritas](#) on [Vimeo](#).

A local commitment to the cause

During the Q & A, several Brazilian HD-affected individuals and caregivers spoke of their many struggles with the disease.

They also expressed excitement about the Isis clinical trial.

[Carmen Paiva, Ph.D.](#), spoke of her lab's work in HD genetic and epidemiological research among Brazilian HD families. She told the audience of other local researchers and physicians focusing on the disease.

Recognizing common struggles

At the close of the session, Prof. Gómez de Souza evoked a key point of my presentation: the interconnectedness of neurological disease research and the common struggles of the afflicted.

He spoke with profound emotion about his brother, the renowned actor [Paulo José Gómez de Souza](#), who has suffered from Parkinson's disease for more than two decades but has successfully strived to continue working.

The struggles are shared among diseases – and among nations.

I look forward to celebrating with my Brazilian relatives and friends the defeat of HD, Parkinson's, and other neurological disorders as a result of a truly global effort.

Posted by [Gene Veritas](#) at 2:22 PM      

Labels: [Aloysio Nunes Ferreira Filho](#) , [Associação Brasil Huntington](#) , [bioethics](#) , [biotechnology](#) , [Brazil](#) , [disabled](#) , [Enroll-HD](#) , [genetic discrimination](#) , [Huntington's disease](#) , [Isis Pharmaceuticals](#) , [Paulo Vannuchi](#)

3 comments:

 **Jimmy Pollard said...**

One big world. One big family. United in a singular cause. The struggle continues...

And...one awesome guy...you. Ken!!!

6:35 AM, August 16, 2015

Anonymous said...

Yes, one awesome guy doing amazing work for HD!

Mickie Toetz

4:14 PM, August 16, 2015

Anonymous said...

Thank you Ken...on behalf of two who have passed, two who have the disease symptoms now, and 6 who are at risk as we speak....all in my wonderful family. I pray that Isis will have the cure and it will be accessible to you and my family.

1:15 PM, August 17, 2015

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