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'Dancing at the Vatican,' about Huntington's families' remarkable papal audience, premieres July 27

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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, JULY 22, 2019

'Dancing at the Vatican,' about Huntington's families' remarkable papal audience, premieres July 27

Dancing at the Vatican, a short documentary featuring South American Huntington's disease-afflicted families' remarkable 2017 encounter with Pope Francis at the Vatican, will premiere in Los Angeles on July 27.

The 38-minute film captures key moments of those impoverished, disease-stricken families' extraordinary journey – some had never ventured beyond their home towns; some even lacked birth certificates – to their meeting with the Spanish-speaking Francis, the first Latin American pontiff in the Catholic Church's 2000-year history.

The documentary is narrated by Emmy-award-winning former NBC-TV foreign correspondent Charles Sabine – like me, an asymptomatic HD gene carrier – and one of the lead organizers of “[HDdenomore](#): Pope Francis' Special Audience with the Huntington's Disease Community in Solidarity with South America.”

“In the course of 26 years as a television journalist, living through more than a dozen wars, five revolutions, and four earthquakes, I witnessed many examples of people achieving the seemingly impossible,” Sabine says in introducing the film, which I previewed online July 21. “None, though, was as inspirational as the tale I'm about to tell.”

The film portrays the struggles of HD family members such as Dilia Oviedo Guillén, a Colombian woman who lost her husband and five children to the disease.

Dilia provides 24-hour care to four more adult children. “I have to wash, cook, and feed them,” she says in the film. “You have to do all that for them. They can't use their hands to eat. They're my children, so I feel as if I have their illness.”

Dilia has no professional caregivers or physical therapists to assist her. The family is so poor that she had to bury three of her children in a single grave.

In showing the struggles of Dilia's family and others, *Dancing at the Vatican* captures the underside of the HD world. Such families deal with one of the humanity's most devastating diseases *and* severe poverty, lack of opportunities, poor or non-existent infrastructure, neglect by the government and society, and stigma and discrimination.

However, as Sabine wrote me in an e-mail today, he and the filmmakers also sought to include “*happy* tales set against the dark canvass of our disease.”

“‘Pope meets sick people’ was not a headline the world's media would care about,” Sabine wrote. “‘Pope meets sick people with an extraordinary visual backstory,’ was.”

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The film follows Dilia's family and four others as they tour Rome; are received in the Italian Senate by its president and world-renowned HD researcher, Senator for Life, and #HDdenmore organizer Elena Cattaneo; and anticipate the big moment with Pope Francis.



From the Dancing at the Vatican website. Dilia Oviedo Guillén is pictured in the center.

Proceeds benefit Factor-H

The premiere will take place at the [SilverScreen Theater](#), Pacific Design Center, 8687 Melrose Avenue, West Hollywood, CA. Doors open at 5:30 p.m., with a screening of the film at 6 p.m., followed by a Q&A and refreshments. Actress and singer [Kate Miner](#), also from an HD family and a participant in the papal audience, will emcee the evening. Self-parking on the street or at the Center (\$10) is available.

Directed at the HD community and the general public, the event and the film seek to raise awareness about HD and, as key HD researcher Ignacio Muñoz-Sanjuan, Ph.D., wrote in an e-mail, “the desperate situation of many HD families in Latin America.”

Sponsored by HD-focused drug developers [Ionis Pharmaceuticals, Inc.](#), [Genentech](#), and [Wave Life Sciences](#), admission to the premiere is free. ([Click here to register.](#))

Sabine recorded a one-minute [video](#) personally inviting the HD community to participate in this “extraordinary celebration.”

Those who wish can contribute to [Factor-H](#), a nonprofit that seeks to improve the quality of life of poor HD families in Latin America. Founded by Spanish-born neuroscientist Dr. Muñoz-Sanjuan and the Argentine physician Claudia Perandones, both featured in *Dancing at the Vatican*, Factor-H currently supports families in Chile, Colombia, Peru, and Venezuela. Venezuela's Lake Maracaibo region has one of the world's densest clusters of HD families, with many residents donating blood in the scientific quest for the HD gene.

Instrumental in #HDdenmore, Drs. Muñoz-Sanjuan and Perandones saw the papal audience as a way to further Factor-H's work. The organization seeks to expand assistance to other nations.

Sabine and the filmmakers chose Los Angeles for the world premiere because Southern California is a “perfect storm” of the HD community – a collaboration of the best of researchers, advocates, clinicians and support groups,” Sabine wrote. However, he also recalled the “truly international nature of the event and film,” noting that 28 countries were represented at #HDdenmore.

In fact, the film has planned premieres in Washington, D.C., London, Rome, Glasgow (Scotland), and South America. Later it will become available online.

Bringing joy and hope

My wife Regina, daughter Bianca, and Brazilian mother-in-law Lourdes took part in #HDdenmore ([click here](#) to read more).

We watched Pope Francis declare that HD should be “hidden no more.”

“It is not simply a slogan, so much as a commitment that we all must foster,” the pope urged the audience of some 1,500 HD community members from around the world.

The film depicts how, after his speech, Francis greeted and hugged each member of the HD-afflicted South American families, sometimes caressing their heads as they spoke to him and cried.

Watching *Dancing at the Vatican* took me back to those poignant moments in the papal meeting hall. I teared up, as I did that day.







As Sabine states in the film, #HDdenmore was “the biggest event in the history of Huntington’s disease.”

Dancing at the Vatican underscores the deep medical and social suffering of HD, which, in South America, is exacerbated by poverty and inequality.

However, as the film also shows, those HD families got a wonderful moment to celebrate, smile, and dance.

Thanks to the organizers of #HDdenmore, Factor-H, and Pope Francis, the terrible burden of HD perhaps feels a bit lighter for all affected families. We can all share in that joy – and the hope offered by Francis – by watching *Dancing at the Vatican*.

(For background on #HDdenmore and its impact, click [here](#) and [here](#). A future article will explore Factor-H in depth.)

Posted by [Gene Veritas](#) at 2:42 PM      

Labels: [#HDdenmore](#) , [advocate](#) , [Catholic Church](#) , [Charles Sabine](#) , [Dancing at the Vatican](#) , [Dilia Oviedo Guillén](#) , [Elena Cattaneo](#) , [Factor-H](#) , [Huntington's disease](#) , [Ignacio Muñoz-Sanjuan](#) , [Pope Francis](#) , [poverty](#) , [South America](#)

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