Huntington’s Disease Heroes: A Gratitude Day Feature on Factor-H

In honor of #HDGratitudeDay, happening today, March 23, 2025, HDBuzz interviewed Dr. Ignacio Muñoz-Sanjuán, President and Founder of Factor-H—a nonprofit dedicated to supporting Huntington’s disease families in Latin America.


By Dr Rachel Harding and Dr Sarah Hernandez **March 23, 2025**

Edited by Dr Sarah Hernandez and Dr Rachel Harding

There are heroes who walk among us. In the Huntington’s disease (HD) community, some of those heroes are the leaders of **Factor-H**—*a nonprofit organization dedicated to improving the lives of HD families in underserved communities by providing humanitarian aid, education, and advocacy*. Huntington’s is an unrelentingly cruel disease that afflicts families with generation after generation of trauma, medical challenges, and overwhelming emotional, financial, and social burdens that can make even the simplest aspects of daily life a struggle.

What could make HD worse? Abject poverty so extreme that families are left utterly resourceless, living in tin-roofed huts with dirt floors without mattresses, electricity, or running water. This is the reality for some of the largest clusters of HD families in the world, located in South America—the same families that contributed to the research that discovered the gene that causes HD. Even still, every scientific advancement that the HD community hopes for and closely scrutinizes likely won’t make its way to these unimaginably vulnerable populations of people without help. That help is **Factor-H.**

This year, in honor of **Gratitude Day—happening today, March 23rd**—the HDBuzz editorial team is shining a light on the heroic work being done by Factor-H in an interview with Dr. Ignacio Muñoz-Sanjuán (aka Nacho), President and Founder of Factor-H. Here, we are joining in the spirit of the day, showing gratitude for all that they’re accomplishing for a community to which the global HD families owe so much, while helping to amplify Factor-H’s mission.

Some of the largest clusters of people with Huntington's disease are in South America. Some of those people live in extreme poverty, housed in tin-roof huts, without proper bedding, electricity, or plumbing - conditions that make living with HD tremendously more difficult.

Image credit: Vladimir Marcano

The Beginning

HDBuzz: Can you introduce yourself and tell us about your background in Huntington's disease research and advocacy?

Nacho: I'm a neuroscientist with a specialty in Huntington's disease. I worked at CHDI Foundation for 15 years as their Vice President for translational biology where my focus became very much concentrated on all aspects targeting huntingtin lowering and then circuit-related therapeutic development. Pretty much anything that related to advancing novel therapeutics for Huntington's disease, I was responsible for on the biology side.

I came into the field of Huntington's purely by serendipity. It so happened that one of the science directors of CHDI was a colleague of mine. And back in 2006, they were looking for a head of biology. So, she contacted me, I came down and I decided to venture into this new world of nonprofit foundations doing research. So that's how I landed in Huntington's disease.

On the advocacy side, it was a completely unplanned life trajectory. Soon after I started at CHDI, in 2008, I got people affiliated with the organization to come with me to Mexico City, because I had a friend who was the director of the Genomic Medicine Institute in Mexico. I was encouraging people in South America to participate in research studies. And a friend of mine told me, "Nacho, don't you know the history of Venezuela? We've been asking people to participate in a lot of things and they don't even have any food to eat." I really didn't know that aspect of the situation in Venezuela. So, it kind of got me thinking, okay, well, there's a history here that I don't understand and I should try to understand. And through that meeting, I got to know some people from Colombia and Venezuela.

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So, I spent two summers traveling through Brazil, Colombia, and Venezuela. I was able to see firsthand the magnitude of the problem and what I consider an amazing disconnect between the progress that we were making scientifically with the lack of progress in terms of these people being cared for adequately.

A second thing that happened, after I finished a talk I gave in Brazil, there was an older HD patient from Brazil with his wife. He was in a wheelchair. His disease was pretty advanced, and he did not speak Spanish or English. His wife translated for him when he held my hand and he told me, “Please, please, I know it’s too late for me, but please help my daughter.” At that point, it really made me feel for the first time that the work that we were trying to do was really transgenerational. I might not be able to help many of the other people I would meet directly, but the work I was doing in the advocacy realm could help build a better future for future generations.

So those two things were really impactful for me and it kind of launched me into understanding better the patient perspective by visiting these communities. After I did, I decided I needed to do anything to help them, and that’s how Factor-H was born.

HDBuzz: What’s the story behind the name of Factor-H?

Nacho: I struggled a little bit with a name that could resonate in Spanish and in English. The word “factor” is the same in both languages, number one.

