

HOPE HUNTINGTON'S HUMANITY

2021
ANNUAL REPORT







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# MESSAGE FROM THE PRESIDENT

Dear Friends,

2021 was a challenging year, due to the arrival of omicron mid-year. Many friends and close partners suffered the wrath of the pandemic, losing loved ones. Access to the communities was challenging and the pandemic worsened access to education, employment, and healthcare. However, our staff and affiliated organizations persevered and carried out their functions in very significant ways. Factor-H increased our impact via virtual meetings – at an educational, psychological, medical, and humanitarian level. We provided psychological support for kids and caregivers; we structured covid- and disease-relevant educational courses and medical activities remotely; we conducted virtual events to keep the kids we support engaged and supported – via a photography competition, and via virtual meetings with educators and psychologists who volunteered to help us. We also completely re-structured the kids' program and expanded it largely to better support educational and professional training opportunities for youth. In Colombia, the kids received donations of tablets so they could continue their education.

Back in late 2020, Factor-H re-structured our programs and developed a 5-year plan, focused on preserving, defending, and expanding the rights of patients, their caregivers, and their families, including at-risk children. We introduced a new website. We created electronic databases to gather and track information about the structure, socio-economic, medical, and housing conditions of the families we represent; initial surveys were conducted house-by-house in regions of Colombia and Venezuela. Throughout this process, we identified many new HD families and kids at-risk for HD, many living in extreme poverty. We now assist 200 HD affected individuals under our care in Venezuela, 95 in Colombia, and 72 in Peru. For our redefined youth program (The Horizons Program), we now assist 237 kids in Venezuela, and 110 in Colombia. We also started working, along with

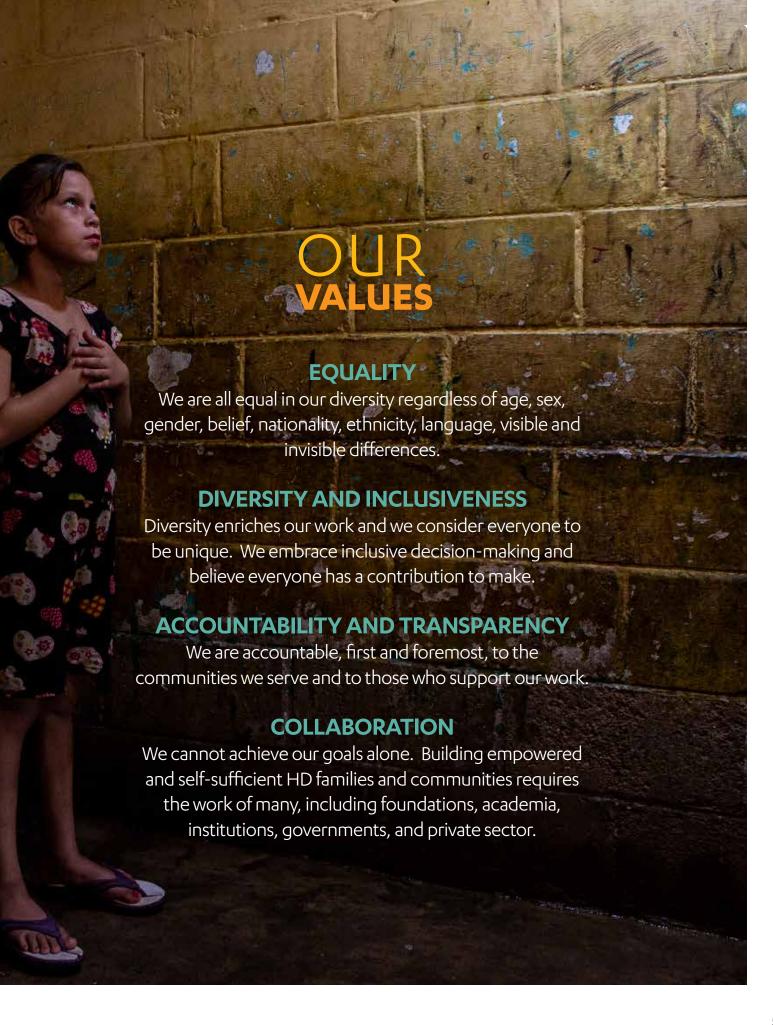
University of Antioquia and University of Medellin, on a web- and phone-based app to enhance caregiver support, which we hope to fully launch in 2022.

