



FACTOR



HOPE  
HUNTINGTON'S  
HUMANITY

# 2020

## ANNUAL REPORT







HOPE  
HUMANITY  
HUNTINGTON

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# FROM THE PRESIDENT

Dear friends,

2020 was a year like no other. The global Covid-19 pandemic impacted the entire world, but it has taken a heavy toll on poor communities. Most of the families we assist live in vulnerable conditions, and their access to employment and medical assistance were significantly impacted. We reacted to these challenges by organizing a large campaign to assist our communities. More than 400 families received food, masks and disinfectants monthly for most of 2020. Overall, 2000 family members were aided through our program. We also instituted online educational campaigns

We also added new Factor-H members, grants manager Oxana Lavrova and movement disorder specialist Dr. Adys Mendiázabal.

We published 20 blog and news articles and gave seminars in the United States and Colombia. I gave the annual “Insights of the Year” conference for the Huntington Study Group (HSG). The Dancing at the Vatican documentary was made available freely on YouTube and has more than 20k views. Roche financed a year-long project whose objective is to

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***Factor-H has undergone a strategic review and has developed a 5-year growth plan. We have defined 4 key areas of work: Health & Disease Management, Youth, Community Development, and Data Collection & Advocacy. We have redefined our mission and vision, and are establishing a road map for each area, in collaboration with a large team of institutions and consultants.***

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as well as via our social agents. An emergency program ensured access to medication and transportation to medical centers. A telemedicine program was established to hold medical consultations. The real toll of the pandemic in these communities has been very high. The food assistance program allowed families to survive. The kids had to learn remotely, and many suffered significant delays in attending school. In Maracaibo, we started a small school for 12 of the most vulnerable children, who received daily classes in socially distanced conditions in Barranquitas. With grants from the Rainwater and the MJB Foundation, we expanded the number of at-risk children receiving assistance through our Abrazos program to 157 between Colombia and Venezuela. We worked with illustrator Matt Rota to create images to commemorate its 5th year anniversary.

Factor-H has continued to grow and deliver on our objectives. We experienced an increase in corporate donations, and we initiated a grants initiative for areas outside of health. The traffic to the Factor-H website increased by 50% in 2020 and we added 5.5k new visitors. With increased donations, we were able to hire two additional social agents in Colombia, and we extended our programs to help the Peruvian HD association and to Avehun, the largest Venezuelan association.

generate an evidence-based disease management clinical consensus for the treatment of HD. The first meeting was attended by 40 HD leaders from most Latin American countries, from Mexico to Argentina.

Finally, we established new agreements in Colombia with Universidad of Antioquia, Universidad Metropolitana, and Area Andina. In Venezuela, we strengthened our relationship with local institutions, and are now assisting all 3 patient associations in the country. Finally, we extended our area of work to Perú and begun formally to assist families in the Cañete region.

None of this would be possible without the generous contributions of institutions and individuals who have financed these programs. Thank you. Let's work together to make the world a more equitable and hopeful place for those living in conditions of vulnerability.

Nacho



HD families suffer stigma, discrimination, social and institutional exclusion, and more often these instances are aggravated by extreme poverty and vulnerability



## OUR VISION

A world in which families and communities impacted by Huntington's disease live in dignity, equality and prosperity exercising their basic and fundamental rights, including their right to health and education.

## OUR MISSION

To create the necessary conditions that build empowered, cared for, and self-sufficient families through alliances with their communities, local and international partners and organizations, both private and public.





## OUR VALUES

**Equality:** We are all equal in our diversity regardless of age, sex, gender, belief, nationality, ethnicity, language, visible and invisible differences.

**Diversity and inclusiveness:** Diversity enriches our work and we consider everyone to be unique. We embrace inclusive decision-making and believe everyone has a contribution to make.

**Accountability and transparency:** We are accountable, first and foremost, to the communities we serve and to those who support our work.

**Collaboration:** We cannot achieve our goals alone. Building empowered and self-sufficient HD families and communities requires the work of many, including foundations, academia, institutions, governments, and private sector.