Factor-H is a humanitarian-based non-profit, focused on helping the most vulnerable Huntington’s disease families in Latin America. Through donations - 100% of which go to supporting the people they serve - they organize necessary supplies for HD families in these areas, like food, basic medical supplies, and toiletries.

Image credit: Vladimir Marcano

I started thinking about the fact that Huntington’s disease can become the dominant factor in people’s lives. It’s just all encompassing for everybody who is affected and their family members. And I wanted to create an organization where the factor “H” for Huntington’s brought us together, but slowly the H of Huntington's will be replaced by the H of hope and the H of humanity. So that's why I call it Factor-H, Huntington's, Hope, and Humanity.

The idea is hopefully, through science and through our advocacy work, we can support those families so that they develop other factors in their lives that really bring them satisfaction, happiness, stability, and growth.

HDBuzz: What inspired you to start Factor-H, and what is the organization's primary mission?

Nacho: I have to be honest, at the beginning it was like, "I have no idea what I'm getting myself into. I don't know what to do. I just saw some horrible things and I want to help."

So I started organizing parties in my house and collecting clothes and toys. Essentially Factor-H was a project between myself and the other co-founder, who is a clinical geneticist from Buenos Aires, Dr. Claudia Perandones, who now manages the Enroll-HD project in South America, Spain, and Portugal. The two of us decided we needed to do anything that we could think of, but it wasn't meant to be an organization. It was meant as a project to try to help people. But the more I started going every year, or multiple times a year, people started joining the project. At some point a few years later, I said, "Okay, well, we need to formalize this."

> **"We took a very holistic approach and we reframed Factor-H as a human rights-based organization, focused on Huntington's disease, because that's the disease we know best. Not just taking care of the health implications of having the disease, but rather a broader approach for community development, education, supporting children, supporting caregivers, and essentially filling in for the gaps in access to all kinds of support and care that these communities experience. "**

That's when we created Factor-H as a nonprofit registered in the United States, six years after I started, in 2018. I think by then the mission was quite clear, which is that we're using Huntington's disease to help communities that sit at the interface of neurodegenerative genetic disorders and poverty or conditions of extreme vulnerability. That's why we focus on the communities that we do, which are the largest clusters of HD families in the world, in South America. They all have very similar characteristics in terms of lack of access to education, to medical care, and suffering from extreme discrimination, and a lot of psychological issues with children.

We took a very holistic approach and we reframed Factor-H as a human rights-based organization, focused on Huntington's disease, because that's the disease we know best. Not just taking care of the health implications of having the disease, but rather a broader approach for community development, education, supporting children, supporting caregivers, and essentially filling in for the gaps in access to all kinds of support and care that these communities experience.

We decided to focus on four major pillars, or areas of work. The first one is health, then is youth, community development, and data collection and advocacy. For community development, that includes anything from humanitarian assistance to renovation of homes, to buying adequate bedding for people, to eventually things like adequate bathrooms and septic tanks. A lot of these communities are living with no infrastructure, so to speak, that we're used to.

For data collection and advocacy, this included establishing our own internal databases where we capture all medical, social, economic, educational information for all the families, so we have maps with the location of every family member that we've identified. We know how many kids, what their ages are, what their educational level is. So that's all included in that area, and that enables us to prioritize the work, but also to begin to influence local entities to support those families when they can. So in many ways we have become the representative voices from those communities, both internationally and locally. Under the advocacy umbrella, we also organize conferences in Latin America, like scientific and medical conferences and other types of educational activities.

Factor-H's Work & Impact

Health and disease management is a central pillar of Factor-H's mission. They help families affected by Huntington's disease who live in Latin America access multidisciplinary and quality care, provide health-related legal assistance, and get them medicines.

Image credit: Vladimir Marcano

HDBuzz: Some of what you're describing are really quite basic things that you're providing to people. Help us illustrate the level of poverty that we're talking about and the difficult situations that these people are living in. Can you tell us: What is the typical situation of a family that's living with Huntington's disease in Venezuela? What kind of house are they living in? Do they work? Do they have income? What is their life like? Can you paint a picture of what that is like for these families?

Nacho: In Venezuela particularly, we're working in two main communities. One is located very close to the city of Maracaibo, which is the capital of Zulia state and is the second largest city in the country. There is essentially a small municipality, called San Francisco, of about 4,000 people north of the city, where about 10% of the people will develop Huntington's disease.