Programmatically, the defense of individual rights requires the support and cooperation of many government and non-profit institutions. Factor-H expanded its range of activities through collaborations with local governments, the Universidad Metropolitana (volunteer department) and Universidad Area Andina (legal support) in Colombia, and with CEVAZ (Centro Venezolano Americano del Zulia) and Latin Ladies of Houston, in Venezuela. For the first time, information was shared between the Peruvian HD association and the National Neurogenetics Institute in Lima, enabling genetic diagnosis and better access to health, including to covid vaccines. We met our goals of ensuring basic assistance to more families and kids than before and continued to enable medical care. In Venezuela, we assisted 15% more families than in 2020. Our emergency medical strategy enabled getting people to hospital when no other means existed. We expanded our special assistance program to safeguard families in extreme duress, avoiding evictions, providing financial support, and expanding our micro-credit program.

Many plans were put on hold during this period, but we are committed to bring additional resources each year. In Venezuela, we expanded our team on the ground with two social workers, and we initiated the Latin American Professional Exchange Program (LA PEP), through which we will be fostering a climate of educational and medical exchange between professionals across Latin America and Europe. And finally, our work with the clinical consensus of Huntington's disease in Latin America brought together 43 HD professionals working to generate an evidence-based set of clinical recommendations, which is a first step in improving access to medicines and care.







# DRIVING FORCE OUR PILLARS AND OBJECTIVES







YOUTH

Ensuring patient's right to health

Resilient, informed, and empowered new generations

# Promote a comprehensive, multidisciplinary and timely attention to health

- Identify institutions and create alliances
- Training of disease to health professionals
- Specific health care
- Legal actions to obtain health care

# Provide psychological support to at risk population and families with HD

- Identify needs for psychological attention
- Provide psychological attention to at risk population and families with HD

#### Guarantee genetic counseling programs

- Training of and/or identify professionals
- Identify institutions and create alliances for the access to testing
- Education of sexual and reproductive rights and family planning

# Empower future generation to take informed decisions

- Impart disease information
- Establish support groups
- Provide specific health care
- Provide information on sexual and reproductive rights

### Reduce inequality to access to education

- Generate learning centers with local actors
- Provide support to obtain technical/higher education

# Promote a healthy and happy child development

- Create spaces for personal development
- Promote belonging to social groups
- Provide psychosocial care







Empowering families and communities

Holding duty bearers to account

# Improvement of housing and environmental conditions

- Provide direct support of housing rehabilitation
- Establish alliances to improve public services

# Increase the capacities to become economically self-sufficient

- · Distribute humanitarian aid
- Create revenue-generating initiatives
- Identify and facilitate training and employment programs

# Generate and maintain a sense of belonging and mutual support

- Create community spaces
- Create programs with community activity and psychosocial support
- Impart disease information

# Characterize the socioeconomic situation and access to health services

- Conduct surveys and collect information
- Obtain information on health, legal and mediative entities
- Create an integrated platform for Latin America, dully codified

# Reach the recognition and full enjoyment of rights

- Provide information regarding fundamental rights
- Create disease-awareness initiatives for local authorities and general public
- Educate on mechanisms of citizenship and participation

# Establish strategies for a unified approach and treatment in Latin America

- Generate and implement unified consensus
- Train health professionals on consensus
- Follow-up and modify according to obstacles encountered

# WHERE WE WORK



In collaboration with our local partners, Factor-H aims to provide support to families in Latin America living with HD and in vulnerable conditions, particularly to those families living in towns where the disease is most prevalent (in Venezuela, Colombia and Perú)