# INTERSECTION OF



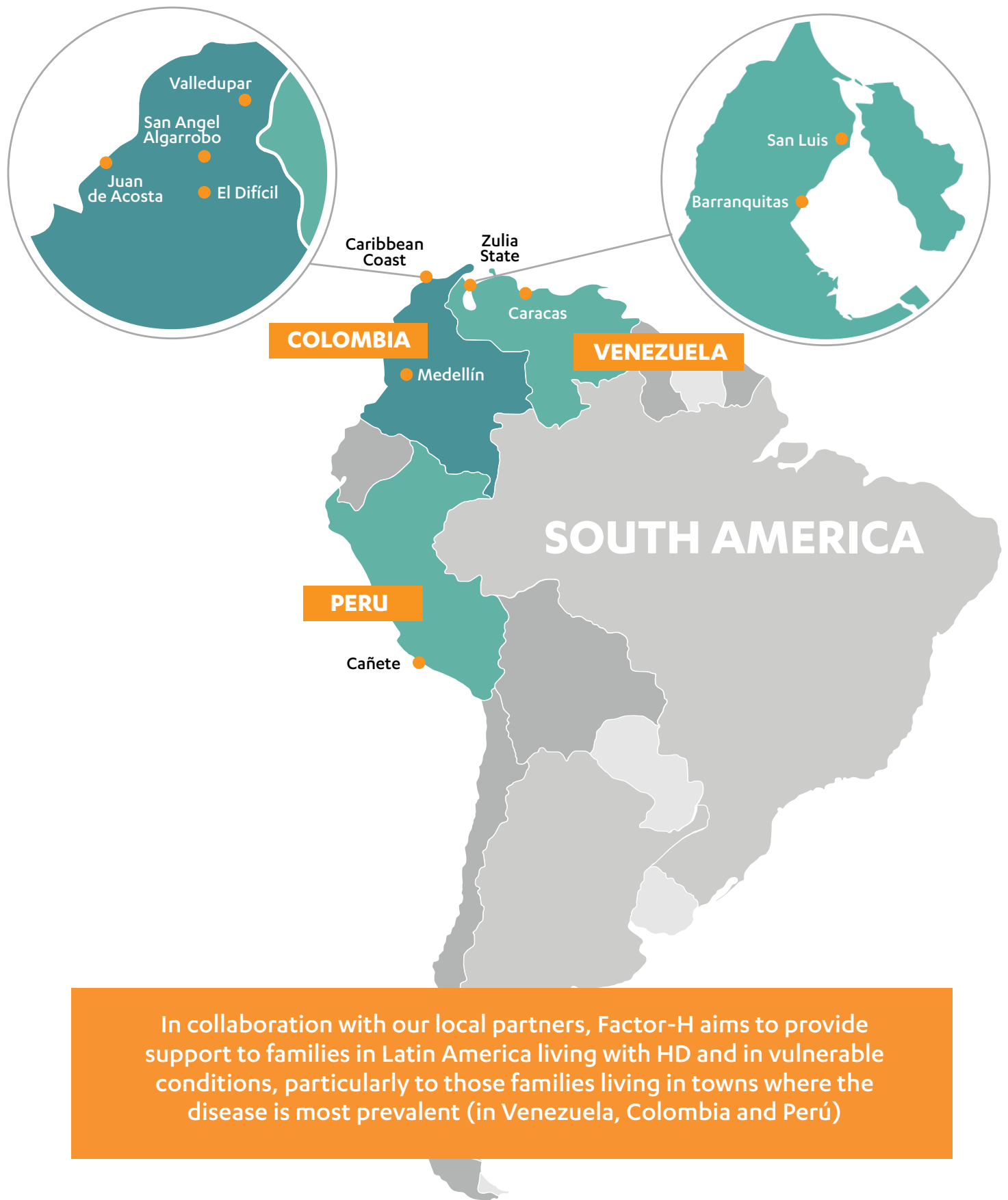


# DISEASE & POVERTY





## WHERE WE WORK







## HEALTH & DISEASE MANAGEMENT

Ensuring  
patient's right  
to health



## YOUTH

Resilient,  
informed and  
empowered  
new generations



## COMMUNITY DEVELOPMENT

Empowering  
families &  
communities



## DATA COLLECTION AND ADVOCACY

Holding duty  
bearers to  
account



# WHO WE ARE

## MANAGEMENT & BOARD



**Dr. Ignacio Muñoz-Sanjuan**  
Founder & President  
Member of the Board



**Dr. Claudia Perandones**  
Co-Founder



**Dr. Roger Cachope**  
Vice President  
Member of the Board



**Bianca Moura**  
Executive Director



**Jamie Levey**  
Treasurer  
Member of the Board



**Evelyn Galstian**  
Secretary



**Dr. Adys Mendiazabal**  
Neurology Associate

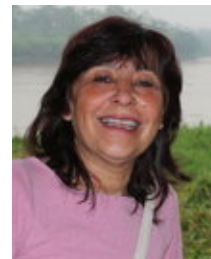


**Oxana Lavrova**  
Grants Coordinator

## LATIN AMERICAN ASSOCIATES



**Marina Gonzalez de Kaufman,**  
Country Coordinator  
Venezuela



**Dr. Sonia Moreno**  
Associate  
Colombia



**Dr. Lennie Pineda**  
Associate  
Venezuela



**Arnel Arroyo**  
Social Agent  
Colombia



**Leyla Miele**  
Program Coordinator  
