



Photos: Gindel Delgado

A Factor-H volunteer feeds hungry children in Barranquitas, Zulia state, Venezuela.

Bringing hope to HD families in Venezuela

Ignacio Muñoz-Sanjuan, President, Factor-H

Earlier this year, while walking with colleagues through the dusty, garbage-filled streets of Barranquitas in Venezuela's Zulia state, I noticed a small boy following us. Barefoot and dirty, he wore tattered clothes. I asked his name: Brayan. He was 11 or 12 years old, he thought, but he didn't know his birthday or his last name. "My mother died of HD when I was very young," he told us. "My father was killed a few years ago." At first he was too embarrassed to show us where he lived, but after some encouragement he led us to a hot tin shack. There, on a filthy mattress on the ground, he spent his nights alone and afraid.

Barranquitas is typical of many poor towns in Venezuela, but for one thing: hundreds of its inhabitants have either died from HD, are symptomatic or—like

Brayan—have been orphaned by the disease and are at risk of developing it. If they are none of these things, they are probably caring for one or more sick relatives. The crisis that has engulfed Venezuela has exacerbated an already dismal situation in Barranquitas, where poverty has eroded family support networks and basic infrastructure is lacking. Power outages are the norm, the local school has stopped functioning, and many children spend their days roaming the streets.

My colleagues and I created Factor-H, a Los Angeles-based non-profit organisation, to try to bring assistance and hope to impoverished communities with a high prevalence of HD, including families from Venezuela's Lake Maracaibo region who contributed to scientific progress. It was tissue samples donated by residents of

Barranquitas and other towns in that region—the parents and grandparents of children like Brayan—that enabled the identification of the HD mutation, yet these same children are likely to be among the last to benefit from any interventions that result from that knowledge. We believe they deserve better.

Factor-H came into existence seven years ago, with the goal of providing food, clothing, medicines, school materials, counselling and social support for HD families living in poverty in Latin America. Our first projects focused on northern Colombia, but two years ago we signed a collaborative agreement with the Hábitat Luz Foundation, a non-governmental organisation associated with the University of Zulia. The foundation is managed by architect Marina González de Kauffman, whose team provides logistical support on behalf of Factor-H, and last February we extended our children's programme to Zulia. A hundred youngsters like Brayan are now being sponsored there.

The institutional breakdown that has accompanied the Venezuelan crisis presents formidable challenges. Few HD specialists remain in the country, and the Maracaibo communities have little or no contact with them. We have therefore established an agreement with Zulia's neurology association and local psychiatrist Rey Varela to provide at least some of the care they need. Thanks to the European neurologists who support us, led by Anna Rita Bentivoglio, we collect medicines in Europe and ship them to Maracaibo, where they are distributed by a local NGO called Primeros Auxilios. We also support local patient associations and local geneticist Lennie Pineda, who aims to survey the populations of Barranquitas and San Luis, to identify those at risk for HD, and to establish counselling and educational programmes for them. Eventually, we hope to establish an exchange programme under which young, local healthcare professionals study in European clinical centres, and then bring back their expertise to improve HD care in their communities. Plans are also afoot to build a community centre in Barranquitas for the care of late-stage and abandoned patients.

Earning the trust of a community that has long been ostracised is not easy, which is why Factor-H Vice President Roger Cachope, Gianni Munizza from Italy and I took toys and supplies to Lake Maracaibo last Christmas, and why we helped organise the visit of some [Latin American HD families to the Vatican](#) to meet Pope Francis in May 2017. We aim to restore these families' dignity to them, and to fight for the futures of children like Brayan. Please help us if you can.

For more information about Factor-H or to make a donation please visit www.factor-h.org. A [film](#) about the HD families' visit to the Vatican will premiere in Los Angeles on 27 July.