# WHO WE ARE

## **MANAGEMENT & BOARD**



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



**Dr. Claudia Perandones** Co-Founder Member of the Board



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



Bianca Moura Executive Director



Jamie Levey Treasurer Member of the Board



**Evelyn Galstian** Secretary



**Oxana Lavrova** Grants Coordinator



**Mati Gomis** Member of the Board



**Catherine Martin** Member of the Board



**Jimmy Pollard** *Member of the Board* 

## **LATIN AMERICAN ASSOCIATES**



Marina Gonzalez de Kaufman, Country Coordinator Venezuela



**Dr. Sonia Moreno** Associate Colombia



**Lennie Pineda** Associate Venezuela



**Arnel Arroyo** Social Agent Colombia



**Leyla Mieles** Program Coordinator Colombia



Carlos Diaz Legal Advisor Colombia



**Zuleima Bonilla** Program Coordinator Colombia



**Dr. Rey Varela** Psychiatrist Venezuela



Oscar Mario Associate Colombia

## **EUROPEAN ASSOCIATES**



**Dr. Elena Cattaneo** Senior Advisor Europe



**Gianfranco Munizza** Associate Europe



**Selene Capodarca** Associate Europe

# **OUR COLLABORATORS**

### **COLOMBIA**





















#### **PERU**







## **VENEZUELA**









Venezuelan Neurology Association Zulia Chapter





### **OTHERS**















## **HD Patients directly supported** by Factor-H



**SAN LUIS VENEZUELA** 



**BARRANQUITAS** VENEZUELA



**VENEZUELA** 



**CARIBBEAN REGION ANTIOQUIA** COLOMBIA



COLOMBIA



## Youth at-risk for Huntington's Disease in our orbit



**SAN LUIS\*** MARACAIBO



**BARRANQUITAS\*** ZULIA



**CARIBBEAN REGION COLOMBIA** 



PERU

<sup>\*</sup>Data only reflects current children being supported out of hundreds of at-risk youth.

## **VENEZUELA**

## **2021 PROGRAMS**



**Families** 

**Beneficiaries** 



Children







**Christmas Event** 



## **COLOMBIA**

## **2021 PROGRAMS**



**Basic Needs for** 

Families Beneficiaries



**Project Abrazos** 

Children



**Housing Improvement** 



**Families** 



**Legal Actions** 



**Success Rate** 





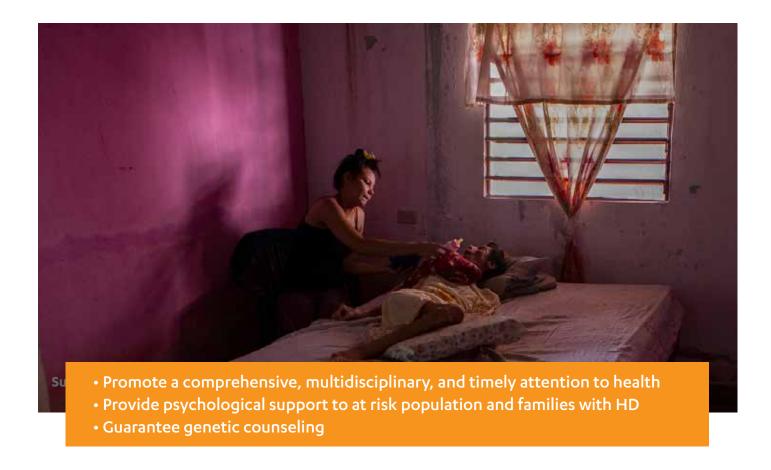


## **PERU 2021 PROGRAMS**



Families Beneficiaries

# HEALTH & DISEASE MANAGEMENT



### MEDICAL ASSISTANCE PROGRAM

Factor-H was able to assist 72 affected individuals in Peru, 95 in Colombia, and 197 in Venezuela. We established an emergency fund in each country, which enables rapid access by our social workers to cover emergencies (transport to hospital, purchasing medications), and to support vital needs, particularly during the worst months of the pandemic.

In Colombia, thanks to Drs. K. Cervantes, Villa and Quintero, 32 patients received medical attention for various conditions, some of them via telemedicine, 30 home visits took place, 37 received assistance with scheduling appointments, and 23 were taken to hospital. Our social workers responded to 320 requests for help and facilitated the delivery of medicines, diapers, nutritional support, and covid-relevant packages (266 in 2021). In total, 79 patients

received medicines and 101 received nutritional supplements.

