

## **HDdenmore Press Kit**

17 May 2017

FOR IMMEDIATE RELEASE

## **POPE FRANCIS TO BECOME THE FIRST WORLD LEADER TO RECOGNIZE THE GROWING GLOBAL BURDEN OF HUNTINGTON'S DISEASE (HD)**

Patients from South America, where the disease is most prevalent, will meet with Pope Francis on May 18 to prompt global action to improve the plight of those affected by HD

**ROME, 17 May 2017** – Huntington's disease (HD), an incurable genetic brain disorder, will be recognized by a world leader for the first time on May 18 when Pope Francis holds a special audience with hundreds of Huntington's disease families and over 30 patient organizations from more than 20 countries. The gathering marks the beginning of a global movement to drive awareness and action, and lift the stigma around the disease.

The movement was inspired by the plight of families from South America where prevalence of HD is up to 1,000 times higher than the rest of the world. The *huntingtin* gene was identified nearly 25 years ago in patients living next to Venezuela's Lake Maracaibo. However, despite two decades since the discovery of the gene, HD has no cure, nor are there treatments to slow the progression of the disease.

The symptoms of HD, including involuntary movements as well as cognitive and mental health challenges, have forced many of those affected to hide the disease for fear of public criticism, discrimination and unfair treatment. Stigma around the disease has persisted for generations, hindering the availability of treatments and services to improve the lives of those living with and affected by HD.

"Recognition by Pope Francis is an important step forward for the HD community especially given the influence of the Catholic church in South America," said Elena Cattaneo, Senator for Life, Italian Senate, and professor at the Department of Bioscience and Center for Stem Cell Research, University of Milan. "On May 18, HD patients, caregivers, researchers, students, advocates, industry, church leaders and servants, politicians and citizens willing to learn more and contribute will come together to shine a light on a disease that has been hidden for far too long."

"Our hope is that this historic day will trigger further action by the political, medical and religious communities of every faith so that we may create lasting positive change in the lives of those affected by this cruel disease," said HD advocate and Emmy Award-winning news producer and correspondent Charles Sabine, who also carries the HD gene. "Huntington's disease needs to be hidden no more."

Cattaneo and Sabine were instrumental in bringing this issue to Pope Francis, along with several other leaders of the HDdenmore coalition, including neuroscientist and co-founder of Factor-H, Ignacio Munoz-Sanjuan, Claudia Perandones, a neuroscientist with the Scientific and Technological Coordination Unit of the Board of the National Administration of Laboratories

and Institutes of Health of Argentina (ANLIS), and Louise Vetter, Chief Executive Officer of the Huntington's Disease Society of America.

Pronounced 'Hidden No More' ('Ocvlta Nunca Más' in Spanish or 'Mai Più Nascosta' in Italian), HDdenmore is a global coalition of HD advocates dedicated to raising awareness of HD, ending the stigma and shame around the disease and spurring action to affect change.

In addition to the Special Audience with Pope Francis on May 18, the HDdenmore team has coordinated a series of other events to kick start this global movement, including a learning exchange between researchers and physicians from Latin America and Italy's Gemelli University Hospital, Rome to share learnings and best practices for the care and treatment of those affected by HD.

The event is a collaborative convening, made possible through the financial and in kind support of a wide array of corporations, foundation and private citizens, including Teva Pharmaceutical, Griffin Foundation, Wicklow, BioRep, Virgin Group, IRBM, Sbarro Health Research Organization, Evotec, PsychoGenics, Fondazione Zoè, U.C.I.D., Fondazione Neuromed and numerous other individual donors.

"We are proud to stand with the HD community as a supporter of this important initiative," said Michael Hayden, M.D., Ph.D., President of Global R&D and Chief Scientific Officer at Teva. "At Teva, we are committed to increasing awareness and addressing the unmet needs of those living with Huntington disease and their families."

**The historic event will take place from 9:30 – 1 pm (doors open at 8 am) in Aula Paolo VI in Vatican City, Rome. The event will be livestreamed through the Vatican You Tube Channel starting at 11 am CEST.**

Visit [hddenmore.com](http://hddenmore.com) for more information.

**MEDIA CONTACT:** For media inquiries, and to register for the event, contact: [hddenmoremedia@gmail.com](mailto:hddenmoremedia@gmail.com)

#### **ACCREDITATION INFORMATION:**

All journalists and media operators wishing to apply for accreditation may request TEMPORARY accreditation through the online form available in the Accreditation Section of the Holy See Press Office website:

<http://press.vatican.va/content/salastampa/en/accrediti/pubblico/accredito.html>

Journalists and media operators regularly accredited at the Holy See Press Office may send their request through the usual channels. All requests must be sent no less than 48 hours before the event.