Colombia



**Alexis Garces**  
Social Agent  
Colombia



**Zuleima Bonilla**  
Program Coordinator  
Colombia



**Dr. Rey Varela**  
Psychiatrist  
Venezuela

## EUROPEAN ASSOCIATES



**Dr. Elena Cattaneo**  
Senior Advisor  
Europe



**Gianfranco Munizza**  
Associate  
Europe



**Selene Capodarca**  
Associate  
Europe

# OUR COLLABORATORS

## COLOMBIA



## OTHERS



## PERU



Asociación de Familias  
Huntington Peru

## VENEZUELA



Fundación Amigo  
Huntington  
(FAHUN)



Venezuelan  
Neurology Association  
Zulia Chapter



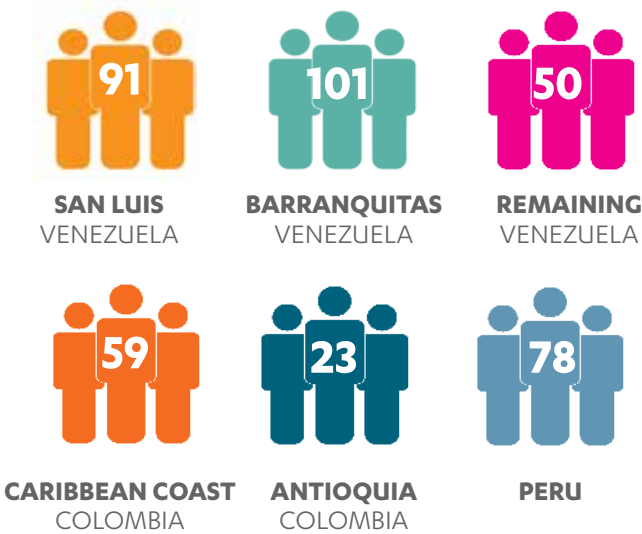




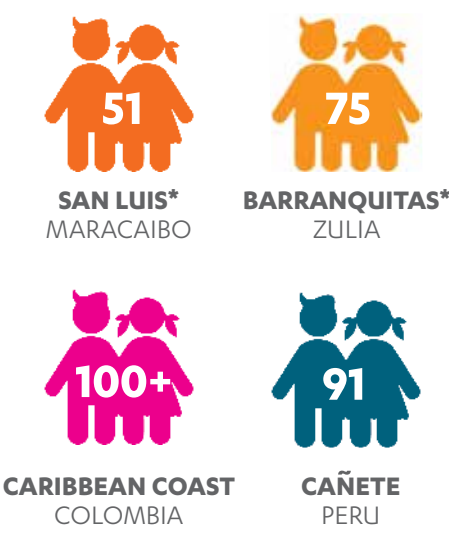
# OUR WORK AT-A-GLANCE

- Neurological and psychiatric medications
- Medical assistance for community
- Psychological support for families
- Caregiver training
- Raising awareness at national and local levels
- Health professional training
- Legal rights support
- Plans for specialized care centers

Number of HD Patients directly supported by Factor-H



Number of children at-risk for Huntington’s Disease in our orbit



*\*Data only reflects current children being supported out of hundreds of at-risk children.*