In Peru, we were able to foster a collaboration between the local HD association with the Instituto Nacional de Ciencias Neurológicas. We facilitated information exchange, enabling access to genetic diagnosis and treatment, for families outside the national registry, and facilitated access to covid-19 vaccines for HD patients. The HD association in Peru conducted workshops and medical assistance providing general medical, dental, physiotherapy and psychological care, in Cañete province, for 62-72 patients per event.

In Venezuela, we expanded our professional network and assembled a medical team formed by Dr. Olmedo Ferrer, Dra. Gabriela Ríos, Dr. Máximo

Quintero, Dr. Miguel Yáber, Dra. Mónica Mosquera, and Dr. Rey Varela. We identified 111 manifest individuals in San Luis and 95 in Barranquitas.

### PSYCHIATRIC CLINIC IN SAN LUIS, VENEZUELA

Psychiatric consultations by Dr. Rey Varela, with the assistance of Nelly Guerra and Carla Soto, were carried out bimonthly in San Luis. We assisted 93 individuals, 74 of which were HD patients, assisted via 276 medical visits, 189 in the clinic, 69 via telemedicine, and 18 via home visits. This represents a significant increase (from 67 in 2020) due to enhanced local management.

Periodic telemedicine consults were conducted to support patients from adjacent neighborhoods and in Barranquitas. Despite the lock-downs, we maintained regular in-office/at-home and telemedicine care throughout 2021. Electrical improvements were carried out at the clinic where patients are seen to ensure adequate lighting and ventilation.

The clinic also serves to identify people in extreme need and expand access to nutritional assistance. Through a donation from the Latin Ladies Foundation of Houston, we provided multivitamins and nutritional supplements, and 277 prescribed medicines were delivered. Habitat LUZ signed an agreement with the medical distributor company COBECA, to lower medicine costs and increase access to medicines.

# LA PEP PROGRAM – TRAINING LOCAL PROFESSIONALS

We launched the LA PEP training program thanks to a fellowship grant from the European Huntington's Disease Network. Dr. Rey Varela attended a 6-week training program in three Barcelona Enroll-HD centers, at the Hospital Sant Pau, at the Hospital Clínic, and at the Hospital Mare de Deu de la Mercé. The program aims to train professionals that work in Latin American enclaves with a high incidence of Huntington's disease. We seek continuity of health care as well as providing opportunities for young medical professionals.

### **PSYCHOLOGICAL SUPPORT**

Factor-H significantly expanded our work in supporting the psychological well-being of the families we serve. Habitat Luz launched a project to provide psychological attention for children affected by or at risk for HD in Zulia State. A total of 15 children and adolescents were seen by Dr. Luxelia Portillo. Through the Psychology Program at Universidad Metropolitana in Colombia, a series of virtual workshops took place, directed at children's well-being. Over 50 children and adolescents participated.

# EXPANDING OUR CAREGIVER ASSISTANCE PROGRAM

Caregivers typically lack access to adequate information to care for their affected relatives. Due to the motoric and cognitive impairments as HD progresses, the type and quality of care must be adapted to the needs of the patients as the disease progresses. Caregiver fatigue is a very serious problem that affects the quality of life of the caregiver and the patients alike. The lack of dedicated centers near the families we serve has made providing help very challenging, particularly in rural areas. Therefore, we partnered with the University of Medellin, the University of Antioquia, the University Metropolitana, and the company Ingrapes, to create a caregiver education app termed 'Cognoceme'.

We conducted beta-testing of the app and an initial deployment, setting up the framework for a wider roll-out of the app throughout Colombia. The goal is to strengthen the capabilities of informal caregivers and promote best practices of care, including exercises to improve mobility, provide nutritional advice, recipes, psychological support, and assess caregivers' fatigue.

You can see a video of the app here:



You can read more about the program here:



# YOUTH PROGRAMS



## PROGRAMA NUEVOS HORIZONTES/ NEW HORIZONS

In 2021, we restructured our Abrazos Program to provide equity and integral well-being to all the identified children and adolescents of families affected by HD and living in vulnerable conditions. The New Horizons program was created. This comprehensive program is divided into two subprograms - Abrazos for the younger ones (3-12 years old) and Growing Together for those older than 12 - so that the health, educational and recreational activities are specifically catered to individual age groups.

