

ABOUT THE SOUTH AMERICAN PATIENTS & FAMILIES TRAVELING TO ROME

April 2017

Jhon: Robbed of his Job, Robbed of his Family

Amalfi, Colombia

High in the foothills of the Andes mountains, near the western coast of Colombia, sits the state of Antioquia and the small town of Mutatá. It was here that Jhon Jairo was raised.

In small towns, news spreads fast – rumors spread even faster. Mutatá was no different in this way. Like most children, Jhon Jairo had no reason to believe that he was anything but ordinary. Still, there was something in the way his neighbors would treat him and his family.

There would be a whisper, a rumor about the family. People spoke of a curse. Eyes would follow Jhon Jairo and his siblings wherever they went – watching, waiting to glimpse the evil that was said to be lurking inside the children.

While it wasn't a curse that afflicted his family, it was indeed an illness. It was Huntington's disease and it has already claimed Jhon Jairo's mother and one sister, with two other siblings also currently affected by the disease.

To protect themselves from stigma, the family moved to a larger town. Jhon Jairo found work in construction and things seemed stable. But after he started showing symptoms of HD, he was let go. Eventually, due to the country's ongoing political conflict, the family moved to Medellin.

But peace did not follow: murder and drug-trade violence were so common that the family began to sleep in the same bed just to feel safe.

Together, with his wife and three children, Jhon Jairo will travel to Rome. For Jhon Jairo's son, Jhon Freddy, just 20, the trip will be especially impactful: young Jhon Freddy was genetically diagnosed at 16 years old, but he is not yet aware of his condition.

Stigma has followed Jhon Jairo and his family nearly all his life. It stalked him in his hometown and it caused him to lose his job. Some of his children might follow a similar fate. Economic conditions are intensely difficult and the entire family fears eviction, which happened to his affected siblings.

But there is hope that his family will experience HD with dignity as the community comes together to lift the stigma that plagues HD families. HD should be Hidden no more.

Dilia: A Matriarch's Grace

El Difícil, Colombia

Life at the family's rural Colombian compound can be challenging. Access to running water is limited. Electricity is intermittently available. And with 21 family members, feeding everyone can be difficult.

But for this 79-year-old matriarch, these challenges are unequal to the scourge that shadows her family's health. Huntington's disease is a fact of life for the family. It robbed Dilia of her husband and it persists in her children, slowly taking more and more of them with each passing year.

People often say that, as a mother, there's nothing more heartbreaking than hearing that your child is sick. Dilia knows this tragedy all too well: of her 11 children, four have already passed away from the disease, as well as a granddaughter, and four more are currently living with HD. Five grandchildren have started showing symptoms and she has no social or institutional support. Because of financial issues and the practice of renting grave plots, she had to exhume three of her children and bury their bones together in a small urn, together with her husband's remains.

HD doesn't hold back – and neither does its stigma. So, the family sticks together, living on their secluded compound outside of town. This allows Dilia and her daughter Maribel to care for those who are sick and it shelters the family from the judgements of those who don't understand what life with HD means.

Traveling to Rome will be a new experience for Dilia and her family. But it's likely not the travel that will be most meaningful; it will be the acceptance that Pope Francis will demonstrate towards the family. It will be the opportunity to relinquish shame. And it will be – for perhaps the first time – a chance for Dilia's children to be accepted purely for who they are. She hopes the Pope might be able to bring help to them, so that she can better care for her sick children.

Brenda and Norma: Childhood is Too Precious a Thing to Lose

Buenos Aires, Argentina

She used to spend her days running and jumping in the streets of Buenos Aires. Then Huntington's changed everything. Brenda, now 15, can hardly remember what it life was like before being diagnosed with juvenile Huntington's disease.

Prior to her own diagnosis, fate dictated that Brenda comfort and care for her father, Daniel. He suffered from HD for almost her whole life.

It wasn't long after Brenda's diagnosis that her mother decided to leave for good, taking Brenda's only sibling away.

Being a child who is ill is hard enough. Watching your father struggle with the same affliction is hard to imagine. Worse still, is having your mother leave in the middle of all of this.

No one chooses Huntington's disease; rather family history and fate choose them.

Fortunately, Aunt Norma stepped in to care for the daughter and father.

Brenda realized early on that Huntington's disease affects people differently – even those who aren't sick themselves. The disease's stigma is what drove her mother to leave. It's hard to understand that truth at as a child, but that precocious insight is also what gave Brenda her stoicism and fortitude.

And she needed that fortitude. On the day of her quinceañera, just a few months ago, Brenda lost her father. At just 15 years-old, Brenda has navigated struggles few of us could imagine.

Fortitude is an antidote to hardship. When Pope Francis blesses her, it will be an act of grace because he will offer Brenda a deeper fortitude; the kind that lets her know she is loved and accepted.

Maria Esther, Franklin & Yosbely: The Three Siblings of Barranquitas Barranquitas, Venezuela

This is the story of the three from Barranquitas.

For better or worse, we are bound to our siblings. They're our first support system and often our last goodbye. They lift us up, make us laugh and, sometimes, they struggle through the same struggle we ourselves face.

For siblings Maria Esther, Franklin and Yosbely, living with Huntington's disease is a shared experience. It began when their father started to twist and tic and twitch and thrash. It was slow at first, but with each passing day, his symptoms grew more pronounced. He became unfamiliar, almost a stranger.

Then one day, he was gone. Huntington's disease had taken him.

For a time, they went about their lives. Maria Esther had four children, Franklin had one, and Yosbely had two. One worked in the cement business, another in the fishing industry. Life marched on.

But one by one, each of the three siblings was diagnosed with HD. Thankfully they had a healthy sibling to care for them, as the onset and impact were abrupt. Maria Esther was abandoned by her husband. Franklin's wife died of a suspected case of juvenile HD; this gives his daughter a 75% chance of developing the disease.

They have faced this challenge together – as a family.

For Maria Esther and Franklin, HD has been a daily reminder of their father and the intense toll that the disease takes on the human body. It has been a reminder of the cruel stares from a passerby and the isolation from those who harbor prejudice. And for the better part of a decade, they've lived his story. Yosbely has lived this story for five years.

This is the story of the three from Barraquitas. This family's story is just one example of what it's like living and confronting HD. There are some 150 other families facing similar challenges in this slum.

This is why HD should be Hidden No More.