## Spokespeople Biographies

### **Ignacio Munoz-Sanjuan**

Title: Vice President, Biology, CHDI Management; Founder, Factor-H

Bio: Ignacio is a neuroscientist working to develop treatments and gene therapies to halt the progression of Huntington's disease. Ignacio is also the founder of a humanitarian project called Factor-H. The project aims to improve the quality of life of impoverished families in South America living with HD, working alongside non-for profit organizations in affected countries, as well as raising awareness about the conditions of the communities most affected by HD. He is the author of over 60 scientific publications and book chapters. Ignacio will be accompanying the families as they travel from South America to Italy.

### **Elena Cattaneo**

Title: Department of Bioscience and Center for Stem Cell Research, University of Milan; Senator For Life, Italian Senate

Bio: Elena is a professor of pharmacology and a researcher working on HD. For her scientific merits, in 2013 she was appointed senator for life by the President of the Italian Republic. Cattaneo has advocated for many causes including opposing unfounded claims made by different entities offering stem cell remedies and raising awareness of HD. Elena will be joined by patient advocate Charles Sabine in delivering a formal pledge to Pope Francis during the 18 May event. Along with Charles, Senator Cattaneo will be speaking at the event.

### **Charles Sabine**

Title: Degenerative Brain Disease Patient Advocate

Bio: Charles was an Emmy Award winning news producer/correspondent for NBC News for 26 years before becoming an advocate and spokesman for people and families affected by degenerative brain diseases. Charles is especially interested in HD, which has ravaged his family; he too carries the gene responsible for the disease. Charles contributed to drafting the late Senator Edward Kennedy's last act of legislation—the Genetic Information Nondiscrimination Act ("GINA") – which was designed to protect the rights of individuals with genetic predispositions in the American workplace and insurance markets. Charles will be joined by Italian Senator Elena Cattaneo in delivering a formal pledge to Pope Francis during the 18 May event. Along with Senator Cattaneo, Charles will be speaking at the event.

### **Claudia Perandones**

Title: Scientific and Technological Coordination Unit of the Board of the National Administration of Laboratories and Institutes of Health of Argentina (ANLIS)

Bio: Claudia is a physician specializing in medical genetics, and has a Master's degree in Molecular Biology and Genetic Engineering. She focused her PhD thesis on Molecular Biology of Neurodegenerative Diseases. She has published 30 peer-reviewed papers, two books, and has contributed to multiple chapters of books about movement disorders. She has received numerous awards for her scientific and humanitarian work, including helping Ignacio Munoz-Sanjuan co-found Factor-H. Claudia will be accompanying the families as they travel from South America to Italy.

### **Louise Vetter**

Title: CEO, Huntington's Disease Society of America

Bio: Louise Vetter is the Chief Executive Officer of the Huntington's Disease Society of America (HDSA), the largest public not-for-profit organization devoted to the fight against Huntington's disease (HD). Since joining HDSA in 2009, she has led the expansion of the Society's reach with new programs and initiatives to strengthen the web of support for the HD community, advocate for better access to care for those affected by the disease, improve physician understanding of HD, and support scientific exploration to bring new treatments to HD families.

### **Cardinal Gianfranco Ravasi**

Title: President of the Pontifical Council for Culture, Roman Curia

Bio: Cardinal Gianfranco Ravasi, President of the Pontifical Council for Culture and President of the Pontifical Commission for Sacred Archeology, was born in Merate, Italy on 18 October 1942. He was ordained a priest of the archdiocese of Milan on 28 June 1966 and studied at the Pontifical Gregorian University and at the Pontifical Biblical Institute. He taught the Old Testament at the theological faculty of northern Italy and from 1989 to 2007 he served as prefect of the Ambrosian Library in Milan. In addition, Cardinal Ravasi has written many books, articles for L'Osservatore Romano and L'Avvenire and hosts the television show Frontiers of the Spirit.

## About the South American Patients & Families Traveling to Rome



### **Jhon: Robbed of his Job, Robbed of his Family** Amalfi, Colombia

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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 Medellín.

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.



## **Dilia: A Matriarch's Grace**

El Difícil, Colombia

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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.



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

Buenos Aires, Argentina

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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 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

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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% change 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. One example out of some 150 other stories of families facing similar challenges in this very same slum.

Their story is why HD should be Hidden No More.