The Abrazos Program started in Colombia in 2014 and in Venezuela in 2017. It provides food, medicines, clothes, materials for school, health & hygienic support, shoes, and toys. We also provide recreational and educational workshops and gatherings, so that all at-risk youth can develop in a balanced, healthy social and family environment.

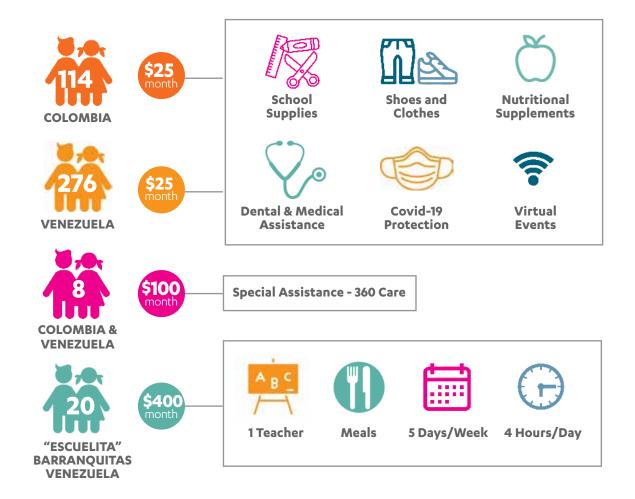
Through our registry efforts, we identified a total of 237 at-risk children between ages 3-12 in Venezuela (76 kids in San Luis and 161 in Barranquitas) and 110 in Colombia.

In Venezuela, we undertook a survey of socio-economic conditions of the families with at-risk children and determined an adequate nutritional strategy according to guidelines from the WHO. Finally, at the end of 2021, we started the program "deportes, arte y recreación" (sports, art and recreation) in San Luis (to benefit 70 kids) and the "grupos de apoyo juvenil" (youth support groups), to initially benefit a group of 12-15 youth, providing psychological support.

#### **FDUCATIONAL STRATEGIES FOR YOUTH**

Increasing access to education remains a top priority. Because of omicron, many school activities were stopped in Colombia, and in Venezuela, schools have been closed for more than 18 months. To facilitate access to remote learning, we delivered 23 tablets with internet access to youth in Colombia. These devices ensured the children continued their education virtually.

## **PROGRAM NUEVOS HORIZONTES - SUMMARY**



In Venezuela, we continued with the "Escuelita"/Little School in Barranquitas, where 12 children, between 8-16 years of age, who were not schooled and/or have learning disabilities, participated and reached the basic levels of reading and mathematics. The school had to close due to the omicron pandemic. In 2022, this program will be expanded to include 20 older youth and will also incorporate a training program in agriculture, to facilitate economic independence and ensure better compliance.

Throughout the year, Factor-H organized a set of virtual courses and workshops for kids of all ages, including a photography contest were more than 40 youth submitted their own photos with the theme "What is beautiful to me".

In Peru, we coordinated educational/entrepreneurial workshops and fun activities such as 'build your dream house' contest, creating Christmas cards and trees with recycled materials.

### SPECIAL ASSISTANCE PROGRAM

Finally, several families with children living in conditions of extreme poverty were cared for through our special assistance program, which fully covers housing costs and full maintenance. A total of 8 families were included in the program between Colombia and Venezuela.



Factor-H provided
assistance to over 500
families.
Family assistance is one of
our key goals



Access to medicines, food, nutritional supplements & vitamins remains a key need for these families



# BASIC



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



A micro-credit program enables HD families to make a decent living and escape poverty



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



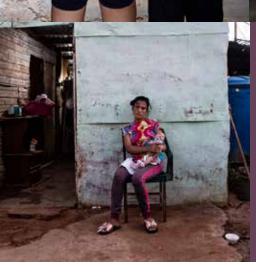
# YOUTH PROGRAMS



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Our Kids' program is now called New Horizons and has more than 300 kids being supported by our donors. Some of the kids have been in the program for 8 years



Taking care of pediatric HD cases remains a high priority for Factor-H under our Youth programs



# COMMUNITY



#### **BASIC & SPECIAL ASSISTANCE PROGRAMS**

Thanks to generous individual and institutional donors such as BMS, Ultragenyx, Latin Ladies Foundation of Houston, Evotec, CRL, Procaps and many local volunteers from affiliated universities (>100), relief aid was provided in Peru, Colombia and Venezuela throughout the year, covering basic necessities, sanitation and preventive items to the >450 HD families we support in these countries. The distribution was made according to the number of members of the family group to ensure adequate and fair distribution of our donations.

