

## This Gratitude Day, HDBuzz Is Grateful For The Partnership Between HD Families And Scientists

This #HDGratitudeDay, we're going beyond science & getting to the heart of what drives this community—the people. Learn how Factor-H is bringing hope & humanity to the most vulnerable within the HD community, and join us in amplifying their message.



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**G**ratITUDE Day—Sunday, March 23rd—is a global initiative organized by [Factor-H](#), celebrating the resilience and strength of Huntington's disease (HD) families, particularly those in underserved communities—the same communities who have historically partnered with the medical and scientific community to advance research. In particular, the families from Venezuela, who did so much to help with our understanding of the disease.

It's a day to reflect on the power of compassion, solidarity, and support, recognizing the contributions of caregivers, researchers, and advocates working to improve the lives of those affected by HD. For the HD community, Gratitude Day is an opportunity to amplify awareness, and inspire continued action toward a future with better care, resources, and ultimately, effective treatments, which must include families living in conditions of extreme vulnerability.

In honor of Gratitude Day, the HDBuzz editorial team interviewed Dr. Ignacio Muñoz-Sanjuán (aka Nacho), President and Founder of Factor-H, to learn more about their mission, help amplify their message and share in the meaning behind this inspiring day.



*Factor-H is a non-profit organization dedicated to alleviating the suffering of individuals affected by Huntington's disease in Latin America by providing medical services, social support, education, and advocacy for communities experiencing extreme poverty and high disease prevalence.*

*Image credit: Vladimir Marcano*

## Factor-H

HD is a devastating genetic neurodegenerative condition, but today, we're focusing on the people affected by this disease rather than the science behind it. Specifically, we're diving into the work of Factor-H, an organization dedicated to supporting HD families in Latin America.

Factor-H is much more than just an organization; it's a movement. The name itself stands for Huntington's, Hope, and Humanity, reflecting its mission to shift the dominant factor in these families' lives from the disease, to hope and the human connection.

Through its four key pillars—health, youth, community development, and data collection and advocacy—Factor-H is making a tangible impact in some of the most underserved HD communities in the world. Nacho describes the work Factor-H is doing as, “using Huntington's disease to help communities that sit at the interface of neurodegenerative genetic disorders and poverty or conditions of extreme vulnerability.”

## The Communities at the Heart of HD Research

Many people are unaware that some of the world's largest clusters of HD are found in Latin America, particularly in Venezuela, Peru, and Colombia. In these regions, entire families, and sometimes entire villages, are devastated by the disease. In some communities, a staggering 10–20% of the families have a history of HD—a heartbreaking reality.

Adding to the challenge is the extreme poverty that these families face. In Venezuela, many HD families live in tin-roofed huts without running water or electricity. Basic necessities such as food, medicine, and education are often out of reach. Meanwhile, in Colombia, HD families may not experience the same level of economic hardship, but they endure severe isolation, completely cut off from care and resources.

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Nacho shares that, “Overall, about 80 to 90% of all the families we have been supporting live either in poverty or extreme poverty by international standards. 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.”

These are the very communities that played a pivotal role in the discovery of the HD gene, published in 1993. Despite this monumental contribution to science, many of these families still lack access to the most basic needs. Factor-H exists to bridge this gap, offering immediate relief while also working toward long-term solutions.

## Providing Aid and Creating Lasting Change

Factor-H’s approach is holistic. It recognizes that HD cannot be addressed in isolation from the broader socio-economic challenges these families face. That’s why the organization’s efforts go far beyond medical assistance. Factor-H works closely with essential partners in the various countries where it operates, namely Fundacion Habitat LUZ in Venezuela, the Fundacion Amigos Huntington in Peru, and Fundacion de Antioquia and Universidad Metropolitana in Colombia, among others.

- **Humanitarian aid:** Factor-H provides essential supplies such as food, bedding, and medical care to families struggling with extreme poverty.
- **Medical aid:** Factor-H promotes, facilitates, and provides access to specialists for symptomatic patients and at-risk children including neurology, pediatric neurology, vaccinations, dental and eye care, speech therapy, among other forms of support.
- **Housing improvements:** Many HD families live in unsafe and unstable conditions. Factor-H helps renovate homes to provide safer, more comfortable living environments.



*Families affected by Huntington’s disease in Latin America often live in extreme poverty. They face inadequate healthcare, malnutrition, poor housing conditions, and limited access to basic necessities.*

*Image credit: Vladimir Marcano*

- **Education for children:** The organization runs a scholarship program that has helped dozens of children stay in school, giving them hope for a better future despite their families' struggles with HD.
- **Training caregivers:** Local caregivers are trained to support people with HD, ensuring that families have access to knowledgeable and compassionate care.
- **Legal advocacy:** Factor-H has successfully helped families in Colombia secure disability benefits and medical assistance, empowering them to navigate systems that might otherwise leave them behind.

## The Balance Between Immediate Needs and Research

One of the more complex issues surrounding Factor-H's work is the balance between direct support and research. While the organization prioritizes immediate needs—understandable given the level of suffering—there is also the question of how these communities might benefit from participation in ethically-designed research projects.

