



HOPE
HUNTINGTON'S
HUMANITY

2019 **ANNUAL REPORT**





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FROM THE PRESIDENT

Dear friends, a very happy 2020!

Since its foundation as a project in 2012, Factor-H has run several successful programs in the largest HD communities in Latin America while maintaining the same mission to assist in the sustainment of families and communities affected by Huntington's Disease (HD) in Latin America. 2019 was the first full year of Factor-H's operations as a non-profit organization and we have some pivotal news we wanted to share with you.

Because of the nature of HD, primarily its fatal, genetic, and degenerative aspects, having the disorder signifies that the

vulnerable (patients, youth, and caregivers), community development, and advocacy/education.

Thanks to the generous donations from our network, we were able to recruit our Executive Director, Bianca Moura, who leads the day-to-day operations from our Los Angeles office. We also support a team of associated individuals in each community, including the financial support for all major patient associations in Venezuela, Colombia and Peru. Factor-H carries out its mission via strategic partnerships

In this first Annual Report, you will find information about our accomplishments this past year together with ongoing and planned programs for 2020, which we think will position Factor-H for success in ensuring that these communities provide improved better care and living conditions for their affected members.

disease is present in families and will continue to affect its family members for generations to come. Currently, HD families suffer stigma, discrimination, social and institutional exclusion, and more often these instances are aggravated by extreme poverty and vulnerability. In collaboration with its local partners, Factor-H aims to provide support to families in Latin America living with HD and in poverty, particularly to those families living in towns where the disease is most prevalent in the world (in Venezuela, Colombia and Peru).

Factor-H strives to transition from an assistance-based organization to a community-development organization in order to better enable HD communities to exit the poverty and disease cycle. We might not yet have effective treatments for the disease, but we have our knowledge, talent and desire to bring a better life to a community that desperately needs our help.

In this context, Factor-H has defined 4 major areas of focus going forward, as illustrated in this Annual Report: improvement in health care, assistance to those most

with a number of international and local NGOs as well as universities to implement our projects in Latin America.

We remain deeply committed to our mission focused on offering every HD family with a better chance to live with dignity and hope, and on enabling a future less difficult for new generations of at-risk children living in these communities. Seeing their smiles is enough of a reward for all of us who work in Factor-H sponsored projects.

Factor-H programs and achievements are yours as a volunteer or donor to our efforts. We cannot do this without your support, either individual or institutional. We believe in social justice and in a world where being born with a genetic disease does not prevent individuals from flourishing.

We count on your support of our programs so we can best serve HD families living in poverty.

Thank you
Nacho



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

OUR MISSION

OUR MISSION

Our mission is to build communities of cared for, resilient and self-sufficient HD families through alliances with local and international organizations.

AREAS OF FOCUS

Basic Needs

Medical Assistance
Nutritional Assistance
Energy & Water

Assisting the most vulnerable

Kids Project
Youth Project
Sponsor Families

Community Development

Habitat Improvement
Micro-lending
Education
Art 4 HD

Advocacy/ Education

Community Research
Professional Training
Social Engagement

WHERE WE OPERATE



WHO WE ARE

MANAGEMENT & BOARD



Dr. Ignacio Muñoz-Sanjuan
Founder & President



Dr. Claudia Perandonos
Co-Founder



Dr. Roger Cachope
Vice President



Bianca Moura
Executive Director



Jamie Levey
Treasurer

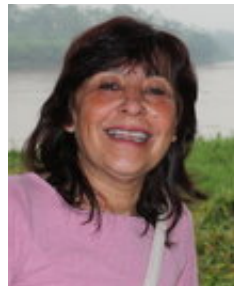


Evelyn Galstian
Secretary

LATIN AMERICAN ASSOCIATES



Marina Gonzalez de Kaufman,
Program Coordinator
Venezuela



Dr. Sonia Moreno
Associate - Colombia



Dr. Lennie Pineda
Associate - Venezuela



Alexis Garces
Social Agent - Colombia



Arnel Arroyo
Social Agent - Colombia

EUROPEAN ASSOCIATES



Selene Capodarca
Associate - Europe



Dr. Elena Cattaneo
Senior Advisor - Europe



Gianfranco Munizza
Associate - Europe



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



OUR COLLABORATORS

COLOMBIA

VENEZUELA



Fundación de Antioquia
 2 Full-time Employees
 - *Social Agents*
 1 PhD Colombian Associate
 University of Antioquia
 Movement Disorder Specialists