Almost 30 to 40% of all the families in that municipality have a history of HD. Now, we don't have access to genetic testing in that town, but we can tell you based on the number of patients and the number of individuals at risk, because we've characterized every family member there.

The community of Barranquitas, which was very instrumental to the identification of the gene that causes HD, is one of the largest in the world. It's about 6,000 to 7,000 people, more or less. And again, based on our accounts, anywhere between 10% and 20% of the population will be affected with HD. That community is extraordinarily poor. Overall, about 80 to 90% of all the families we have been supporting live either in poverty or extreme poverty by international standards.

The vast majority don't have an education. They're relatively large family structures—five, six, ten children. For many of them, if the mother is affected with HD, it's fairly typical that they get abandoned by the father, so the kids grow up taking care of a mom and other sick relatives. Their houses, in many cases, lack electricity and running water. They are essentially tin-roofed huts with one room, with maybe a mattress on the floor or a few hammocks, that people have to share. We prioritize helping those extreme cases, but in these communities, the average family typically earns a very minimal income. So, it's as extreme as you can think about.

> **"In many cases, families don't eat more than once a day and the meals are not very nutritious. So, just trying to get regular support on nutritional supplements and adequate food is a problem with the numbers of families that we are supporting. "**

HDBuzz: HD in and of itself brings intense, difficult challenges, but to imagine going through that in those conditions of extreme poverty presents incredibly unique challenges. Can you talk about some of those challenges that are specific for that population?

Nacho: The challenges really depend on where these families are living. We have different programs that are geared to Venezuela and Colombia, depending on what we think we can realistically do, and also to the level of support that they might have access to.

In Colombia, a lot of the families are dispersed in rural areas. So, basically, you are in the middle of a rural area with a house that is maybe a mile or two or three miles away from any other house. Then you have patients that have been kept in an isolated room without any type of social visits or interactions for years and years.

In Venezuela, because the communities are so affected, the patients are, in many cases, just walking around the streets and they are living close to family members. They might lack some resources that are available in Colombia, but they don't lack social interactions. So, the way that the disease impacts quality of life really depends on these elements, which wasn't clear to me until I started visiting a lot of these families where they may be in a room with no TV, with nothing to do for years at a time, with nobody coming to see them.

That's part of the reason we established the social agents. They're essentially social workers, but they're not formally trained in social work—they go visit people regularly, they sit with them or they wash them. They also act as their representatives when problems arise or the people they visit lack medications or food.

Social agents are a key part of Factor-H's mission - they're local community members who visit people in Latin America affected by Huntington's disease, and step in to act as their representatives for day-to-day issues, like acquiring medication or food.

Image credit: Vladimir Marcano

In Venezuela, there are challenges everywhere. When I first went in 2013, there were very good neurology, psychiatry, HD specialists that were taking care of and visiting people. There was access to the genetic test. All of those professionals left the country. So, one of the biggest problems is trying to reconstruct basic neurological and medical services in a landscape where people are continuously leaving the country. We managed, I think, to build an infrastructure in Venezuela that now works and many people are being seen regularly, but it took us a while to figure out how to actually do it.

Access to potable water and adequate food is a big problem for HD patients and children. There's a lot of parasitic infections because they don't have septic systems, for example, in Barranquitas. In many cases, families don't eat more than once a day and the meals are not very nutritious. So, just trying to get regular support on nutritional supplements and adequate food is a problem with the numbers of families that we are supporting. In Venezuela alone, it's about 600 families with a history of Huntington's disease that we're trying to support. At the present moment, I think we have about 205 patients that are clearly symptomatic. It's probably quite a few more, but we are not calling them HD cases because we don't have genetic testing.

In Colombia, depending on where people live, we have different sets of problems. The advantage of Colombia is that the healthcare system is operative, even though it's very challenging for HD families to navigate. I'll give you an example of one of the programs that I'm really proud of. The Colombian government has included Huntington's disease in their rare disorders' legislation, which guarantees access to medications and support like wheelchairs, mattresses, diapers, etc.

The problem is that a lot of the families we represent are poorly educated—many of them don't know how to read and write, and they certainly don't understand the rights from a legal perspective or how to access those rights. So, one of the things that we've done is to initiate a legal assistance program, where we have a lawyer that works at Factor-H, and now we teamed up with another legal non-governmental organization, and we are aiming to legally support every Huntington's family that needs help throughout the country so that they know they legally have access to these resources.

For example, there's a disability legislation that applies to people with Huntington's disease, but most people don't know they have those rights that covers a basic income. So, we've been doing all the paperwork to ensure that those individuals that don't have disability status can get it, and therefore we help the affected individual, and also we help their family economically.

