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Pope Francis I to meet with victims of Huntington's disease, a first for a world leader

Kenneth P. Serbin
University of San Diego

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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MONDAY, MARCH 13, 2017

Pope Francis I to meet with victims of Huntington's disease, a first for a world leader

In an unprecedented encounter, the first for any pope or world leader, Pope Francis I on May 18 will meet with Huntington's disease sufferers at the Vatican, bringing new attention to this affliction.

The key papal guests will hail from Latin America, the pope's home region, the area with the world's most Catholics, and a key locus of the quest for the HD gene from the 1970s to the 1990s.

Several HD-affected HD individuals (with both juvenile and adult onset), three at-risk relatives, and other relatives and caregivers – a total of 16 people – will travel to Rome from Colombia, Venezuela, and Argentina, the pope's birthplace.

The news was announced today via e-mail by an international coalition of patient advocates and organizations: "save the date for the largest global gathering of the Huntington's disease community!"

The coalition includes [Elena Cattaneo, Ph.D.](#), a prominent HD scientist and senator-for-life in Italy; Factor-H, a humanitarian project founded by HD researchers Claudia Perandones, M.D., Ph.D., and Ignacio Muñoz-Sanjuan, Ph.D.; global HD advocate Charles Sabine; and the [Huntington's Disease Society of America](#) (HDSA).

Many physicians in Latin America laid the groundwork for the event through their long-term dedication to local HD communities and assistance in selecting the families.

The announcement comes, coincidentally, on the fourth anniversary of Francis's election as the first pope from the Americas.

"What I want him to say, in some way, is that the disease should not be hidden anymore," Sabine, an HD gene carrier, told me. "That's the theme of the event: that people should not feel any shame or stigma about the disease."

"This is a dream which has come true," Dr. Perandones affirmed in a written response to questions about the event. "After working for nearly 20 years in Latin America in order to try to improve the quality of life of patients, and feeling so alone in this endeavor so many times, it seems unbelievable that the pope will receive us."

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Pope Francis I (above, photo by Argentine Presidency/Wikimedia) and the Soto family of Barranquitas, Venezuela, after receiving the invitation to the papal audience in Rome (below, photo courtesy of Dr. Ernesto Solis)



Putting HD on the global stage

The South American HD families will be joined by three dozen advocates and HD family members from other countries, including HDSA CEO Louise Vetter and leading American HD advocate [Katie Moser](#), the 2010 HDSA Person of the Year. Latin American Catholic leaders will also take part.

“As a global leader, Pope Francis has the power to elevate the conversation about HD to an international stage with a call for compassion – and action,” Vetter said.

I was also invited to meet with the pope, because of my interlocking [connections with the Catholic Church](#), Latin America, and [HD advocacy](#).

My mother died of HD, and I carry the genetic defect.

I am thrilled! I consider it a privilege and a responsibility to attend, and expect to bring my wife Regina and teenage daughter Bianca. We will represent the HD community in both the U.S. and Brazil, Regina's homeland. At least three HD-affected individuals will attend from Brazil, according to advocates there.

(Portuguese speakers can watch my report in that language in the video at the end of this article.)

Help desperately needed

Scientists and advocates began discussing an appeal for the Church to help – and then a papal audience – in 2015.

Dr. Perandonnes, a clinical geneticist with the National Administration of Laboratories and Institutes of Health in Argentina, and Dr. Muñoz-Sanjuan, of Spain, a vice president at CHDI Foundation, Inc., the nonprofit virtual biotech dedicated solely to the development of HD treatments, first raised the idea of seeking Church support for Venezuela's isolated HD people during a February 2015 CHDI conference. Talking with Sabine and Senator Cattaneo, Drs. Perandonnes and Muñoz-Sanjuan said that those families desperately needed help.

With aiding those people in mind, Sabine, a native of England, and Senator Cattaneo came up with idea for a papal audience in fall 2015 after Sabine saw a man with Parkinson's disease have his picture taken with Francis and also learned the poignant story of an HD-affected teen from Buenos Aires. Sabine and the senator found no "reference anywhere by any pope to Huntington's disease," he explained.