Fundación Hábitat-Luz
 Dedicated Program Managers
 1 Genetic Counselor
 University of Zulia
 Management of Associations
 6 Full-time Employees



University of Antioquia
Grupo de Neurociencias
 School of Medicine



Healing Venezuela



AcolpEH
Colombian HD Association



Primeros Auxilios Luz



Universidad de los Andes
Grupo PAIIS



Fundación Huntington Zulia (FHZ)



Universidad Metropolitana



Fundación Amigo Huntington (FAHUN)



Fundación Tito



Fundación Avehun



Fundación Funmart

Agencia Viajes Wayira Paradise



Venezuelan Neurology Association Zulia Chapter



PERU



Asociación Peruana de EH

OTHERS



HD Center CETRAM, Chile



Healing Venezuela, UK



Huntington's Disease Youth Organization

HD Medical Centers, Barcelona, Spain



• **Sant Pau Hospital**



• **Hospital Clínic**



• **Clínica La Merced**

HD Association, Barcelona, Spain

We remain deeply committed to our mission focused on offering every HD family with a better chance to live with dignity and hope, and on enabling a future less difficult for new generations of at-risk children living in these communities. Seeing their smiles is enough of a reward for all of us who work in Factor-H sponsored projects.

OUR WORK AT-A-GLANCE

NEUROLOGICAL AND PSYCHIATRIC MEDICATIONS

MEDICAL ASSISTANCE FOR COMMUNITY – EVERY 2-3 MONTHS

PSYCHOLOGICAL SUPPORT FOR FAMILIES

CAREGIVER TRAINING

PLANS FOR HEALTH PROFESSIONAL TRAINING

LEGAL RIGHTS SUPPORT

RAISING AWARENESS AT LOCAL & NATIONAL LEVELS

PLANS FOR SPECIALIZED CARE CENTERS

Number of HD Patients directly supported by Factor-H and affiliated institutions



SAN LUIS VENEZUELA



BARRANQUITAS VENEZUELA



REMAINING VENEZUELA



CARIBBEAN COAST COLOMBIA



ANTIOQUIA COLOMBIA



PERU

Number of children at-risk for Huntington's Disease



SAN LUIS MARACAIBO



BARRANQUITAS* ZULIA



CARIBBEAN COAST COLOMBIA



CAÑETE PERU



*exact numbers not known yet



Number of medical assistance days with multidisciplinary medical teams

4
DAYS

SAN LUIS
VENEZUELA

2
DAYS

BARRANQUITAS
VENEZUELA

3
DAYS

CARIBBEAN COAST
COLOMBIA

400+ MEDICATIONS DELIVERED ACROSS ALL DAYS



HD Neurology



General Medicine



Pediatrics



Psychiatry

One hired psychiatrist providing support in San Luis, Venezuela

28

WEEKLY VISITS

195

APPOINTMENTS



60
PATIENTS



300+ MEDICATIONS
DELIVERED

Shipments of medicine with *Healing Venezuela*



July 2018
Hosted First Latin
American Huntington
Disease Conference
Barranquilla, Colombia



FACTOR-H EVENTS

July 2018
First HD Youth Camp
with Huntington
Disease Youth
Organization - HDYO
Barranquilla, Colombia



December 2018
Factor-H and Milan
University site visits
to Colombia and
Venezuela