In Venezuela, 110 patients in San Luis and 95 in Barranquitas, were assisted through the program. Depending on needs, every quarter, between 190 and 295 families, including those of at-risk children and those with at least an HD affected individual, were supported, benefiting a total of approximately 1500 individuals, with more than 5500 donations provided each quarter of 2021. This included

more than 2500 adult diapers for late-stage patients, medications, and covid-19 assistance packages for more than >400 families. Our assistance programs were greatly facilitated by an expanded team on the ground (Nancy Cepeda, Nelly Soto, Argenis y Kimberly Gotera y Samuel Nova) and social workers recently hired for both San Luis and Barranquitas.

The food hall we operated in 2020 in Barranquitas together with the local church 'El Renacer" had to be closed down due to Covid in 2021, although this enabled the repair and maintenance of the building and equipment, including AC units, kitchen equipment, and electrical improvements, setting up the building for resuming operations in 2022.

In Peru we assisted 72 families in the Cañete province and assisted with 3 burials of individuals who died of covid-19 infections.



In Colombia, 95 patients and a total of 211 families were assisted, benefiting more than 600 individuals, most of which were in the Caribbean region of Colombia. We created the "Canasta (Basket) Express" project, a food drive at participating markets in Colombia for the collection of food and supplies.

#### HOUSING IMPROVEMENT PROJECTS

In 2021, thanks to donations obtained through DonorSee (https://donorsee.com), we financed 6 home improvements in Peru, Venezuela and Colombia, for the benefit of disadvantaged HD families. You can see the videos of the program here.

For those who watched the documentary 'Dancing at the Vatican' from the 2017 audience with Pope Francis, you might remember the three Soto Soto siblings who traveled to Rome from Barranquitas. After 3 years of attempts, Factor-H managed to purchase a home for the 3 families, ensuring a better quality of life for them and their children.

#### MICRO-CREDIT PROGRAM

In Colombia, we closely monitored the micro credit program we initiated in 2018 with a \$2,000 funding (half interest-free loan/half donation) to a family for the purchase of livestock and to sell cow's milk. The family made the first payment in September and will be making their second payment in the fall of 2022. Additionally, with a micro-credit support grant from UniQure, we facilitated our second micro-credit to a shoemaker from Medellin who inherited a family business and needed seed money to upgrade his machinery. Mr. Barrera, whose 2 brothers with HD work with him, received an interestfree loan for a term of 2 years. He made his first payment in December. A program has been designed for the remainder of the grant funds to be implemented by Q2 2022. These revenue-generating initiatives have improved the quality of life and will keep providing a sustainable impact on the beneficiary families.

# ADVOCACY AND DATA COLLECTION



#### **DATABASE & INFORMATION MANAGEMENT**

To better serve the families we work with, we need to characterize their socio-economic and medical conditions. We deployed electronic databases for Colombia and Venezuela and begun to gather home-by-home information detailing the medical, socioeconomic, and housing conditions of each family in our orbit. The IT projects were financed entirely through grants. A Bristol Myers Squibb (BMS) grant received in 2020 enabled the design of a cloudbased customized platform, the purchase of necessary equipment (tablets and computers), and the training of our staff and volunteers. A grant by Caritas Italiana enabled the work in Venezuela.

We commenced the in-person surveys in the Atlantic coast of Colombia. In this initial phase, 238 individuals and 19 patients from 58 families were characterized with the assistance of 35 volunteers from the Universidad

Metropolitana. Consent forms for information gathering was obtained in all families and we observed good participation from the families. In 2022, we plan to complete the initial survey to the rest of the families in Colombia.