## 2020 VENEZUELA PROGRAMS



Basic Needs for

**192** **1223**

Families Beneficiaries



Project Abrazos

**120 + 14**

Children Volunteers



Dining Hall in Barranquitas

**300** **102** **3x** **25**

Children Patients A week Volunteers



Dignified Burials

**13**

Persons



Celebration

**1**

Virtual Christmas Event



Healthcare Items

**130+**

Delivered



Food Delivery

**30,000+**

Food items

## 2020 COLOMBIA PROGRAMS



Basic Needs for

**82** **321**

Families Beneficiaries



Project Abrazos

**37**

Children



Freshwater Well

**1**

in El Difícil



Microlending Program

**1**

Family



Legal Advocacy for Medication

**6**

Lawsuits



Medication Deliveries

**50%**

Success Rate



Dignified Burials

**8**

Persons



Celebration

**1**

Virtual Christmas Event

## 2020 PERU PROGRAMS



Basic Needs for

**78** **465**

Families Beneficiaries





# HEALTH & DISEASE MANAGEMENT

Support provided to patients in Zulia State, Venezuela

in Colombia



**Factor-H implemented mechanisms to decrease the risk of coronavirus, and to address the medical needs of the families during the pandemic.** First, selected infographics were disseminated by our social agents to the families via digital media. Second, basic assistance packages for each family included food, soap, medical grade alcohol, pamphlets about hand washing, mask wearing, and physical distancing. Third, by the end of March, with a panel of HD neurologists and health professionals, we implemented telemedicine for HD families. In Venezuela, we switched the weekly psychiatric visits to telemedicine. In Colombia, a system was put in place in which our social agents received the requests from the patients or family, and then routed them depending on the nature of the request (HD related, general medical care, COVID-19 related, etc.). Our social

agents helped the families by providing internet access for the online medical visits, procured the treatments, as needed, and coordinated the follow-ups. Overall, 175 patient visits took place in Zulia State, Venezuela (half of them women). In Colombia, 55 patients received medical attention via telemedicine, including 29 patients seen by the Universidad de Antioquia, and 81 patients received medications.

Our Covid-19 special assistance program provided food security for over 400 families, including 192 in Zulia State, 60 in Caracas region, Our Venezuelan partner Habitat LUZ Foundation provided additional nutritional assistance, including calcium and vitamins, to 128 families in San Luis, and 170 families in Barranquitas, including 120 children.

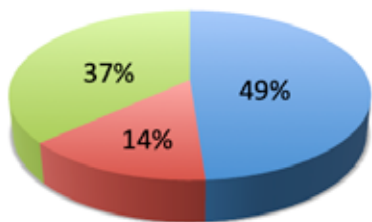




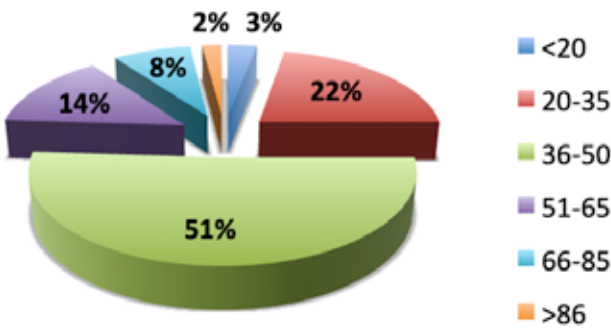
The medical needs of the families in Zulia State is extreme. Factor-H works to facilitate access to physicians and medicines. Our ultimate goal is to build a dedicated medical teams and care centers.

**San Luis Psychiatry Services**

■ Outpatient visits ■ Home visits ■ Telemedicine



**Patients' Age Range**







## YOUTH PROGRAMS

**In 2015, while we visited families in the region of San Angel, Colombia, delivering food, we met two young children, Eduardo and Olver, living in precarious conditions, without running water or electricity. A common story threaded them together- abandonment, poverty, and the specter of Huntington's. Such were the origins of the Abrazos projects, a project that has just culminated five years of helping kids at risk for HD in Colombia.**