December 2018
Meeting with the
Venezuelan National
Patient Association,
Avehun
Caracas, Venezuela



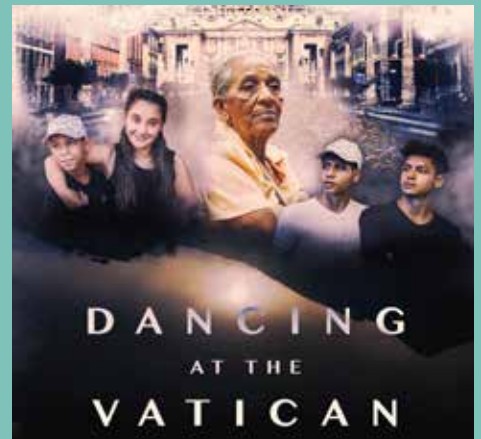
December 2018
Collaboration
meeting with three
Colombian patients'
association
Bogota, Colombia

May 2019
2 Week HD Training
Course for Care
Providers at
CETRAM Center
Santiago de Chile



2018–2019
Medical Assistance
days in Colombia
and Venezuela

July 2019
Premiere of the HD
documentary
Dancing at the Vatican
Los Angeles, CA



June 2019
Street Art 4 HD
project launches
Colombia



September 2019
Participation at a
legal rights workshop
at University of the
Andes
Bogota, Colombia



2018–2019
Abrazos Kids' Project
camps every 6 months.
Christmas celebration
Colombia, Peru, Venezuela

BASIC NEEDS

The basic needs program is an assistance program which aims to provide the most basic form of assistance to vulnerable HD families living in extreme poverty.

We assist families in Colombia and Venezuela by providing sustenance, clothes, shoes, mattresses, cleaning supplies and nutritional supplements for patients. The most important assistance program we have initiated in 2019 is the re-opening of a dining hall in the town of Barranquitas, Venezuela, where we feed over 300 children and 50 patients. For some families, we try to remediate lack of access to fresh water and electricity, although thus far these efforts have been limited due to lack of funding.

Our basic needs program also covers health-related programs focused on patients and young children. Several times a year we organize medical and dental assistance days, together with local physicians and volunteer organizations. In Venezuela, we have a staff psychiatrist who visits the San Luis patients weekly, providing specialized care. We place a premium on pediatric care for those children most vulnerable due to malnutrition, particularly prevalent in Barranquitas.



2019 ZULIA STATE PROGRAMS VENEZUELA



Basic Needs for

105

Families



Project Abrazos

101 + 14

Children Volunteers



Mattresses

22

Delivered



Opening of Dining Hall in Barranquitas

300

Children

20

Patients

3x

A week

25

Volunteers



Dignified Burials

9

Persons



Recreation

1

Summer Event



Celebration

1

Christmas Event



Healthcare Items

600+

Delivered



Food Delivery

2500+

Pounds

2019 CARIBBEAN COAST PROGRAMS COLOMBIA



Basic Needs for

37

Families



Project Abrazos

37

Children



Microlending
Program

1

Family



Freshwater Well

1

in El Difícil



Legal Advocacy
for Medication

9

Lawsuits



Medication
Deliveries

50%

Success Rate



Recreation

1

Summer Event



Celebration

1

Christmas Event

COMMUNITY DEVELOPMENT PROGRAMS FOR ZULIA STATE, COORDINATED BY HABITAT LUZ

Burial Assistance Program

Recycling Program

Youth Sports Program

"Mama Huntington" Program

Institutional Awareness Program

Design of a "Safe Center" in Barranquitas

"Street Art 4 HD" Contest

ASSISTING THE MOST VULNERABLE



The HD communities in Colombia and Venezuela live in very precarious conditions, and we have identified some groups or families considered to be extremely vulnerable that deserve special attention.