In Venezuela, the electronic databases were designed to access information in three areas of work. The first module, the "Quality of Life" database, was completed and implemented in a pilot phase in San Luis, registering 107 people with HD and 76 children. Additionally, 96 people with HD have been registered in Barranquitas. A second module focuses on children in the New Horizons Program. A total 161 children between 3-12 years old, as well as 20 teenagers were registered. A third application was created to facilitate the registration of the medical records of the children of the Program and is in the planning stages for the adults. All instruments were developed in Survey123@ of ArcGis@, with the purpose of being able to collect and georeference all the data without the need to be connected to the internet.

#### **LEGAL ASSISTANCE PROGRAM**

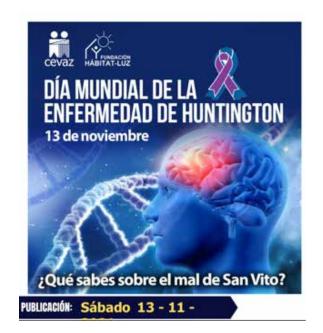
We established a legal assistance program in Colombia, together with the University of Area Andina, led by Dr Yeni Coronado, J.D., to support the legal needs of families. Families who need assistance will now be able to receive free legal assistance. Thus far, 22 families are being helped through this program, which also serves to educate families about their rights.

The Latin American clinical consensus program aims to generate an evidence-based analysis of best practices for care of HD patients, tailored to Latin America based on cultural, legislative, and medical standards. Thanks to Roche's sponsorship, in a program coordinated by Drs Claudia Perandones and Valeria Confalonieri, 43 HD specialists from 13 Latin American countries are participating in this project that follows the GRADE (Grading of Recommendations, Assessment, Development, and Evaluation) methodology and provides a tool for rating the quality of evidence for systematic reviews and clinical guidelines. Its final publication entitled "Clinical Recommendation Guide for the diagnosis and treatment of Huntington's Disease in Latin America" is set to be finalized in 2022.

GRADE is a method used by systematic reviewers and guideline developers to assess evidence quality and decide whether to recommend an intervention. A series of meetings took place throughout 2021, and several teams were assembled to enable the consensus.

### **SEMINARS & EDUCATIONAL WORKSHOPS**

Educating the community at large about HD is a necessary step to improve institutional and social support for affected families. In addition, there is a general lack of access to information for affected families about the disease, its origins, symptoms, and disease management options. Therefore, Factor-H undertook a series of steps to increase access to information at multiple levels (family and professional), in 2021, via workshops, scientific conferences, and social media campaigns.



A series of internet campaigns called "Knowing HD" ("Conociendo HD") was launched, a collaboration between Habitat Luz and Cevaz (Centro Venezolano Americano del Zulia) to inform and guide families affected by HD as well as the public in general, about HD, through short social media messages and simple language, reaching over 51,000 people.

Two virtual scientific and medical symposiums took place in Colombia, organized by UniMetro and University of Antioquia, which were attended by hundreds of participants from around Latin America.

Finally, through the newly designed Factor-H website, additional material is available in the form of recorded lectures and podcasts given by Factor-H management, in both English and Spanish.



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.





































### FRIENDS: \$500+

Alice Wexler Anne Dyer & Daniel O'Reilly Foundation Balajee Somalinga **Bethany Fitzsimmons** 

### **SUPPORTERS: \$5K+**

Ignacio Munoz-Sanjuan Colombo Family Evotec Elena Cattaneo Hargreaves Family MJB Charitable Trust **PTC Therapeutics** Rainwater Foundation uniQure

Celia Dominguez Dimitri Poffé Dr. Bill Kaemmerer George McAllister Huntington Liga vzw Belgium Jeremy Nathans & Thanh Van Huynh

### **ADVOCATES: \$10K+**

Bristol-Myers Squibb Charles River Elena Cattaneo Haney Family Ultragenyx

John Grieco & Manish Champaneria John Lee Longbin Liu Mai Huynh Manyee Lieu

Margaret Lam Mark & Debbie Romano Michele Lodigiani Milken Institute Vahri Khakh **Vogt Family** 

#### **CHAMPIONS: \$50K+**

**Griffin Foundation** Roche

#### **SPECIAL THANKS**

Vladimir Marcano - photography Charlie Cordero - photography Gindel Delgado - film Nicanor Cardeñosa - website design Manyee Lieu - graphic design