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Reaching out to the 'HD family' at the World Congress on 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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TUESDAY, SEPTEMBER 24, 2013

Reaching out to the 'HD family' at the World Congress on Huntington's Disease

As I returned on the plane from Brazil and the sixth World Congress on Huntington's Disease, held September 15-18 in Rio de Janeiro, I was thrilled about my fortified connections to the emerging global movement to defeat HD.

I greatly expanded my contacts within the Brazilian HD community, which had the largest representation of HD family members, with more than 60 attendees.

After months of frequent contact via e-mail, phone, and Skype, I was delighted to meet in person Taíse Cadore, the president of the [Associação Brasil Huntington \(ABH\)](#), and neurologist Francisco Cardoso, M.D., Ph.D., two key organizers of the event. Along with Dr. Mônica Santoro Haddad, Cadore, Cardoso, and I have worked to raise the profile of HD in Brazil and to involve the government in improving the care provided to patients.

ABH volunteers helped put on the congress, staffed an information table, and attended many of the scientific and HD-family-oriented activities. Along with the organizing committee and many other Brazilians contributing to the event, the ABH volunteers made the congress a success.

In the coming days, I will prepare a comprehensive report on the congress, including a video of my presentation on coping strategies for living with the HD gene, plus many of the other presentations.

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](#)



Taise Cadore (photo by Gene Veritas)



Gene Veritas with (from left to right) ABH volunteers Carmen Faccio, Maria Eni Souza, Carmen Varalta, Majida, and Tereza Portigliotti and Zulay Final Romero of the Venezuelan HD association. The t-shirts say "embrace this cause."

Cramming in activities

For now, I am focusing on the transition from the cultural environment of Brazil – my “other home” – back to my life in San Diego.

International journeys require intense, detailed preparation. This one proved especially demanding.

After a 25-year stretch in which I visited Brazil annually, including long periods living there, I declined to travel there

in 2011 and 2012. Those years my time was taken up by my increasingly public HD advocacy and my added focus on the history of science, technology, and medicine in the context of the Huntington's movement. The trip felt like a whirlwind: it included the congress, four presentations, other Brazil-related research, and visits with relatives and friends crammed into just ten days.

It didn't help matters that my connection to Rio was delayed some 13 hours, obliging me to spend the early morning of September 13 sleeping on a cot in the Dallas-Fort Worth airport. The trip to Rio wound up taking 30 hours!

A life-affirming quest

This was not just another of my expeditions to Brazil.

Once again, I was on a mission to help defeat Huntington's disease, the condition that, unless a treatment comes soon, will relentlessly attack my brain. In addition to helping with advocacy in Brazil and planning a bit of the congress, I spent more than 30 hours preparing the speeches I would deliver in Brazil.

The day before I left the U.S., I gave a 90-minute Skype interview to journalist Marcelo Leite, who published [an article in the Folha de S. Paulo](#) titled "It's necessary to pass laws against genetic discrimination," says historian."

The ABH circulated copies of the article at the congress. A radio reporter who had seen the article interviewed me and others. [Senator Aloysio Nunes Ferreira](#), one of three senators representing the state of São Paulo, Brazil's most populous and economically powerful state, wrote me a personal e-mail pledging to push for passage of such legislation in Brazil's Congresso Nacional.

I felt a deeply visceral satisfaction meeting with so many of the HD movement's advocates. It was emotionally wrenching to see people with HD and hear the affected, gene carriers, at-risk, and caregivers tell their stories.

Hugging my fellow "HD family" members from far-off lands or shaking their hands joined us in a lifelong, life-affirming quest.



Gene Veritas with actress and ABH volunteer Luiza Portigliotti



Gene Veritas with Carlos and Elieze Adriani of Campinas, Brazil

Stark challenges, seeking advice

One woman, a middle-aged dentist from Rio in the early stages of HD but still completely lucid, wanted to know about supplements and other remedies that I take.

The mother of Priscila, a 31-year-old Rio woman with pronounced chorea, the involuntary, dance-like movements produced by HD, asked how she might get her daughter into a clinical trial for the HD “vaccine” they heard was in development in California. The newspaper O Estado de S. Paulo featured Priscila and her family in an article about the world congress and HD.

Priscila's mom was referring to the gene-silencing approach at Carlsbad-headquartered Isis Pharmaceuticals, Inc., which, along with pharmaceutical giant Roche, hopes to start Phase I of the trial by the end of 2014. I explained that Isis and Roche had not yet announced the trial sites and suggested that she and her family should keep abreast of news on the project.

Others shared with me their stories of testing positive for the gene, the stark challenges of family planning, and learning that a potential future mate is at risk.



Priscila, a 31-year old Rio resident who suffers from HD (photo courtesy of *O Estado de S. Paulo*)



Priscila on the beach in Rio (photo courtesy of *O Estado de S. Paulo*)

In sync with the movement

During this trip, I reached many milestones.

I felt fully in sync with the HD movement, its values, and its supporters, as I took 13 congress participants and leading HD researchers to my favorite Rio steakhouse and bar; for the first time met Nancy Wexler, the dean of HD scientists; and delivered my speech on HD and bioethics and engaging with the emotion-charged audience at a college in São Paulo on September 21.



As waiter serves steak, Gene Veritas (right) converses with HD specialist Dr. Ed Wild, global HD advocate Charles Sabine, and HD drug-hunter Dr. Doug Macdonald at Café Lamas in Rio de Janeiro (photo by Alice Wexler).

I felt vindicated in my decision to go fully public about HD late last year and meld my professional and personal lives with my advocacy.

I smiled and got a warm feeling inside as I spoke of this big transition in my life with a long-time Brazilian friend and professional colleague.

As she observed, I was doing the right thing.



Gene Veritas (aka Kenneth P. Serbin) in Rio (photo by Tim Power)

Posted by [Gene Veritas](#) at 2:12 PM



Labels: [Associação Brasil Huntington](#) , [at-risk](#) , [brain](#) , [Brazil](#) , [care](#) , [caregiver](#) , [chorea](#) , [coping](#) , [gene carrier](#) , [genetic discrimination](#) , [Huntington's disease](#) , [Isis](#) , [medicine](#) , [science](#) , [World Congress on Huntington's Disease](#)

3 comments:

🌀 **Anonymous said...**

Welcome home and congratulations, Ken!!!

Jimmy Pollard

[6:54 PM, September 24, 2013](#)

🌀 **Marc - HDBuzz tech guy said...**

It was great to meet you at the conference Ken and thanks for showing us that fantastic steakhouse.

[9:03 AM, September 30, 2013](#)

🌀 **Ami said...**

Fantastic read, thanks for keeping all of your friends back home updated on your important work and personal journey!

[12:44 PM, October 21, 2013](#)

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