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Planning a 'Dancing at the Vatican' screening to celebrate the global Huntington's disease community's journey

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, JANUARY 13, 2020

Planning a 'Dancing at the Vatican' screening to celebrate the global Huntington's disease community's journey

On February 19, the [University of San Diego](#) (USD) will host the world's third screening of *Dancing at the Vatican*, the short documentary featuring South American Huntington's disease-afflicted families' historic 2017 encounter with Pope Francis at the Vatican.

As I noted in my [preview](#) before the July 2019 premiere of this 38-minute film in Los Angeles, *Dancing at the Vatican* captures key moments of those impoverished, disease-stricken families' journey to their meeting with the Spanish-speaking Francis, the first Latin American pontiff in the Catholic Church's 2000-year history. It was extraordinary: some had never ventured beyond their home towns; some even lacked birth certificates.

Now, as both an HD advocate and faculty member in USD's [Department of History](#), I'm helping organize the upcoming screening, and hope many more people will see it.

Dancing at the Vatican also will be shown [in London](#) on February 5. Showings are also confirmed for Washington, D.C., in March (date and place TBA), and at the [Huntington's Disease Youth Organization conference](#) in Glasgow, Scotland, in May. Screenings are under consideration for South America, too. Ultimately, the film will become available online.

In the [words](#) of producer and narrator Charles Sabine – like me, a presymptomatic HD gene carrier – coming together to view *Dancing at the Vatican* is an occasion of “extraordinary celebration” for the Huntington's community.

An Emmy-award-winning former NBC-TV foreign correspondent, Sabine helped spearhead “[HDdenomore: Pope Francis' Special Audience with the Huntington's Disease Community in Solidarity with South America.](#)” Both Sabine's father and brother died from HD.

While *Dancing at the Vatican* captures what I called in my preview “the underside of the HD world” – families dealing simultaneously with one of humanity's most devastating diseases *and* severe poverty and discrimination – it also portrays what Sabine described as “*happy tales set against the dark canvas of our disease.*”

At HDdenomore, and as the film recalls, Francis became the first world leader to recognize this horrible disease. And he declared that it should be “hidden no more.”

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HD Blogs and Individuals

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Pope Francis with HD families in Rome, May 18, 2017 (photo by #HDdenmore)

Faith, reason, and advocacy

At USD, the primary sponsor of the screening is [Frances G. Harpst Center for Catholic Thought and Culture \(CCTC\)](#). Along with other USD units, the CCTC co-sponsored my trip to Rome for #HDdenmore, and also my public presentation on the event ([click here](#) to watch).

USD is a Catholic university where “faith and reason are compatible in education,” and it “welcomes students, faculty and staff of every faith tradition,” according to its [statement on Catholic identity](#). Indeed, since [my arrival](#) in 1993, I’ve faced no restrictions on my research on abortion in Brazil, and have taught students from many religious backgrounds.

I have explored the nexus between faith and reason/science in this blog, including the in-depth article [“God, Huntington’s disease and the meaning of life.”](#)

After CCTC Director Jeffrey Burns, Ph.D., read my preview of *Dancing at the Vatican* last July, he e-mailed me to ask whether we could bring the film to USD. Sabine readily agreed to the idea; he’ll introduce the film and take questions afterwards.

[Ignacio Muñoz-Sanjuán, Ph.D.](#), a leading neuroscientist seeking HD treatments at the Los Angeles office of the nonprofit [CHDI Foundation, Inc.](#), also will speak. Dr. Muñoz helped organize #HDdenmore. He co-founded [Factor-H](#), which aids Latin America’s poor HD-affected families. Both Sabine and Muñoz will also meet with students and faculty interested in their respective professional fields.

We selected the February 19 date because Sabine, based in London, will join Muñoz and several hundred researchers from around the globe the next week at the CHDI-sponsored 15th Annual HD Therapeutics Conference in nearby Palm Springs, CA. I will also attend.

In planning the screening, I’ve strengthened the bond between advocacy and academic work that USD values and that I began to establish after exiting the terrible and lonely “HD closet” in 2012 ([click here](#) to read more).



Dr. Ignacio Muñoz-Sanjuán entering the Vatican with Dilia Oviedo Guillén, a Colombian woman who lost her husband and five children to HD (photo by #HDdenmore)

A free event, with many sponsors

The screening will take place from 6:30-8:30 p.m. in USD's Manchester Auditorium (located in Manchester Hall) and will be followed by a reception. The event is free and open to the USD community, the local HD and biomedical communities, and the public. Attendees must register at cctc@sandiego.edu or 619-260-7936.

To fund the event, we have secured support from Ionis Pharmaceuticals, Inc., the developer of the gene-silencing drug currently under study in a historic Phase 3 clinical trial by Roche. ([Click here](#) for a recent update on the trial.) Ionis is located in Carlsbad, CA, part of the San Diego-area biotech hub, one of the world's most important. Ionis' chief scientific officer and HD team leader, Frank Bennett, Ph.D., donated to #HDdenmore.

In addition, Roche's U.S. subsidiary Genentech will also sponsor the screening. Headquartered in South San Francisco, CA, Genentech also has a facility in Oceanside, just north of San Diego.

Another local company, Origami Therapeutics, Inc., is supporting the event. It also seeks to develop an HD treatment. It was founded by Beth Hoffman, Ph.D., the former president of the San Diego chapter of the Huntington's Disease Society of America.

Other USD co-sponsors include the International Center, the Enhanced Student Faculty Interaction Fund, the Humanities Center, the above-mentioned Department of History, the Program in Latin American Studies, and the Department of Communication Studies. The College of Arts and Sciences also has lent its support.



Charles Sabine dancing at the Vatican with #HDdenmore participants (photo by #HDdenmore)

'All of us standing together'

On January 10, I had a long lunch with George Essig, a well-connected veteran radio ad salesman and former HDSA-San Diego president. Essig's extended family is affected by HD. As I wrote in a 2014 article, Essig "epitomizes the dedication of the unaffected relative." ([Click here](#) to read more.)

In discussing the screening, we noted that it will be a unique event for the San Diego HD community and its supporters. Over the years, most events – such as galas, marathons, and walks – have focused on raising funds and awareness.

Echoing Sabine, I stressed that this event would be a celebration.

We brainstormed on the meaning of "celebration" for the local HD community – and for the many donors Essig has brought into the cause.

Their support had helped HD "become hidden no more," he said.






The screening also will be about "the evolution of the cause," he added.

With that in mind, Essig said he would tell supporters that he would be "remiss not to invite you to this celebration."

The *Dancing at the Vatican* screening will also celebrate the progress in research, which has advanced thanks to the donors and broad collaboration in the HD community, he noted.

Essig summed it up: the *Dancing at the Vatican* event will be "all of us standing together and saying: I helped bring a cure to an incurable disease, even if it's just \$10 that I gave."

(Disclosure: I hold a symbolic amount of Ionis shares.)

Posted by [Gene Veritas](#) at [10:00 PM](#)     

Labels: [#HDdenmore](#) , [Charles Sabine](#) , [Dancing at the Vatican](#) , [Genentech](#) , [Huntington's disease](#) , [Ignacio Muñoz-Sanjuan](#) , [Ionis](#) , [Origami](#) , [Pope Francis](#) , [presymptomatic gene carrier](#) , [South America](#) , [University of San Diego](#)

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