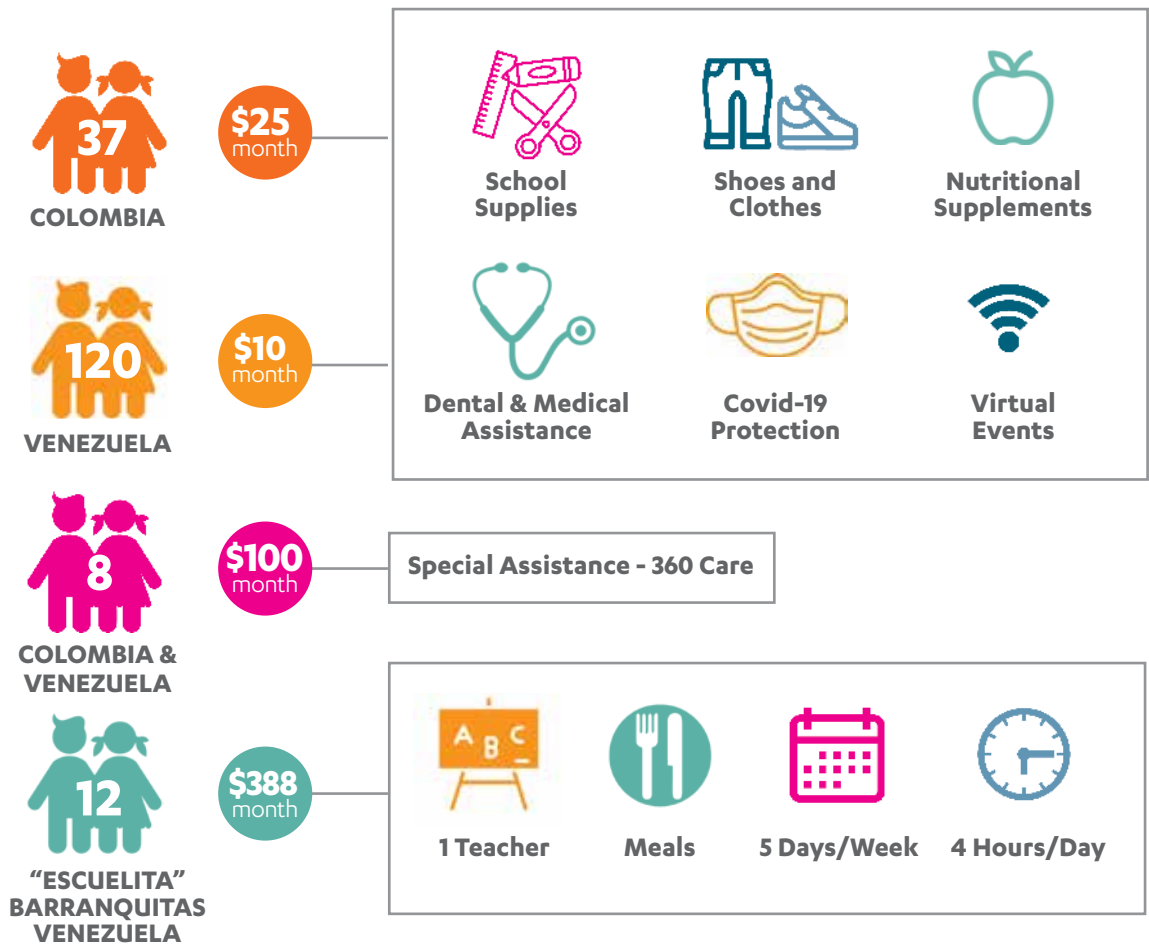
Through the generosity of our donors, we are now also sponsoring 120 children at risk for HD in Venezuela, and 37 in Colombia. In order to celebrate this anniversary, artist Matt Rota and Ignacio Muñoz worked together to create illustrations depicting some of the memorable moments we have experienced. You can see them on our website.

In 2020 we ensured that the 157 children received food, medicines, medical attention, clothes, shoes, and school supplies throughout the year. In Colombia, 37 kids continued to be supported through the fifth year of the program. In Venezuela, we supported 50 kids in San Luis and 70 in Barranquitas.