Thanks to Cattaneo's connections and the Vatican's receptivity, they were able to schedule the papal audience. Now, Sabine says of the upcoming meeting, "It is perhaps one of the most historic moments in the history of the HD community."

According to Sabine, it will mark the first time that any world leader, including a U.S. president, will meet with HD families.



Charles Sabine (above, photo by Gene Veritas, aka Kenneth P. Serbin) and Senator Elena Cattaneo (below, photo from Cattaneo Lab)



A major opportunity to overcome shame, stigma

Sabine, a former foreign correspondent for NBC News, has pursued activism since the mid-1990s, without being yet symptomatic. His father died of HD, and an older brother has the disease.

“I had spent a lot of time working for NBC at the Vatican,” he said. “I know that the pope is the hardest person on the planet to get to – much harder than the American president.”

By blessing and speaking to HD-afflicted families publicly, Francis can make a “profound difference” in combatting the shame and stigma surrounding HD, Sabine added.

“We want as much press on this as possible,” he continued. “We want to engage as many people as possible around the world, not just Catholics, to make this into a larger sum than the parts.”

“Furthermore, we hope this will lead to action, both by the Catholic Church, with its strong presence in Latin America, as well as from local and national institutions,” Dr. Muñoz-Sanjuan wrote in an e-mail.

The public event will take place in a 7,000-seat auditorium, where attendees can observe the pope’s interaction with the South American families and HD advocates. Event organizers want as many representatives as possible from the HD community to attend.

“Anyone can go,” Sabine emphasized. “They don’t even need to be HD-affected. They might just care about HD.”



HDdenmore

SAVE THE DATE
For the largest global gathering of the Huntington's Disease community!

ON MAY 18, IN THE FIRST EVER PAPAL AUDIENCE WITH HD FAMILIES, POPE FRANCIS WILL MEET WITH PEOPLE AFFECTED BY HUNTINGTON'S DISEASE FROM SOUTH AMERICA – and we extend a warm welcome to the entire HD community to attend!

WHAT: The largest global gathering of the Huntington's Disease community
WHEN: May 18, 2017
WHERE: Vatican City, Italy

The purpose of the event is to raise awareness of Huntington's Disease and the overwhelming challenges faced by the patients, families and caregivers affected by the disease. As part of the **HDdenmore** initiative (pronounced "Hidden No More"), the event aims to shine a light on and bring global attention to the HD community, and to mobilize action to improve the lives of those affected by HD.

As leaders of the HD community, your help is critical to help us achieve this goal. We will be in touch soon with additional details on the event and opportunities to get involved.

Stay tuned, and we hope to see you in May!

HDdenmore and the event with Pope Francis is made possible by a global coalition of patient advocates, including Factor-H, the Huntington's Disease Society of America (HDSA), Elena Cattaneo (professor and lifetime senator) and Charles Sabine.

Visit www.HDdenmore.com for the latest information on this event.

The announcement made today by the international HD coalition; click on image to view larger (photo courtesy of HDSA).

A humanitarian endeavor

The organizers also hope the meeting galvanizes the HD community worldwide. Members of groups such as the global [Huntington's Disease Youth Organization](#) could meet beforehand and go to the event together, Sabine suggested. Other events in Rome will celebrate the unity of the HD movement and solidarity with the plight of Latin American HD communities.

All attendees are required to register on the event's official website, HDdenmore.com, by May 5. The URL means "HD Hidden No More," a theme of the papal event linked to Sabine's previous [awareness campaign in the UK Parliament](#).

The site will provide information on hotels, accommodations for special needs of the affected, and more.

Noting the "[immense pressure](#)" on Francis I from ultra-conservative Catholics because of his purported liberal stance, Sabine said that Senator Cattaneo and her staff have stressed the non-political nature of the HD event.

"It's a humanitarian one," he said. "It's a pastoral event. This is about regarding people with compassion and humanity. This pope has shown humanitarian credentials unlike any other."

South America's HD-affected: deep struggles

The papal event builds on work by Factor-H, a small nonprofit organization, to improve the living conditions in the Lake Maracaibo region of Venezuela, and other sites where poor HD families cluster. Many HD families in the region live in dire conditions. In some clusters, many generations of intermarriage mean many families have passed on the genetic disease.

