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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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MONDAY, AUGUST 12, 2019

Factor-H partners with Latin American organizations to aid destitute Huntington's disease families, seeks to expand support

Looking to aid some of the destitute Latin American families whose critical participation in research led to the discovery of the Huntington's disease gene, the humanitarian organization [Factor-H](#) is poised to seek new funding sources to expand its support in the region.

Founded in 2012 and based in Los Angeles, Factor-H has spent several hundred thousand dollars on projects for and direct aid to poor HD families.

On July 27 in Los Angeles, Factor-H president and co-founder Ignacio Muñoz-Sanjuán, Ph.D., took part in the world premiere of the short documentary film *Dancing at the Vatican*, which features South American HD-afflicted families' remarkable 2017 encounter with Pope Francis at the Vatican.

At the [historic Rome event](#) – for which Factor-H played the key role of selecting and arranging logistics for South American families – Francis declared to a global audience of 1,500 HD family members, scientists, and supporters that HD should be “hidden no more.”

Known as [#HDdenomore](#), it was the first time any pope or world leader met with HD-affected individuals.

“It was probably the most significant milestone of what we’ve done,” Dr. Muñoz said in an interview with me on July 29 at the Los Angeles office of [CHDI Foundation](#), the nonprofit virtual biotech focused exclusively on developing HD treatments and where he is vice president for translational biology. “I think it did give us, as an organization, visibility and some credibility that we can do things that are of a certain magnitude.”

The *Dancing at the Vatican* premiere launched a new fundraising effort by Factor-H. Dr. Muñoz and the film's producers, including [#HDdenomore](#) organizer and *Dancing at the Vatican* producer and narrator Charles Sabine (like me an HD gene carrier), are seeking to distribute the film widely. In about a year, it will become available online for free. ([Click here](#) for my preview.)

[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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Dr. Muñoz holding hand of HD man in South America (Factor-H photo)

HD Blogs and Individuals

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

'A very compelling story'

"It's a very compelling story, very moving, and very positive in its approach," Dr. Muñoz observed about the film. Viewing it can help people "fully grasp" the extreme poverty and challenges faced by many Latin American HD families.

Dr. Muñoz said Factor-H will use the film to raise awareness about those families' needs and reach out to donors. "H," according to the organization, means "hope, humanity, Huntington's."

According to Dr. Muñoz, the film captures well "the intersection of disease with poverty and social justice, which I think the HD experience really highlights very well, and I think the documentary does a very good job of highlighting that."



Dr. Muñoz answering a question at the Dancing at the Vatican premiere (photo by Eddie Sakaki)

Hiring an executive director

Also, Factor-H has received a grant from the Griffin Foundation to hire an executive director, Bianca Moura, to assist with fundraising and media exposure, and to ease the burden on the all-volunteer board by handling day-to-day operations.

The Brazilian-American Moura, who holds a B.A. in development studies from the University of California, Los Angeles, has worked the past 25 years in business leadership positions and as a consultant. She served as board president and executive director for the Miami Beach-based cultural nonprofit Rhythm Foundation.

She will join the Los Angeles-based Factor-H on September 1.



Gene Veritas (aka Kenneth P. Serbin) with Bianca Moura at Dancing at the Vatican premiere (personal photo)

Challenges in Latin America

In recent decades, Latin American countries have generally experienced stronger democracy and rising living standards. However, in the past few years Venezuela has slipped into a deep political and social crisis, causing four million people to flee the country, a record for Latin America.

Also, Latin American societies remain deeply unequal. In many parts of the region, especially outside the developed neighborhoods of the large cities, the social, medical, and governmental infrastructure is poor and sometimes even non-existent.

There is also little knowledge or understanding of HD.

In 2006, as newsletter editor for the San Diego Chapter of the [Huntington's Disease Society of America](#) (HDSA), I published an article by 2001 HDSA Person of the Year Phil Hardt documenting the private “jails” in which HD-affected people were locked up by ill-informed relatives in the small town of Juan de Acosta in rural Colombia. The town, about 24 miles west of the city of Baranquilla, has the world's second largest cluster of HD-affected individuals. Hardt works with Factor-H in the implementation of a children's project in Colombia (see below).

As Dr. Muñoz observed in our July 29 interview, today some HD families lack fresh water and sewage systems. They live in shacks with little or no furniture. Because physicians specializing in neurology and movement disorders like HD also tend to concentrate in the cities, many of the families living in rural areas or in small towns do not have access to specialized care, he added.

In such a setting, families with Huntington's disease face enormous challenges.

Giving back to poor communities that helped

Visiting such places in Colombia, Venezuela, and elsewhere was a “life-changing experience” for Dr. Muñoz, he told the audience after the screening of *Dancing at the Vatican*. He saw people from HD families searching for food in the streets, many abandoned children, and young children caring for their HD-stricken parents.