Because we couldn't organize our usual bi-yearly gatherings, we engaged our at-risk kids, including those in Peru (for the first time), at a distance. In the "When I Grow Up" campaign, we asked them to share their dreams through videos and photos. In December, we encouraged the kids to create holiday cards with their wishes for the HD community, to share them in their social media pages. We made a collage of a few from each country for our organization's holiday card. For the holidays, the kids were treated with a Christmas playful show on Zoom. And in all 3 countries, our masked local partners and agents delivered clothes and presents to the kids (in Medellín, even Santa was masked).

Education was already difficult prior to the pandemic; it then became precarious. To bridge the inequality gap, we created our first education crowdfunding. We were selected by the **GlobalGiving Foundation** to participate in its **Accelerator** fundraising opportunity for nonprofits around the world. The donations received, together with The Rainwater Charitable Foundation's grant in support of our kids' program, helped us launch a "Abrazos Little School" in Barranquitas, consisting of daily (Monday – Friday) nutritious breakfasts and classes for 4 hours for 12 children living in the most extreme poverty. The individual teaching method ensures the students receive early literacy, numeracy and critical thinking skills.

# PROJECT ABRAZOS - BENEFICIARY SUMMARY







## COVID-19 ASSISTANCE

Factor-H provided assistance to over 450 families across Colombia, Perú, and Venezuela



Youth and adults received health education and information, from mask wearing to personal hygiene, as soon as the Covid-19 pandemic started

Our affected individuals received much needed supplies and food during the pandemic.





Youth participated in programs to encourage exploration about careers and goals for their future.



## CHILDREN'S' PROGRAM



Our 2020 holiday celebration included a virtual community celebration along with gift delivery for every child in *Project Abrazos*.



The new *Escuelita* program in Barranquitas provides education in a stable environment where children learn how to read and write while receiving daily meals.





# COMMUNITY DEVELOPMENT

**The long-term vision of Factor-H is to build a community of HD affected families that is resilient, educated, and independent of external assistance.**

Our focus was on assisting vulnerable families whose debilitated economic and health conditions put them at high risk. In March, we began channeling received donations to our local partners, ensuring essential supplies for sanitation, non-perishable food, personal hygienic products, locally made soaps, protective face masks and disinfectants to reduce covid transmission. We conveyed official guidance on signs, symptoms, and prevention of the virus. We were able to help 402 HD-affected families in the most vulnerable areas of Venezuela, Colombia and Perú. December's aid included a special holiday basket. Even though we lost a few friends to Covid, we helped keep these families safe and secure.

We couldn't have done it alone. We received a 2020 **Rare Patient** Impact Grant from **Global Genes**. Upon learning of our pandemic relief initiative, the **Griffin Foundation**, our biggest supporter, generously granted us additional funds.

**The Procaps Foundation** and the **Volunteer department at UniMetro** (Universidad Metropolitana, Colombia), provided nutritional supplements. In Venezuela, we reactivated the "Comedor" (dining room) in Barranquitas. We can serve 300 children and 102 people with HD. Improvements were made to electrical installations and equipment repairs. Agreements were made with the FHZ and the local church to initiate special pandemic operations. We conducted the "Recycle San Luis" program through a series of workshops organized by Habitat Luz and affiliated organizations. 32 youth (13 men and 19 women), aged 13-20, graduated from the program, including 3 HD patients. Recycling is a source of income and our first effort directed at economic independence.

Finally, we collaborated with the **Lyle Center for Regenerative Studies** at Cal Poly Pomona University for the design of a community center for HD patients in Barranquitas. Dr. Pablo La Roche, Director of the Center, assigned a project to his students to generate a design for our future first HD center. The students spent 10 weeks learning about the Maracaibo region including natural habitats, rain, temperature and sun patterns, as well as about HD. A final design was selected which has been further developed by local architects in Venezuela, and which we hope to build in 2021. The center will use solar energy and will be environmentally sustainable, and adapted for people with disabilities. The design includes improving the town center located accross from the facility.





**Every HD community's desire is to have a center where patients can be helped and feel welcome.** The design for Casa Dignidad was created by students from the Lyle Center for Regenerative Studies in Pomona, CA, and with the team of Habitat LUZ in Maracaibo, Venezuela. We expect to raise funds and build the Care Center for Barranquitas in 2021.