Nacho acknowledges this challenge. Even if new therapies are developed, ensuring accessibility in these regions will be a major hurdle. He has suggested advocating for free access programs, particularly for treatments that could be administered locally, such as oral medications. However, achieving this goal will require major shifts in healthcare policies and infrastructure, and will require the support of companies working to develop novel HD therapeutics.

## Battling Stigma and Misconceptions

**“Factor-H is a testament to the power of human connection and compassion. It demonstrates that even in the face of immense challenges, change is possible when people come together with a shared vision of hope and dignity.”**

Beyond the physical and economic struggles, many HD families in Latin America also face deep-seated stigma and misinformation about the disease. This is further potentiated by a lack of education in these areas, often to the level that people can't read or write.

Nacho highlighted the widespread misconceptions about HD, saying, “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 when people know they come from an HD family.” These harmful beliefs contribute to social isolation and further hardship for affected families.

Education and awareness are crucial. Factor-H works to dispel myths and foster greater understanding, not only within HD communities but also in the broader society. This is where global initiatives like **Gratitude Day** come in.

# HD Gratitude Day 2025: Honoring HD Families

March 23rd marks **Gratitude Day**, an annual event recognizing the contributions of HD families to research while also raising awareness of their ongoing struggles. This day was chosen because it marks the anniversary of the 1993 publication detailing the discovery of the HD gene—a discovery made possible in large part by families in Latin America.

Gratitude Day is not just about reflection; it's a call to action. The 2025 celebration includes:

- **Kids Lab Day (March 18th):** A virtual event connecting children from affected communities with a research lab in France, headed by HD researcher Dr. Christian Neri, inspiring them to engage with science.



*Gratitude Day is a global celebration dedicated to expressing appreciation and recognizing the resilience and strength of Huntington's disease families, particularly the vulnerable and underserved communities in Latin America.*

*Image credit: Factor-H*

- **Candlelight vigils (March 19th & 21st):** Families in Venezuela will gather to honor those lost to HD.
- **Pediatric Medical Day (March 20th):** A healthcare event dedicated to children in affected communities.
- **Live Stream from Venezuela (Sunday, March 23rd):** A global event providing an intimate look into the lives of HD families.

Anyone can participate by joining the live stream—we encourage everyone reading this to pop on to the Zoom and say hi! You can also share messages of support on social media using **#HDGratitudeDay**, or simply learn more about Factor-H’s work and follow them on Facebook and Instagram.

The Gratitude Day live stream is not just a celebration; it’s an opportunity to challenge misconceptions around HD and shine a light on the strength and the resilience of these communities.

## A Model for Sustainable Change

One of the most inspiring aspects of Factor-H’s work is its emphasis on sustainability. The organization is fostering self-sufficiency by empowering local communities. It does this by fully reinvesting into the communities they’re seeking to help—*100% of all donations to Factor-H go to supporting these communities in South America.*

**“This Sunday, March 23rd, take a few minutes to extend your hand to the most vulnerable members of the HD community and participate in the hope and humanity that are the primary factors in HD by joining Factor-H’s Gratitude Day live stream. ”**

A key part of this effort is the concept of **social agents**—local individuals who step up to provide companionship, support, and advocacy within their own communities, and who act as representatives of these families and to facilitate aid. These social agents aren’t necessarily medical professionals; they are trusted members of the community who understand its unique challenges. Their role is invaluable in providing both practical assistance and emotional support to families who might otherwise feel abandoned.

Factor-H is also working to strengthen healthcare infrastructure by training caregivers and advocating for better medical access. Their long-term vision is to create lasting change that extends beyond immediate relief and builds true resilience in HD-affected communities.

## A Future of Hope and Humanity

Factor-H is a testament to the power of human connection and compassion. It demonstrates that even in the face of immense challenges, change is possible when people come together with a shared vision of hope and dignity.

For those of us in the HD community and beyond, Factor-H’s work serves as an urgent reminder that scientific progress must go hand-in-hand with social responsibility. While we continue striving for treatments and a cure, we must also ensure that the families who made these advancements possible are not left behind. Nacho said, “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.”

As Gratitude Day 2025 approaches, let's take a moment to honor these families, amplify their voices, and reaffirm our commitment to a future where hope, not hardship, is the defining factor in their lives. So, this Sunday, March 23rd, take a few minutes to extend your hand to the most vulnerable members of the HD community and participate in the hope and humanity that are the primary factors in HD by [joining Factor-H's Gratitude Day live stream](#).

You can [find the Zoom link for Factor-H's Gratitude Day celebration HERE](#).

*Stay tuned for our [full interview with Dr. Ignacio Muñoz-Sanjuán, President and Founder of Factor-H](#), to be published on Gratitude Day, Sunday, March 23. There, we'll do a deep dive into the unexpected genesis of an organization born out of the desire to make a positive change, the inspiring work that Factor-H is doing, and the unique issues faced by these incredibly vulnerable populations of HD families. It truly is a profoundly moving and eye-opening read on what we all have to be grateful for—a must read.*

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*The authors have no conflicts of interest to declare. [For more information about our disclosure policy see our FAQ...](#)*

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## GLOSSARY

**neurodegenerative** A disease caused by progressive malfunctioning and death of brain cells (neurons)

**therapeutics** treatments

**prevalence** A figure estimating how many people there are in a particular population who have a certain medical condition.

**dominant** A genetic condition that only requires one copy of a mutation to occur

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