> **"There's another parallel path, which are the things that we can do today. That really opens up a world of possibilities, because as long as you make people feel good and supported, this can improve their quality of life. "**

If the insurance companies in Colombia do not prescribe medications or wheelchairs or diapers, we present a case to them. We've done about 40 or so cases in the last two years, and we've won all of them. Now from that point on, the family gets all of the medical assistance the government is obligated to provide. That would never happen in Venezuela, because there is no such system in place, but in Colombia it does. So, a lot of the things that we do are really very much connected with the needs and the context in which these families are living and in what country.

Research & Scientific Collaboration

HDBuzz: In the US, we largely think about HD as a scientific problem. Especially as researchers, often from our view a critical thing is research and getting the research out to the people. But for the areas Factor-H serves, it's almost an entirely different problem.

Nacho: The way I always think about it is that there are two parallel paths. There's the path of science and medicine, which is the ultimate solution. We all work in this space and we all know why it's so important, but it's very slow. We don't know when it's going to happen.

When it happens, how will these families get access to those medications? This is a big area for me in the health domain. But there's another parallel path, which are the things that we can do today. That really opens up a world of possibilities, because as long as you make people feel good and supported, this can improve their quality of life. That's the approach that we take with Factor-H as a parallel avenue from scientific work. I think both are needed.

Factor-H empowers families and communities through development, providing basic assistance for extremely vulnerable Huntington's disease families, promoting educational opportunities, and aiding in access to water, electricity, and funeral services.

Image credit: Vladimir Marcano

HDBuzz: Can you tell us about how data collection ties in with your work with researchers and clinicians and other stakeholders within this space to try and advance your mission.

Nacho: The only thing we don't do at Factor-H is research, in the way we understand it—meaning participating in a study monitoring sleep or asking them to give us blood, for example.

The reason is that in Venezuela and in Colombia, and to some extent in Peru, most of the time outside doctors would only go and visit these people to study them. They would come one time, they would tell them all the wonderful things they were doing, they would ask for blood samples or psychological tests or whatever, they leave, and they would publish their paper, and never return.

It took me a number of years to earn the trust of those communities, to get them to feel, "OK, you're a scientist, but you're not here because you want something from us. You're here to help us." So, from the beginning, we decided that we are collecting this data in order for us to understand and be able to serve them, but not to use this data for medical or scientific research.

HDBuzz: We were wondering about that. How do these families feel about their contributions to research that got us to where we are today, knowing that many advancements, like AMT-130 or brain surgery, may not be accessible to them?

> **"I'm more optimistic that as a community, if there are therapies that are approved and we apply some positive pressure and discussions, the number of families is not so large that it makes this a feasible proposition. "**

Nacho: That's part of the work that we hope to do. I've already started discussing things with some companies that if their therapies get approved, whether we could institute a free access program for people, especially in Venezuela, assuming that we could.

A gene therapy is not going to be easily accessible in Venezuela, for example, but an oral drug or even ASOs could be. There's a lot of excellent neurology centers in Latin America. Venezuela is probably the most isolated place right now in terms of access to some of these novel therapies, but for spinal muscular atrophy, many children in Latin America are benefiting from these ASO injections.

I'm more optimistic that as a community, if there are therapies that are approved and we apply some positive pressure and discussions, the number of families is not so large that it makes this a feasible proposition. But certainly, one of my key goals for Factor-H is to mediate that therapies are made available to people there.

All the money raised by Factor-H goes to South America and all the people who are hired by the charity are in South America. They're all local people. As much as we can, we try to hire social workers for the community, the caregivers that we train are local caregivers. We're trying to invest as much as we can directly or through education or professional training to focus on local people, because they're the ones that are going to tell us if something is working or not working.

HDBuzz: Are there any other big unmet medical or social needs that you haven't mentioned in these underserved regions?

Working to develop a resilient, informed, and empowered new generation aligns with Factor-H's mission to serve the youth of Huntington's disease families in Latin America. Among other things, they promote health and reproductive rights, access to psychological support, and build youth communities through recreational gatherings.

Image credit: Vladimir Marcano

Nacho: Anything that has to do with education is a big problem, especially disease-related education, whether it is the implementation and education around genetic testing and family planning. It's a big problem in South America in general, both for cultural, religious, and educational barriers.