## ADVOCACY & DATA COLLECTION

**Awareness about the situation of these communities is lacking, both at a local and international level. Increasing the understanding of the plight of HD families is essential to bring aid. Factor-H carries out advocacy work by promoting awareness through art projects, meetings and conferences.**

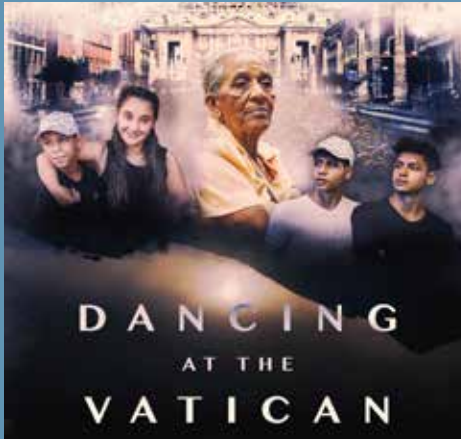
By bringing together affected families, patient associations, local officials, and HD specialists from around the world, we hope to foster partnerships that will improve these communities' quality of life. Absence of social engagement is a major factor in the lack of institutional support for many families, and we aim to bring their reality into full view.

Education about the disease is insufficient, both for the affected families as well as for individuals in government and local institutions, including medical centers. By engaging local universities and NGOs, we hope to promote education about the disease and establish long-term collaborative programs. In 2020, we signed several collaborative agreements with local universities in the Colombian Caribbean coast, and we held a cycle

of conferences at Universidad Metropolitana, which included participation from the National Institutes of Health in Colombia.

We also promoted awareness via our Art4HD program; street murals were painted at the border town of Cúcuta in Colombia, where Venezuelan migrants are fleeing the country, and promoted the Youth programs via illustrations done with artist Matt Rota. We screened the documentary film *Dancing at the Vatican* in London and San Diego, prior to the Covid pandemic. Now the video is freely available in YouTube, subtitled in 5 languages. Finally, Colombian authors Tatiana Hinojosa and Gloria Quijano wrote a book of short-stories depicting the life histories of some of the Colombian youth and caregivers we support. The book entitled 'The Stigma of the Caterpillar' will be printed in 2021.

For data collection, we developed a cloud-backed database, which includes GPS positioning data, to collect information about the families we support - medical and socio-economic. The house-by-house program had to be suspended due to the Covid pandemic but it will start promptly in Colombia and Venezuela. Thank you to **Caritas Italia & BMS** for their generous support for this program.



Before the pandemic struck, we held premieres for *Dancing at the Vatican* documentary in London and San Diego. The film is now available for free on YouTube, subtitled in five languages.



Conference with  
UniMetro  
Colombia

Insights of the  
Year lecture - *The  
Huntington Study Group  
(HSG)*



Art4HD street murals  
created by DJ Lu "Juega  
Siempre" artist from  
Bogotá  
Cúcuta, Colombia

5th Anniversary for Project  
Abrazos, supporting 157 kids  
Illustrations by artist Matt  
Rota, poems by Ignacio Muñoz  
Colombia & Venezuela



My fate is not sealed  
I too Want a canvas to paint  
Help me draw my future  
Give me the paints,  
The canvas,  
and the colors  
The rest I will create



# THANK YOU TO OUR SPONSORS



On behalf of our patients and their families affected by Huntington's Disease, Factor-H would like to thank all of our individual donors, corporations, institutions and foundations who supported our activities in 2020. Your support allows us to provide quality social and medical care programs to the most vulnerable HD families in South America.



## SPECIAL THANKS TO

Dr. Carolina Aristizabal  
Dr. Gustavo Barrios-Vincos  
Vahri Beaumont  
Manish Champaneria & John Grieco  
Maurizio Colombo  
Dr. Jimmy Crump  
Celia Dominguez  
Meghan Donaldson

Hargreaves Family  
Mai Huynh  
MJB Charitable Trust  
Dr. Pablo LaRoche  
Debby and Mark Romano  
Vogt Family  
Our Anonymous Donors

## WITH GRATITUDE TO COLLABORATING ARTISTS

Vladimir Marcano  
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Matt Rota  
[www.mattrotasart.com](http://www.mattrotasart.com)

DJLu "Juega Siempre"  
Nicanor Cardeñosa  
Manyee Lieu