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Preparing for the meeting with Pope Francis, a heartening milestone in the Huntington's disease movement

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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HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
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SUNDAY, APRIL 09, 2017

Preparing for the meeting with Pope Francis, a heartening milestone in the Huntington's disease movement

Ever since I received the [electrifying invitation](#) to meet Pope Francis I, my adrenaline has not stopped flowing.

I will be one of 50 credentialed guests at the historic May 18 papal audience with Huntington's disease families at the Vatican.

After global HD activist and papal event organizer Charles Sabine called with the news on March 3, I immediately shifted my own advocacy into high gear.

That night I dreamt vividly of walking alongside the pope, the leader of the world's 1.2 billion Catholics.

Over the next ten days, which coincided with my spring break at the [University of San Diego](#) (USD), I dropped everything – even exercise some days – to write a detailed post on the event ([click here](#) to read more).

Sabine and other organizers have christened it “[HDdenmore](#): Pope Francis’ Special Audience with the Huntington’s Disease Community in Solidarity with South America,” to involve families primarily from Argentina, Colombia, and Venezuela. The name means HD “Hidden No More” or “Oculta Nunca Más” in Spanish.

I have also helped coordinate efforts to include families and advocates from Brazil, which has the world's fifth largest population and an estimated 20,000 HD patients. My wife Regina, who is from Brazil, and our daughter Bianca will accompany me to Rome. So far, about 30 Brazilians plan to participate, including my mother-in-law, who resides in Rio de Janeiro. The Brazilian advocates will also invite to the audience key Catholic bishops from their country.

Ty, #PopeFrancis!

[Huntington's Disease Lighthouse Hereditary Disease Foundation](#)

[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
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HD Blogs and Individuals

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On March 13, the day HDdenmore was officially announced, I shared the news with colleagues and administrators at USD, a Catholic institution that welcomes people of all faiths and emphasizes the quest for social justice.

“Because of the stigma associated with the disease, HD families often remain in the terrible and lonely ‘HD closet,’” I wrote in an e-mail. “With the pope's blessing and recognition, we can liberate HD sufferers from the shame and stigma and move on to finish the hard work of developing a cure!”

I later shared with them my tweet to Francis: “Ty, #PopeFrancis! Meeting #Huntingtonsdisease victims 5/18. End stigma, shame. #HDdenmore @HDdenmore <http://bit.ly/2nnqAnR> @Pontifex.”

At USD, the [College of Arts and Sciences](#), the [Department of History](#), and the [Frances G. Harpst Center for Catholic Thought and Culture](#) (CCTC) will back my trip.

On April 4, I briefly explained the significance of the papal audience during a CCTC-sponsored faculty-student roundtable on Catholic news. In September, I will give a public, CCTC-sponsored presentation on my trip and HD's profound bioethical and faith-related implications.

I have also reached out to the [Diocese of San Diego](#) in the hopes of fostering collaboration with the [San Diego Chapter](#) of the Huntington's Disease Society of America.

HD's spiritual ramifications

As I write this article, I still can't believe that I'm actually going to meet Pope Francis! I feel great personal satisfaction about meeting a person who wields both great religious and political influence – and who can bring unique, global attention to HD.

Many Catholics hope to at least *see* a pope in their lifetimes. In 1979, from a distance, [I saw the highly charismatic Pope John Paul II](#) during a speech he gave in New York City. In 1990, I attended a Catholic Church symposium in Rio featuring then Cardinal Joseph Ratzinger, the future Pope Benedict XVI.

This time, if all goes as planned, I will *meet the pope in person*.

In the coming weeks, I will contemplate what I want to tell Pope Francis.

As an introduction and sign of appreciation, I will give Francis copies of [my two main books](#) on the history of the Brazilian Church.

I'll also be thinking about the long-term ramifications of this event for the HD cause, Catholicism, and human solidarity both in and out of the context of religious faith. As [Francis himself stated](#) recently, many Catholics act hypocritically, failing to follow the teachings of their faith. "How many times have we all heard people say 'if that person is a Catholic, it is better to be an atheist,'" he said.

HD affects men, women, and children from all parts of the world. As a medical condition, it devastates with no correlation to any religion.

At the same time, the fight against HD clearly involves spiritual questions for which people hunger for answers.