Education of the local family members as to how to deal with psychiatric symptoms in HD is a big problem. You could have a child or adolescent with juvenile HD. They don't know what it is. They don't know how to handle it. So, reinforcing education at all levels of the disease is fundamentally important—that's laypeople, medical professionals, you name it.

Even though they live with this disease for a generation after generation, there's still a lot of stigma and really a lack of understanding of the disease and how to deal with the symptoms. The educational aspect that worries me a lot is the education of the kids. We've been investing in this for more than 10 years now, which is to create a community of kids who are educated about HD, who have a support network with other HD at risk kids. So that when someone starts having problems, they have somebody to go and talk to.

Public Awareness & Advocacy

HDBuzz: How does Factor-H work to raise awareness about HD in the broader global community?

Nacho: Every four years we organize these very large CHDI-like conferences in South America where we fly in all the world experts. This is not limited to research and clinical trials; we include topics such as occupational therapy, legal rights, and other topics seldom dealt with in scientific conferences. That's really created a lot of momentum with the local professional communities, and has brought the patient community closer with the professionals working in HD.

> **"It is my desire to make sure that we get more exposure in the sense that more people at a minimum know that these communities exist and how they live. I think if we can all pull together, we can do a lot of things with a relatively small budget. "**

We're still working on ways to more efficiently connect with the worldwide HD community, to let them know about the situation and to know about the work that we do to try to get more support. Certainly we thank you for this article, as HDBuzz is widely read!

HDBuzz: What are some of the largest barriers for increasing the amazing work that Factor-H is doing? Are they primarily financial, or are there other factors?

Nacho: Well, financial always, but I think if more people knew about Factor-H and more people understand that if they give $20, 100% of that donation goes to South America to help somebody. That $20 helps sponsor a child in our programs.

99% of all the philanthropic donations go to HD research because people want a treatment, and that's not what we do. We also work in relatively small communities, in very poor countries, with a very specific segment of the HD population that not everybody has an interest in. However, it is my desire to make sure that we get more exposure in the sense that more people at a minimum know that these communities exist and how they live. I think if we can all pull together, we can do a lot of things with a relatively small budget.

HDBuzz: What are some of the main misconceptions about HD that you encounter, specifically in the communities that you're working with?

Factor-H works to collect data related to the location of Huntington's disease families so that they can provide medical care, legal assistance when needed, and advocate for education.

Image credit: Vladimir Marcano

Nacho: It's becoming less and less since we've been there, but the biggest misconception was that HD was a curse. That there's a problem with your family and your entire family is being cursed for the rest of life.

In other cases, people who are not from HD families wonder whether the disease is contagious. That really affects a lot of children because they can't maintain friendships in school the moment they start having symptoms or people know they come from an HD family.

A lot of young people, which I don't think is different in South America from Europe or North America, but a lot of kids are ashamed of talking about the disease because they feel that maybe their girlfriends or boyfriends, or potential girlfriend or boyfriend, won't want to date them because they come from an HD family. They fear about their future and feel very alone.

I think in many cases, the fact that it's genetic and the fact that just because your mom has HD doesn't mean that you for sure are going to get HD continues to be a misconception that we're trying to change.

Challenges & Future Goals

HDBuzz: What are the biggest barriers Factor-H faces in its mission, whether logistical, financial, or political?

> **"People who are not from HD families wonder whether the disease is contagious. That really affects a lot of children because they can't maintain friendships in school the moment they start having symptoms or people know they come from an HD family. "**

Nacho: I'm very proud of the infrastructure that we've set up. We have clear goals, we have a lot of projects, but we have little money to implement them. In many cases, I am still dissatisfied with the level of healthcare support that we can provide continuously for these family members, especially the people that live in rural areas. It's very expensive to bring somebody to a clinic every few months, but that's an aspect that we need to expand. If it was up to me, I would have an entire medical team with maybe a medical van that can facilitate going whenever we need.

The lack of access to genetic testing is a big problem in Venezuela, in my opinion, but it's not something that we can tackle at this point for many reasons.

If money weren't an issue, we would do daycare centers for patients and for family members—a place that is safe, that is well conditioned, where they can come and rest and be entertained and where we can organize caregiver support, psychology support, and all the things that we're doing, but in a properly adequate facility. That would be true in Peru, it would be true in Colombia, and it would be true in Venezuela. All these communities really yearn for a place of their own where they can build community and feel welcome and well cared for.

HDBuzz: How can people outside of Latin America—researchers, advocates, and the general public—support Factor-H's mission?