“There is really little chance of a normal childhood,” Dr. Muñoz pointed out. “Many children living with Huntington's disease or from HD families are discriminated against. Their lives are full of fear and trauma, due to Huntington's and social exclusion.”

Dr. Muñoz met patients who went years without any kind of medical or social assistance. Others he met eventually committed suicide.

The Lake Maracaibo region of Venezuela, less than 300 miles east of Baranquilla and also on South America's north coast, has the world's largest concentration of HD-affected individuals – described by Sabine as HD's “ground zero.” There pioneering scientist and HD-family member Nancy Wexler's research, which included collecting blood samples from the people, helped lead to the discovery of the huntingtin gene in 1993. Some villages in the region have as many as 20 percent of their residents living at risk for the disease, Dr. Muñoz observed.

(The Casa Hogar, a nursing home and clinic in the Maracaibo area for persons living with HD, opened in 1999 thanks to the efforts of Dr. Wexler and a Venezuelan physician, Margot DeYoung. At present there are no patients living in the Casa Hogar, although outpatient counseling may be available on a limited basis.)

Factor-H wants to “give back” to those and other impoverished HD communities, Dr. Muñoz concluded, issuing an appeal for support.

“At the end of the day, it's a civil rights issue,” he added in our July 29 interview. “People should have access to fresh water, to decent care, to a bed. Nobody with HD should be dying or in shame or been abandoned by the families, let alone by their governments.”

Supporting basic needs, education, and medical care

As a result, Factor-H has spent several hundred thousand dollars assisting HD families, so far mainly in Venezuela and Colombia, Dr. Muñoz told me in an August 7 e-mail.

Factor-H has focused on helping meet basic needs, arranging for potable water, clothing, medications, specialized medical care, burial services, and legal assistance. It supports the education of children and also of caregivers and patients, including audiovisual materials for the illiterate.

Factor-H also assists with establishing sustainable community development projects to reduce the huge economic burden HD typically causes for families. In the future, it hopes to help establish community centers.

Building a sense of pride for young at-risk people

With its emphasis on children and teens, in 2015 Factor-H established Project Abrazos (“hugs” in Spanish). The program helps children remain in school. The program currently supports 42 Colombian and 100 Venezuelan children ages 5 to 15, all at risk for HD. Factor-H also helps promote sports and recreational activities.

In Colombia, the children also get to vacation during summer and at Christmas “so they have a proper childhood,” Dr. Muñoz said at the premiere. “It’s wonderful to see them doing so much better than when we met them.”

In July 2018, Factor-H co-sponsored the first Latin American Huntington’s Disease Conference in Barranquilla. The conference included activities for Juan de Acosta residents. It was structured to address HD not just as a medical or educational challenge, but also as a social problem, Dr. Muñoz explained.

In tandem with the conference, the Huntington’s Disease Youth Organization (HDYO) organized a meeting for young people from six Latin American countries. For many, it was their first experience of global solidarity and friendship in the HD cause. Factor-H hopes to hold the conference every two years.

Dr. Muñoz described how teens and young people experience the shame, stigma, and social isolation often associated with HD.

“In many cases, they felt nobody was going to love them and marry them, because they came from an HD family,” he explained in our July 29 interview. “In many instances, I felt that people had no hope that they were going to lead a productive life because they were going to die from Huntington’s, so therefore why go to university and so forth.”

To overcome this outlook, Factor-H seeks to build a sense of pride, confidence, and growing sense of community in young people, which will help create a new generation of leaders for the Latin American HD community, Dr. Muñoz pointed out.

Anyervi’s transformation

At the premiere, Dr. Muñoz offered the example of how the life of Anyervi Gotera, 16, of the Maracaibo region, has been transformed by Factor-H and #HDDennomore – despite having learned the day after meeting Pope Francis that he has juvenile HD, in which symptoms appear as early as the toddler years.

Before the pope's arrival in the Vatican auditorium, Anyervi was honored on stage and given a soccer ball and jersey autographed by Brazilian star Neymar.

“When I first met Anyervi a couple years before then, he wouldn’t look at me in the eye,” Dr. Muñoz told the audience. “He was embarrassed, almost ashamed. He didn’t get out of his home in San Luís. He had no friends. He had been pulled out of school because he was being bullied. He usually played alone with a small ball in the back of the house.

“However, today I can say for sure that Anyervi’s story is one of very profound change. He’s adored by his community. He has many friends – his mother would say too many. He’s a very confident teenager, in spite of the disease and because of his speech impediments. In some ways, he has become a hero in his own town.”

Sadly, juvenile HD sufferers like Anyervi rarely live beyond their 20s and often die in their teens. Anyervi’s HD-stricken father, who passed on the gene to his son, died earlier this year. He was in his 40s.