Although blog viewership statistics can mean many things, those for this blog provide some interesting indicators of that hunger. Until my previous posting, on the papal audience, the all-time leading article was my 2010 piece titled "[God, Huntington's disease, and the meaning of life,](#)" with more than 20,000 views – more than double the next most popular article, about the historic launching of the [Ionis Pharmaceuticals, Inc., gene-silencing clinical trial](#) in 2015.

In less than four weeks, the article on Francis has had more than 28,000 views.

I'll revisit the theme of the HD movement's spiritual dimension in future articles.

Remembering the HD warriors

Most importantly, in meeting Pope Francis I want to bear witness to my experience as "Gene Veritas," the HD gene carrier who remained painfully hidden from public view for nearly two decades and lost his mother, Carol Serbin, to the disorder in 2006 at the age of 68.

I also want to recognize the valuable contributions of – and the need to increase support for – caregivers such as my father Paul Serbin, the "HD warrior" who daily looked after my mother during her nearly two-decade struggle. He died with a broken heart in 2009.

I've been channeling my parents a lot. I imagine them standing beside Regina, Bianca, and me, all of us smiling as we meet Francis. As devout Catholics, they would have been thrilled to meet him.

They'll be there in spirit.

I will present Francis with a photo of my parents and ask him to pray for their souls.



Paul and Carol Serbin (family photo)

Ending shame and stigma

The HDdenmore organizers expect as many as 2,000 members of the HD community from around the globe to take part in the audience, and they hope for even more.

The event will take place in the [Paul VI Audience Hall](#), just a few yards from St. Peter's Basilica in Vatican City. It seats 7,000. The event starts at 10 a.m. Doors open at 8 a.m. All potential attendees should register at <http://HDdenmore.com>, which is providing updates via e-mail, Twitter, and Facebook.

The site also has videos featuring the South American families invited to meet the pope, as well as information about HD, discounted lodging, and other aspects of the event.

The organizers revealed that 15-year-old juvenile HD patient Brenda, a native of Buenos Aires, Francis's birthplace, will hand a vellum scroll to the pope during the meeting. It will contain a pledge in English, Spanish, and Italian:

Huntington's is a fatal genetic disease. It has no cure.

For too long, shame and stigma have afflicted HD families, forcing them to hide the illness to the detriment of the health, hope and dignity of those affected by the disease.

Nobody should feel shame about the existence of Huntington's disease in their family.

It is time for Huntington's to be HDdenomore!



Brenda and her aunt (personal photo)

A time for joy

Huntington's disease forces families to face a grim reality. Like so many other HD gene carriers and untested at-risk individuals, I saw my own future when looking into the genetic mirror represented by my mother's condition.

HDdenomore will mark a milestone in the HD cause.

It will provide a stark contrast to the anguish felt by so many.

For the first time in my family's long fight against HD, I feel joyful. I've smiled a lot about the fact that my family and I will meet Pope Francis.

More importantly, I'm thrilled that our HD community will receive recognition and new hope in its struggle to overcome the disease and assist scientists in the search for badly needed treatments.

Who knows? Perhaps Francis, through his kindness, wisdom, and faith, will help bring *all* HD families out of the terrible and lonely HD closet – and provide new momentum for the scientific progress necessary for the miracle of a cure.

Posted by [Gene Veritas](#) at 2:24 PM      

Labels: [advocacy](#) , [Brazil](#) , [Carol Serbin](#) , [Catholic Church](#) , [cure](#) , [faith](#) , [Gene Veritas](#) , [genetic](#) , [God](#) , [HD closet](#) , [HD warrior](#) , [HDdenomore](#) , [Huntington's disease](#) , [Paul Serbin](#) , [Pope Francis I](#) , [shame](#) , [stigma](#) , [University of San Diego](#)

2 comments:



 **Bev said...**

I am thrilled that such a deserving HD Warrior as yourself will meet the Pope. This meeting pulls together so many important parts of your life: your scholarship, your family story, your tireless work on behalf of those of us affected by HD, your own fight to hold off the onset of symptoms, and your faith. Your meeting the Pope seems like a kind of miracle, and I expect another miracle in the form of a scientific breakthrough and a cure for HD in the next few years. I am moved to tears by the anticipation of your showing the picture of your parents to Pope Francis. Today, I said a prayer for you and the Pope. It was a prayer of gratitude and thanksgiving for what you both bring to my life.

9:10 AM, April 10, 2017

 **Akila said...**

I agree with the above comment I hope all the good things will happen in all of the hd families here afterwards

10:01 PM, April 16, 2017

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