Nacho: There's a lot of things that we can collectively do that don't involve money, but involve a little bit of time, like working on generating information in a way that is suitable for children or for teenagers about the disease. If someone does a run, they could choose Factor-H as their charity. We're trying to build an app for caregivers where things are explained in very simple manners, with culturally sensitive language. So, it would be great to have a person that wants to volunteer time to do some coding for app generation, as an example.

Factor-H serves the most vulnerable populations of people with Huntington's disease in Latin America - the same communities that contributed to the research that led to the discover of the gene that causes HD.

Image credit: Vladimir Marcano

All of us that are working on Factor-H all came from the same perspective—we wanted to do something, but we had no idea what to do. If you're interested in helping our mission, get in touch and we'll see what we can do together.

Closing Thoughts

HDBuzz: How can Gratitude Day help HD families reflect on their own struggles while also recognizing the even greater challenges faced by those in poverty who have contributed so much to HD research?

Nacho: That's exactly why we created Gratitude Day. It was Jimmy Pollard's idea as a way of trying to help raise awareness about what we were trying to do. He came up with the idea of using the day of the publication of the paper that first detailed the genetic cause of HD as a day of gratitude to all the families and to celebrate the collaboration between families and scientists and clinicians.

I think that's given Factor-H exposure, but it's also quite beautiful to see—people posting pictures and sending us photographs from all over the world, from India to New Zealand, to Russia, to Turkey, South America, and every year it's growing. It's a beautiful way of feeling part of a bigger purpose or a bigger community than just your family and close ones. I think that really helps patients and family members to understand that they're not alone.

One of the things that I've experienced from the beginning was that a lot of people contact me, and they may be in Guatemala or Ecuador or other places, and they really don't know anybody with Huntington's disease and they don't know any professional who knows about the disease. At Factor-H, we've become a little bit of a reference for those people. So, in many ways, the more exposure, the more that people will know, the more that we will be able to help.

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HDBuzz: Do you have any final messages for HD families around the world that you would like to share?

Nacho: Let's finish it with Gratitude Day, rather than Factor-H. We came up with Gratitude Day because we wanted to make sure that the immense contributions, particularly from the Venezuelan families, to research and clinical development are not forgotten.

Those extend beyond the identification of the gene. Some of the rating scales, including the UHDRS, were first developed and tested in the field in Venezuela. The first scales that incorporate the psychiatric and cognitive tests, the same. The first evidence of the fact that we have modified genes were identified in Venezuela. The brain samples, the cell lines that are still used in research are from Venezuelans—there's about 130 different cell lines that are still available that are from the Venezuelan project. So, their contributions were enormous to science.

The second aspect is, if you ask any of the people that went to Venezuela—fromNancy Wexler to Diana Rosas, William Yang, Leslie Thompson, Gill Bates—their careers were influenced tremendously because they went to Venezuela and they were able to interact with those families. So, the sense of community, the sense of purpose, the sense of mission is still reverberating. I just don't want it to get lost. We're all getting older and some of the people that went to Venezuela might soon retire. I think the younger generations shouldn't forget about everything that the Venezuelans contributed and the fact that they're still there. They need our help, just like we asked for their help when we as a scientific community went there initially.

There are many people with Huntington's living in conditions that are extraordinarily difficult and they need to feel supported. We have grown into a really powerful community worldwide over the last 20 years, but it's not really a worldwide community yet. We tend to focus too much on economically developed countries and forget that there are hundreds and thousands of families who are left out of that conversation and I think it's up to us to reach out to them.

So, for Gratitude Day, I would say try to join us, try to understand why we're doing what we're doing, come and join the cause. It's a wonderful journey and people should just reach out and see where things go from there. Just like I did the first time I went to South America.

To learn more about the inspiring work that Nacho and Factor-H are doing, visit their website. You can stay connected to their mission by giving them a follow on Facebook or Instagram. These heroes are making a profound difference in the lives of the most vulnerable HD families, by bringing hope, dignity, and essential support to those facing unimaginable challenges.

This interview has been minimally edited for length and clarity. For more information about our disclosure policy see our FAQ...

GLOSSARY

neurodegenerative A disease caused by progressive malfunctioning and death of brain cells (neurons)
therapeutics treatments
juvenile HD Huntington's disease where symptoms begin before the age of 20.
dominant A genetic condition that only requires one copy of a mutation to occur
UHDRS A standardized neurological examination that aims to provide a uniform assessment of the clinical features of HD
ASOs A type of gene silencing treatment in which specially designed DNA molecules are

used to switch off a gene
