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Globalizing the fight against Huntington's

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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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FRIDAY, DECEMBER 03, 2010

Globalizing the fight against Huntington's

The participation of HD families in the search for treatments and a cure for Huntington's disease is going global.

Starting in July 2011, registries of HD patients, at-risk individuals, and family members from different parts of the world will be combined into a single database.

Called "Enroll-HD," this new effort aims to make it easier for scientists to understand HD, identify potential participants in crucial clinical trials, and therefore speed the process of finding therapies and a cure.

The Enroll-HD sponsor, the [CHDI Foundation, Inc.](#), released information on the new program on November 19. Backed by an anonymous donor who has contributed tens of millions of dollars, CHDI is informally known as the "cure Huntington's disease initiative." CHDI collaborates with hundreds of scientists from around the world.

Combining databases

Enroll-HD will combine the existing REGISTRY and COHORT databases.

[REGISTRY](#), a Europe-wide study, is run by the Euro-HD Network. Administered by the Huntington's Study Group, [COHORT](#) stands for "Cooperative Huntington's Observational Research Trial." It operates in North America and Australia.

Both databases collect information about the genetic status, lifestyle, medical history, and disease progression of patients and gene-positive individuals.

Enroll-HD also will include participants from the newly founded Latin American network of HD-affected families, physicians, and researchers, the Red Latinoamericana de Huntington. Enroll-HD also will obtain information from countries such as Singapore, South Africa, and South Korea.

"It's a natural progression to combine the successful HD observational clinical studies into one worldwide effort that will harness the power of greater numbers of research participants," said Dr. G. Bernhard Landwehrmeyer, a professor at the University of Ulm, Germany, the chair of Euro-HD, and the principal researcher for Enroll-HD.

People already participating in REGISTRY and COHORT will continue to consult with the same physicians at regular appointment times.

To learn more about Enroll-HD, please [click here](#).

Latin America's contribution

[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](#)
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HD Blogs and Individuals

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One of the most striking aspects of Enroll-HD is the inclusion of Latin America, our neighbors to the south.

Venezuela in particular has played an important part in Huntington's research. Dr. Nancy Wexler of the Hereditary Disease Foundation spent two decades researching the world's largest extended HD family, located in the Lake Maracaibo region. Dr. Wexler developed the pedigree (traced the genetic history) of more than 18,000 individuals and collected more than 4,000 blood samples. This pioneering work helped lead to the discovery of the HD gene in 1993. (To learn more, see her sister Alice Wexler's book *Mapping Fate*.)

About 580 million people live in Latin America – nearly twice the population of the United States. In rough terms, this means that some 60,000 people in the region could have Huntington's. Studying these individuals and their families will provide a greater understanding of HD's devastating effects and its terrible social impact.

It could also benefit HD families victimized by ignorance and poverty. Although conditions have improved for many in recent decades, most Latin Americans are still poor by our standards, and many have little or no access to quality education. In his visits to Colombia, HD activist Phil Hardt observed HD patients living in deplorable conditions – some even in old jail cells.

The Red Latinoamericana de Huntington can help raise awareness about HD throughout the region and perhaps stimulate government support for care programs and research. It also will tie the HD families and researchers from Latin America's countries more tightly together – and also into the global network of researchers and care and advocacy programs.

More and faster research

Above all, by including Latin America's HD families on the rolls of potential participants in clinical trials, Enroll-HD will vastly expand the possibilities of testing more drug candidates and carrying out faster research.

The Huntington's research community faces an extremely difficult problem. As an orphan disease, there may not be enough subjects for trials as potential drugs become ready for testing. This problem is compounded by the fact that researchers have now identified more than 700 potential drug targets. Most trials minimally require dozens of participants, and others utilize hundreds and sometimes thousands of subjects.

In Europe, HD-affected and gene-positive individuals volunteer in sufficient numbers. Ironically, Americans do not. Despite this country's power and overall wealth, denial, fear, and ignorance still dominate many families affected by HD. This lack of American participation makes Enroll-HD even more important.

Guinea pigs?

Some might be concerned that Enroll-HD could become an attempt by scientists from rich countries to use people from poor nations as guinea pigs – that is, subjects tested unethically.

Fear of this kind of unequal relationship definitely exists in Latin America. I have frequently heard such concerns during my own historical research and travel in the region over the past quarter century.

But it's unlikely that Enroll-HD will proceed with any kind of negative or arrogant attitude. All Enroll-HD participants will be protected by the strict protocols that govern research on human subjects.

The official Enroll-HD press release reassured current and future participants that “your samples will continue to be safely stored in the same biorepositories where they are now kept and all information about you will be securely stored in accordance with applicable local laws and regulations regarding the protection of your privacy.”

In addition, CHDI, European researchers, and Latin American representatives held on-the-ground preparatory meetings in Rio de Janeiro, Brazil, in February and Buenos Aires, Argentina, in June. The Rio meeting included representatives from Brazil, Argentina, Chile, Cuba, and Venezuela. Colombian and Peruvian representatives likely will participate in the future.

Reactions to the project

“I went to Rio because I wanted to extend a message of Hope to those in Latin America,” Dr. Ignacio Muñoz-Sanjuan, an HD researcher and the CHDI representative at the Rio meeting, wrote in his [HD science blog](#). “This is not an American or European enterprise. It’s a global fight to find a cure, which should be made available to all, rich or poor, in N[ew] Y[ork] or Maracaibo. But I also went there because we need more people to work with us. I need every affected person to participate: by donating blood, by speaking out, by enrolling in observational studies, in clinical studies. We simply cannot do it without the patients and the people at risk.”

Táise Cadore, the vice-president of the [Associação Brasileira de Huntington](#) (Brazilian Huntington’s Association), wrote in a report that her organization “left the meeting with a great sense of optimism. We recognize the importance of our role in the development of this project and hope to be counting on the participation of our families.”

“The Red Latinoamericana de Huntington is very excited to become a part of the global Enroll-HD initiative and collaborate in this way with the international HD research community to better understand and treat Huntington’s disease,” Rodrigo Osorio, a native of Chile and the president of the Latin American organization, said of the official launching of Enroll-HD.



Bernhard Landwehrmeyer (right) converses with Rodrigo Osorio at the CHDI research symposium in Palm Springs, CA, in February (photo by Gene Veritas).







Inspiring global involvement

As a Latin America scholar and an HD-positive person who lost a mother to Huntington’s disease in 2006, I felt especially heartened with Enroll-HD’s recognition of the global character of disease and the need to include people of all continents in the search for treatments *and* in the resultant benefits.

I was especially happy to see my friends at the Brazilian Huntington's Association receive the attention they deserve as potential contributors to the fight against HD. Without wealthy benefactors or government support, they have fought long and hard to build their organization solely on the grit and donations of HD-affected families.

Their efforts should inspire HD families in America to come out of the woodwork and redouble our efforts to strengthen our own community, educate the public about HD, and prepare for participation in clinical trials. (I will write more on the Brazilian association in my next entry.)

Ultimately, Enroll-HD can help build global awareness about the need to cure Huntington's and other neurological disorders. We all share a common condition and, as we now understand, only together will we defeat HD and these other maladies.

Posted by [Gene Veritas](#) at [2:45 PM](#)      

Labels: [Associação Brasil Huntington](#) , [at-risk](#) , [CHDI](#) , [clinical trial](#) , [cure](#) , [Enroll-HD](#) , [gene](#) , [gene-positive](#) , [genetic](#) , [guinea pig](#) , [HD-positive](#) , [Huntington's](#) , [Maracaibo](#) , [mother](#) , [neurological](#) , [treatment](#) , [Venezuela](#)

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