# ABOUT HUNTINGTON'S DISEASE

## FAST FACTS

- Huntington's disease (HD) is a fatal genetic disorder. It has no cure.
- It has a prevalence of roughly 2.7 per 100,000 people globally. The world's highest concentration of HD is found in pockets of South America.<sup>1, 2</sup>
- HD manifests as a triad of motor, cognitive, and psychiatric symptoms which progress over many years until death. Symptoms generally present between ages 30 and 50.
- Stigma around HD has forced those affected by the disease to hide in shame for generations, hindering the availability of services to improve their daily lives. Tragically, suicide is common.
- Every child of a parent with HD has a 50/50 chance of carrying the faulty gene that causes HD.
- Some treatments to manage symptoms are currently available and potential new medicines that could help to slow its progression are currently being tested.

## WHAT IS THE GENETIC CAUSE OF HD?

Researchers identified the gene that causes HD in 1993 by studying families in Lake Maracaibo, Venezuela. HD is caused by an expanded CAG repeat length on the HTT gene, which codes for an important protein in brain cells called huntingtin. This gene expansion causes cells in parts of the brain to die.

As the brain cells die, a person with Huntington's becomes less able to control movements, recall events, make decisions and control emotions. The disease leads to incapacitation and, eventually, death (generally due to other health complications, like pneumonia).

### What are the symptoms of HD?

- Personality changes, mood swings & depression
- Forgetfulness & impaired judgment
- Unsteady gait & involuntary movements (chorea)
- Slurred speech, difficulty in swallowing & significant weight loss
- Stiff or awkward walking, increased clumsiness or changes in speech for JHD

### When do HD symptoms typically start?

- Symptoms of Huntington's disease usually develop between ages 30 and 50 but can appear as early as age 2 or as late as 80.
- In approximately 10% of cases, HD affects children or adolescents. Juvenile HD (JHD) typically progresses more rapidly than adult onset HD.

## WHY ARE FAMILIES WITH HD STIGMATIZED?

People with symptomatic HD have uncontrolled, irregular, rapid, jerky movements, called chorea, and cognitive challenges such as loss of speed and flexibility in thinking and memory loss.

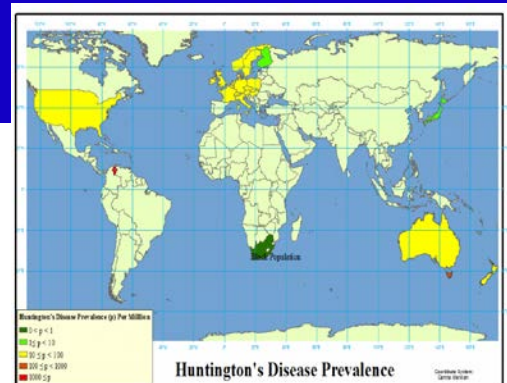
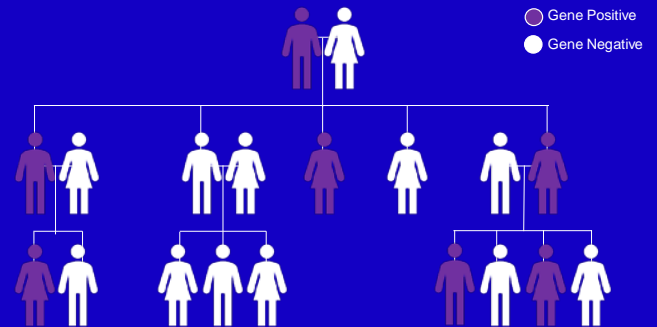
They also have psychiatric disorders including depression and anxiety. In some areas of the world, society has shunned these families, leading those affected to fear public criticism, discrimination and unfair treatment.

## WHO IS MOST AT RISK?

**EVERY CHILD OF A PARENT WITH HD HAS A 50/50 CHANCE OF INHERITING THE EXPANDED GENE THAT CAUSES THE DISEASE.**

If the child has not inherited this expanded gene, he or she will not develop the disease and cannot pass it on to their children.

Diagnostic genetic testing is available for symptomatic individuals. Predictive genetic testing is available for those with a family history of HD.



## WHAT IS THE PREVALENCE OF HD GLOBALLY?

HD is currently found across different countries and ethnic groups, with the highest frequencies found in South America.

In Western countries, it's estimated that about five to seven people per 100,000 are affected by HD. The world's highest concentration of HD has also been found in pockets of South America where the prevalence can be as high as about 700 per 100,000.<sup>2</sup> In Africa, the Middle East and Asia, the prevalence of HD is low.<sup>3</sup>

**To learn more about huntington's disease, visit [WWW.HDDENMORE.COM](http://WWW.HDDENMORE.COM).**

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pubmed/22692795>, <sup>2</sup> <https://www.huntingtonsnsw.org.au/information/hd-facts/how-common>, <sup>3</sup> <https://ghr.nlm.nih.gov/condition/huntington-disease#statistics>