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At Risk for Huntington's Disease

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## Defeating Huntington's disease starts with taking care of yourself and joining Enroll-HD

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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, JANUARY 16, 2016

## Defeating Huntington's disease starts with taking care of yourself and joining Enroll-HD

For those of us affected by Huntington's disease or at risk for it, the fight against the disorder begins by taking care of ourselves.

This idea occurred to me during my daily morning meditation on Jan. 14, 2016, as I anticipated my annual checkup in the [Enroll-HD](#) program later that day.

Many people struggling to come to terms with HD ask: with so much to worry about, how can I contribute to the cause?

You can start simply by committing to care for your health and asking family members and others to help monitor your condition. In doing so, you will help your family, too, by preparing for and perhaps even diminishing the current or eventual caregiving burden associated with Huntington's.

You can extend that assistance to the entire HD community by joining Enroll-HD, a worldwide registry of affected individuals, asymptomatic HD gene carriers, untested at-risk individuals, and other family members. With its growing database, Enroll-HD serves as a platform and research project aimed at facilitating clinical trials and the discovery of treatments.

The greater the participation in Enroll-HD, the faster trials can take place.

### Helping the researchers

Not long after learning of my own risk for HD in 1995, I started participating in research projects based at the University of California, San Diego (UCSD), and San Diego State University (SDSU) ([click here](#) to read about one example).

In January 2015, shortly after my participation in the [PREDICT-HD](#) study ended, [I registered](#) in Enroll-HD.

At this month's follow-up visit at the UCSD [Huntington's Disease Clinical Research Center](#), I once again gave blood that scientists can use in the numerous research projects facilitated by Enroll-HD. I also underwent a battery of cognitive tests.

In addition, I participated in four research projects by scientists at UCSD, SDSU, and other local institutions. Two involved standing on high-tech platforms designed to detect balance problems in people who have brain disorders and concussions. Another involved a measure of fine motor skills, which are seriously affected in HD, by writing on a special tablet connected to a computer.

[Huntington's Disease Drug Works](#)  
[Huntington's Disease Lighthouse](#)  
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## HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)  
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[Heather's Huntington's Disease Page](#)

Finally, I spit into a tiny collection tube for a project involving the detection and study of the huntingtin protein in saliva. Abnormal huntingtin causes HD.



*Gene Veritas (aka Kenneth P. Serbin) writing on an experimental tablet (above) and standing on a platform to detect balance problems (below) (photos by Ayesha Haque)*



### **A neurological exam**

My visit concluded with a standard neurological exam by Jody Corey-Bloom, M.D., Ph.D., the director of the UCSD clinic. Among other tasks, I had to follow her fingers with my eyes, rapidly tap together my thumb with my index and middle fingers, and walk down a straight line for about 25 feet.

To my great relief, Dr. Corey-Bloom noted no irregularities! At 56, I am now past the point at which my HD-stricken mother displayed the characteristic involuntary movements.

Afterwards, I discussed with Dr. Corey-Bloom my questions and concerns about my potential participation in the SIGNAL clinical trial to test a monoclonal antibody as an HD treatment.

I will soon provide an update on SIGNAL.

### **Enroll-HD's positive impact**

The next day, I obtained the latest news about Enroll-HD from Joe Giuliano, the director of clinical operations for CHDI, the multi-million-dollar nonprofit virtual biotech aimed exclusively at developing HD treatments. In collaboration with HD research centers and clinics around the globe, CHDI sponsors Enroll-HD.

Enroll-HD officially launched in July 2012. According to Giuliano, as of January 15, nearly 9,000 individuals from 14 countries and 140 sites had signed up.

Has the program met CHDI's expectations?

"I think there's a high level of engagement among the patient community and among the investigators around the world," he said during a phone interview. "The recruitment has been excellent. We could have 10,000 participants by the end of March, which would be amazing. I'm really pleased with how well the availability of the dataset and the biological samples [blood] has worked out. In other words, people are using the data, and the data is available through the website. It's a great example of making data available quickly."

What's been the impact?

"We've been actively assisting three clinical trials that have been going on – PRIDE, Amaryllis, and LEGATO – with their recruitment," Giuliano continued. "We have released our second periodic dataset, with 4,150 participants. There are 28 projects that are currently using Enroll-HD data, to answer different research questions. We've been actively distributing biological samples for a variety of projects."

As a result of Enroll-HD, scientists are deepening their understanding of the disease, and doctors are finding ways to improve care.

Enroll-HD contributes directly to the quest for treatments. The larger the number of potential clinical trial volunteers, the greater the chance that trial administrators can enlist the required number for each trial. The number of HD trials has increased each year, increasing the demand for volunteers. Without the trials and the volunteers, scientists can't test treatments.



*Joe Giuliano (left) and Gene Veritas at a 2015 CHDI conference*

### **Challenges in Latin America**

On the downside, in one key region, Latin America, Enroll-HD has progressed “very slowly,” Giuliano said. So far, Enroll-HD is only operating in Argentina and Chile.

In October 2015, the National Research Ethics Commission in Brazil – the world’s sixth largest nation, with an estimated 20,000 HD-affected individuals – rejected the proposal to set up Enroll-HD there.

“Obviously we were very disappointed,” Giuliano said. “I think the National Research Ethics Commission rejected based on some areas where there was a perception that the Enroll-HD study was not aligned well with some of Brazil’s legal precedents.”

However, Giuliano said that Enroll-HD will step up efforts to involve Latin America’s HD families. With growing interest in Colombia, that country be the next to join Enroll-HD, he said.

“We’re working harder than ever,” Giuliano affirmed. “You haven’t heard the end of us in Brazil. We’re really committed to Latin America. Many of us believe that Latin America, like in the beginning of their history of HD research in Venezuela, which played an important role – now in the later stages of HD research it’s going to resurge, reawaken, and become an important player in HD research again.”

In a future article I will explore the Brazil decision in depth as well as ways HD families can push for greater acceptance of Enroll-HD there and in other countries of the region.

### **Building a common cause**

As I approach the inevitable onset of HD and feel many of the other effects of normal aging, I realize more than ever the need to stay in shape via a healthy diet, daily stretching and aerobics, meditation and spirituality, and psychotherapy.

Without health, I cannot work, dedicate myself to my family, or advocate for the HD cause.

Caregivers, the "HD warriors" who enter the trenches each day, must also seek opportunities for respite.

With the significant progress towards HD treatments of recent years and growing awareness of the importance of HD and other neurological disorders, advocates have a busier agenda than ever.

I am thrilled to assist HD research and the implementation of the critical clinical trials by taking part in Enroll-HD.

After following the HD movement in Brazil for two decades and participating in the historic sixth World Congress on Huntington's Disease there in September 2013, I aim to join my Brazilian HD brothers and sisters to advocate for reconsideration of the government's rejection of Enroll-HD.

We must not lose the momentum in Brazil and Latin America!

Only by building this common cause can we ultimately defeat HD.

Posted by [Gene Veritas](#) at [10:21 PM](#)      

Labels: [advocacy](#) , [asymptomatic](#) , [at risk](#) , [Brazil](#) , [caregiving](#) , [CHDI](#) , [clinical trial](#) , [Enroll-HD](#) , [gene carrier](#) , [huntingtin](#) , [Huntington's disease](#) , [Jody Corey-Bloom](#) , [Joe Giuliano](#) , [neurological](#) , [SDSU](#) , [treatments](#) , [UCSD](#)

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