Maracaibo has played a key role in HD science. Columbia University scientist Nancy Wexler, Ph.D., started the search for the HD gene among Maracaibo HD families in the 1970s. In 1993, the HD gene was discovered. It was one of the first disease genes to be identified. This research helped stimulate the Human Genome Project of the 1990s. Dr. Wexler also was invited to meet the pope, Sabine said.

“Poverty and disease are a terrible combination,” wrote Dr. Muñoz-Sanjuan, who has taken aid to Maracaibo and other communities. “Not everyone in Latin America with HD is poor. However, the main clusters in Venezuela and Colombia are very poor, and neglected. That’s why we are focusing on these clusters.”

“These are people living maybe in families of 16 in a space the size of an American garage on stilts on a lake,” Sabine observed. “No electricity. No running water. Nothing. It was so clear that there were so many people like the people at Lake Maracaibo who are affected by the disease and who have never had any kind of recognition from their respective governments or churches.”

Sabine said he hoped the Vatican event will empower Catholic HD families everywhere to seek assistance from their local clergy in raising awareness about HD and alleviating the social burden of the disease.



Dr. Ignacio Muñoz-Sanjuan (seated) with Colombian children at risk for HD (personal photo)

Preparing the logistics

Every HD family knows the extremely difficult challenge of travel for affected individuals, whose symptoms include constant involuntary movements, loss of balance, and cognitive decline. Many require wheelchairs.

To underwrite the cost of the enormously complex task of transporting the HD families to Rome, Sabine raised \$100,000 from Israel-based Teva Pharmaceutical Industries Ltd. and \$50,000 from the U.S.-based, HD-related Griffin Foundation.

Almost all of the South American travelers must get their first-ever passports, and in some cases even birth certificates.

The Vatican is helping to speed the acquisition of travel documents and to prepare special accommodations for the families, including lodging at a monastery near the Vatican instead of a hotel.

“We felt they would be more comfortable staying all together in a quiet and peaceful place,” Dr. Muñoz-Sanjuan noted. “We assumed that they will experience some culture shock and wanted for them to be at ease during their stay and make the experience more personable.”

Physicians will accompany the families.

A lonely HD teen in Buenos Aires

On January 6, the Feast of the Epiphany on the Catholic calendar (the day the Christ child was visited by three kings, according to the Bible), each of the South Americans received a red envelope from the Vatican with the invitation to meet with Francis. (Video recordings of these moments will become available at HDdenmore.com.)

One was 15-year-old Brenda, who lives in the greater Buenos Aires area, where Francis served as archbishop. She has juvenile HD, which has severely hampered her ability to speak and learn. She communicates mainly by texting on her cell phone.

“The children don’t play with her, so she’s very lonely,” Sabine said. “She has no friends, because they’re afraid of catching HD. The local school wouldn’t give her access to a laptop, because they said there’s not much point, because she doesn’t have long to live.”

“Brenda is my patient and I have a great affection to her,” Dr. Perandones wrote. “She is very clever and sensitive. We have a great connection.”

According to Dr. Perandones, Brenda and her father - from whom she inherited HD - lived with his sister, Brenda’s aunt, whom she calls “mom.”

“A major concern for the aunt at the time was the fact that Brenda and her father shared the bedroom, and his movements during the night scared Brenda a lot,” Dr. Perandones recalled in an e-mail to supporters about Brenda’s reaction to the papal invitation.

To lift the family’s spirits and improve their living situation, Drs. Perandones and Muñoz-Sanjuan raised funds to make a heartfelt “Christmas for Brenda.” That resulted in the remodeling of the aunt’s home, including a new room for Brenda, a full bathroom, and a recreational area.

“Regrettably, Brenda’s father’s health gradually deteriorated and last year, on the day Brenda turned 15, he passed away,” Dr. Perandones wrote. (For girls turning 15 in Latin America, the *quinceañera* is typically a joyous passage to womanhood.)



Brenda and her aunt (personal photo)

A turning point for HD community

Sabine said “Brenda’s Christmas” helped inspire the idea of a papal audience.