Juvenile HD-affected Anyervi with soccer ball after #HDdenno, May 2017 (photo by Gene Veritas)

Establishing trust

In order to understand HD families’ needs, Factor-H also assists with the socioeconomic mapping of HD communities in Latin America. However, Dr. Muñoz stressed that it does *not* conduct or finance any scientific or clinical research.

Instead, Factor-H aims to form a “trusting relationship” with HD families, he explained in our July 29 interview.

“A lot of the initial experience of impoverished communities with Huntington’s disease with medical or scientific professionals has always been around their participation in a scientific or clinical study,” he said. “So there was a bit of a misperception that I was there as a scientist to study them, which wasn’t the case.

“Our strategy from the beginning was to get to know them as individuals and as a community, understand their history, understand their needs, and also identify local organizations or community leaders who we could work with to channel help and be able to implement projects to their benefit.”

Thus, Factor-H partners with local HD associations, foundations and nonprofit organizations, universities and medical schools, aiming to maintain full

transparency, for example by holding public meetings, Dr. Muñoz said.

(Though #HDdenmore indicates progress, the Catholic Church has offered limited and sporadic assistance so far, but Dr. Muñoz said he believes more help may be forthcoming. Recently, Factor-H received a small grant from the Italian branch of Caritas, the Catholic international aid agency.)

Local HD groups and families need “to be involved at every step of the way,” Dr. Muñoz said. “We don’t want to be an organization that comes in from outside to tell people what they need to do.”

Factor-H and its partners seek to raise awareness regarding HD among Latin American governmental and nongovernmental organizations, then stress the need to assist affected families with specialized support, Dr. Muñoz explained.

Expanding across Latin America – and beyond?

According to Dr. Muñoz, in addition to Venezuela and Colombia, Factor-H has also pursued projects in Chile and Peru. It brought an Argentine family to #HDdenmore and has also done fundraising in that country, and it involved Brazilians in the 2018 HD conference in Colombia. Factor-H has also received inquiries from Ecuador and Costa Rica.

Factor-H would like to extend to all of Latin America, Dr. Muñoz said.

In Brazil alone, Latin America’s largest country (and the world’s fifth largest) with 210 million people, an estimated [20,000 people have HD](#). (Dr. Muñoz visited a poor, isolated HD community there in 2013.) Mexico, the world’s eleventh largest country, also doesn’t yet have Factor-H programs.

Indeed, HD organizations, even in rich countries, have been able to afford family and community assistance at best only on a small scale.

[WeHaveAFace](#) offers a small family assistance program currently operating in Canada, but the U.S. branch is currently out of funding, Kevin Jess, the WeHaveAFace Canada vice president, told me in an August 9 Facebook interview.

HDSA and its [National Youth Alliance](#) provide scholarships to its annual conventions, but have no family assistance program. However, as HDSA CEO Louise Vetter explained in a phone interview August 12, the organization keeps the HD community informed of other assistance programs such as the [Thomas Cellini Huntington’s Foundation](#) and Healthwell Foundation’s fund to [help with HD medications](#).

HDSA assisted Factor-H with #HDdenmore, the shooting of the footage for *Dancing at the Vatican*, and the Los Angeles premiere, Vetter said. It has also helped Factor-H with project management.

“It’s part of our responsibility to the global community that we make sure that all families affected with HD have access to the best information and best resources,” she said, adding that HDSA is also “very active in international partnerships and collaborations” with HDYO, the [International Huntington Association](#), the [European Huntington Association](#), and [HD Cope](#).

Noting that the Factor-H is applicable anywhere, Dr. Muñoz believes that it could someday set up elsewhere in the developing world.

“Any family with Huntington’s that’s living in difficult situations socially or financially, if we can help, we should be able to help,” he said.

For any of this to happen, he added, Factor-H needs broader support among both individuals and institutions.

Watch my July 29 interview with Dr. Muñoz in the video below. Just below that video, watch our additional interview in Spanish about Dr. Muñoz's scientific background and research, Factor-H, and the progress towards HD treatments.



Factor-H: Partnering Locally to Aid Latin America's Destitute Huntington's Disease Families

from [Gene Veritas](#)

39:39 |



Una Revolución en el Tratamiento de la Enfermedad de Huntington

from [Gene Veritas](#)

17:30 |



Posted by [Gene Veritas](#) at 4:18 PM      

Labels: [#HDdenomore](#) , [Brazil](#) , [Dancing at the Vatican](#) , [Factor-H](#) , [HD gene carrier](#) , [hope](#) , [humanitarian](#) , [Huntington's disease](#) , [Ignacio Muñoz-Sanjuan](#) , [juvenile HD](#) , [Latin America](#) , [Nancy Wexler](#) , [Pope Francis](#) , [poverty](#) , [Venezuela](#)

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