Therefore, we initiated specific programs targeted to these groups: our kids' program (called "Project Abrazos") aims to assist young (between 4-15 years of age) children at-risk for HD living in poverty in the Caribbean coast of Colombia and in the Zulia State of Venezuela. At present, we are sponsoring 37 children in Colombia and 100 in Venezuela (40 in San Luis and 60 in Barranquitas). The program is beginning its 5th year in Colombia and 2nd year in Venezuela. Through the program we address nutritional issues, provide clothes, shoes, and school supplies and uniforms to ensure kids can continue to attend school. We also provide recreational and educational opportunities by getting the kids together periodically and organize classes and workshops. As part

of these programs, kids have, for the first time, experienced swimming in the sea, watched movies, and met Santa during Christmas.

The second group we aim to target in 2020 is youth. We organized, together with HDYO (www.hdyo.org) the first Latin American camp for at-risk youth in July 2018 in Colombia, where youth leaders from 6 Latin American countries came together. One aspect that requires specific attention is educational access. Many teenagers cannot complete high school or go to college due to lack of funding to access school or live in towns where few educational opportunities exist.

Finally, in 2019 we initiated a nascent program aimed at providing special assistance to families living in the most extreme poverty (no running water or electricity, few employment options). The "Sponsor a Family" program aims to connect donors to specific families to be able to help selected families living in desperate conditions.



PROJECT ABRAZOS

37
COLOMBIA

\$25
month

101
VENEZUELA

\$15
month

\$100
month

| | | |
|-----------------------------|-------------------|-------------------------|
| | | |
| School Supplies | Shoes and Clothes | Nutritional Supplements |
| | | |
| Dental & Medical Assistance | Personal Hygiene | Recreational Events |

Covers Complete Care

Project Abrazos developing areas and needs
 Educational assistance
 Reading, art, and professional training
 Scholarships for youth

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. To achieve this goal, we are working hard to engage the communities we work with, jointly define priorities and implement projects to benefit the entire community.

This umbrella program encompasses multiple and parallel, efforts in the areas of education (about HD and professional education), art, micro-lending (a critical strategy to promote financial independence), and Habitat-directed strategies to improve living conditions for the community (for example, recycling programs, access to showers, solar electricity, community centers, etc.). In 2019, we gave our first micro-loan to a rural HD family in San Angel, Colombia, by purchasing livestock. We seek to expand this program by partnering with experienced banks working to promote micro-lending and financial education to HD families. The ability to earn a living is central to these families' future independence and this program is a key strategic imperative for Factor-H in 2020.

Art4HD is a specific program which we think is essential as an awareness tool and as a mechanism to bring hope and dignity to these communities. Art is a powerful media for social change. We have a specific program called Street Art4HD, started in Colombia in 2019 where a local artist (DJLu; IG@juegasiempre) painted several murals depicting patients, their caregivers, and children at-risk for HD. The program will expand to Venezuela in March 2020, where DJ Lu and Venezuelan artist Garek (IG@mr.garek) will paint several murals in Maracaibo, with other countries following (Puerto Rico, Scotland and Chile are planned).



Juan De Acosta - Colombia





El Dificil, Colombia



San Angel, Colombia



El Dificil, Colombia

ADVOCACY/EDUCATION

Awareness about the situation of these communities is lacking, both at a local and international level. Increasing the understanding of the plight of these families, and of HD in general in the regions affected, is essential to bring aid. Factor-H carries out advocacy work by promoting awareness at a local level through 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. Our ultimate goal for the medical program is to enable the development of trained local health professionals who can ultimately care for these communities. Plans are advanced to establish a professional training program where local health workers will be trained in HD centers of excellence in Europe and Latin American countries. Finally, care centers need to be established locally in Colombia and Venezuela where late-stage patients can be adequately cared for. This remains a future strategic goal for Factor-H.







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 2019. Your support allows us to provide quality social and medical care programs to the most vulnerable people in South America.

Our special thanks to Vladimir Marcano for providing his photography.

www.vladimirmarcano.com