Dr. Perandones, who describes herself as “totally Catholic,” met Francis (then Archbishop Jorge Bergoglio) before his papal election through her support of a group advocating for victims of human trafficking in Argentina. He “always supported” this effort, she recalled in her written response to my questions.

“Many indigent individuals living in the streets of Buenos Aires have neurological and mental health conditions, including Huntington’s disease,” she added. “Bergoglio was interested in this issue and gave his support to start a Homeless Rescue Program.”

Dr. Perandones hopes the meeting will make HD more visible and attune others to HD families’ regular difficulties and challenges.

“I think that the meeting with the pope will be a turning point for the HD community globally and particularly in Latin America,” she stated.

In addition to Brenda and her aunt, the papal invitees include HD families from the towns of San Luís and Barranquitas in Venezuela’s Maracaibo region and from the city of Medellín and the small town of El Difícil in Colombia.



Brenda flanked by Dr. Claudia Perandones and Academy Award winner Eugenio Zanetti, a supporter of the HD cause, after Brenda received news of the papal invitation (personal photo).

A testament to the world

Rooted in Christian love and compassion, Pope Francis's meeting with the HD-affected of South America should reflect the Church's historic mission of aiding the sick and defenseless. With 1.27 billion Catholics and hundreds of thousands of priests, nuns, and other personnel, the Church runs an enormous, vital network of charitable and social-service entities that could have a significant impact on HD.

With the biomedical revolution, the Church has sought to both apply and adapt its 2,000-year-old moral and theological tradition to today's bioethical challenges.

The Huntington's disease community stands on the bioethical frontier. HD families contribute to advances in neurological and rare-disease research, and they have pioneered ways of dealing with the impact of disease such as discrimination, disability, decisions about genetic testing, family unity, caregiving, suicide, and end-of-life care.

The May 18 meeting with Pope Francis will allow the HD community to provide a testament to the world of human perseverance and solidarity and, ultimately, the need to alleviate and cure devastating diseases.

"Those suffering with HD and living in extreme poverty need urgent help to lead a life of dignity and hope," Dr. Ignacio Muñoz-Sanjuan asserted.

I hope that Francis's Pope's humanitarian gesture serves as a message to the church and to world opinion leaders to address the critical need of ameliorating Huntington's disease.



Janeth Mosquera, of the Colombian HD patient association and Factor-H, hugs an HD man in the town of Choco in the Colombian jungle, April 2016, after delivering assistance (personal photo).



O Papa Francisco encontra com a comunidade de Huntington em maio

from [Gene Veritas](#)

12:14 |

Posted by [Gene Veritas](#) at 2:33 PM



Labels: [Argentina](#) , [at-risk](#) , [caregiver](#) , [Catholic](#) , [Charles Sabine](#) , [Claudia Perandones](#) , [Colombia](#) , [Elena Cattaneo](#) , [HDSA](#) , [Huntington's disease](#) , [Ignacio Muñoz-Sanjuan](#) , [Latin America](#) , [Pope Francis I](#) , [shame](#) , [stigma](#) , [Venezuela](#)

3 comments:



Bev said...

I am so happy to learn that you will go to the Vatican with your family! I know your presence there will help the Pope understand what Huntington's means to at-risk individuals and their families. Safe travels, and from the bottom of my heart, thank you for all you do for our community.

12:02 PM, March 14, 2017

Anonymous said...

Gene my brother this was one of your most thorough blog posts. Like all of your posts it is extremely well written. Your

passion really comes through for this trip. There is no one I am aware of that deserves this opportunity more than you. I would like to join you but have not spoken to my better half Jayne yet. Believe me if there is anyway we can go we will be there! I hope you are able to take full advantage of this opportunity. Please be bold and if there is something you would like to do just do it. If there is a question you would like answered please ask it, and above all completely enjoy the trip, its meaning and the opportunity to share this with your family and the HD community you have served so faithfully for so long! God Bless you man!

Rob Millum

12:53 PM, March 15, 2017



Unknown said...

This is well written and I appreciate the additional details on how this happened. It will be a great day for HD families across the globe as the families meet with our Pope. Thanks!

7:32 AM, March 22, 2017

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