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At Risk for Huntington's Disease

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1-7-2019

## A friend of the Huntington's community receives award for HD article in influential Brazilian magazine

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### Digital USD Citation

Serbin, Kenneth P., "A friend of the Huntington's community receives award for HD article in influential Brazilian magazine" (2019). *At Risk for Huntington's Disease*. 263.  
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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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 GENE VERITAS

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## HD Links

[Huntington's Disease Society of America](#)

MONDAY, JANUARY 07, 2019

## A friend of the Huntington's community receives award for HD article in influential Brazilian magazine

Brazilian journalist [Mônica Manir](#), holder of a doctorate in bioethics and a long-time friend of the Huntington's disease community, received the Prêmio Synapsis (Synopsis Prize) for her in-depth December 2017 article on the disorder in the prestigious Brazilian magazine [Piauí](#).

Titled "[Dançando no escuro](#)" ("Dancing in the Dark"), the article provides a detailed portrait of HD, focusing on families in Brazil and other countries affected by the condition, which causes involuntary movements, cognitive decline, and psychiatric problems. *Piauí* is on the level of *The New Yorker* magazine.

The [Prêmio Synapsis](#) is sponsored by the Brazilian Federation of Hospitals and awarded annually for the best journalistic reports on health issues in the categories of print publications, TV, online, and radio.

For her article, Manir did almost five months of reporting, traveling to the interior to visit a town with a large nucleus of affected families and also to the Vatican in May 2017 to witness Pope Francis' special audience with the global HD community.

Upon receiving the Prêmio Synapsis in Brasília on November 27, Manir recalled the pope's declaration that HD should be "hidden no more!"



*Mônica Manir receiving the Prêmio Synapsis (photo by Federação Brasileira de Hospitais)*



[International Huntington Association](#)  
[Huntington's Disease Drug Works](#)  
[Huntington's Disease Lighthouse](#)  
[Hereditary Disease Foundation](#)  
[Huntington's Disease Advocacy Center](#)  
[Thomas Cellini Huntington's Foundation](#)  
[HDSA Orange County \(CA\) Affiliate](#)  
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## HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)  
[Angela F.: Surviving Huntington's?](#)  
[Heather's Huntington's Disease Page](#)

Manir received her degree in journalism at the Universidade de São Paulo (USP), one of Brazil's leading universities, in 1990. She worked as both a reporter and editor for the Sunday news and cultural section of the newspaper *O Estado de S. Paulo*.

In 2013, she reported for the paper on the sixth World Congress on Huntington's Disease, held in Rio de Janeiro. She also set up a talk by me on HD and bioethics in São Paulo at the Centro Universitário São Camilo's graduate program in bioethics, where she received both her Master's and Ph.D.

She is also doing a post-doctoral study at the USP's Instituto Oscar Freire on the dilemmas of predictive testing for people at risk for HD.

On December 5, Manir granted the following interview via e-mail.

*GV: What led you to study journalism?*

MM: I was always a very curious person. I wanted to understand the “why” of everything. I always pestered my parents with questions. I also loved reading. When I was 14, my sister started studying literature at the Universidade Estadual de Campinas [in São Paulo state] and became a member of the *Círculo do Livro* [a bi-weekly book club]. I couldn't wait to “inherit” from her all of those books that arrived at our house. I also loved writing and was praised for my school reports. In middle school, I discovered that the history taught in the schools had a political bias. I felt the wool had been pulled over our eyes with all of the language that permeated the school texts and that often hid the facts. I decided that, by becoming a journalist, I could try to get as close as I could to the truth to help people become more critical and aware. I wanted to be where things were happening and consider all the angles. To do that, I needed to do deeper reporting. That's why I always preferred working for media that allowed me to do in-depth reporting.

*GV: What inspired you to write an article for Piauí about Huntington's?*

MM: Although I already knew about the disease because of the article I did for *O Estado de S. Paulo* in 2013, I was inspired to do the piece for *Piauí* by the audience with the pope at the Vatican. I thought it was a theme appropriate for returning to the subject, now in a more profound way, because I would come into contact with the affected, the families, and the health professionals from different parts of the world.

*GV: What did it mean for you to receive the Prêmio Synapsis for your article “Dancing in the Dark”? Why is the prize called “Synapsis”?*

MM: It meant for me a big investment in an in-depth article. Just to report it took almost five months, including my trip to the Vatican and to Ervália, a small town with a large enclave of people with the disease in the state of Minas Gerais, and also the reading of articles and books, and long interviews with the affected, family members, specialists, artists. Then came the writing up of all that enormous amount of information, the organization of the text, and the fact-checking, and then the final version, which took up seven pages in the magazine. According to the sponsors, the name of the prize is intended to recognize the brilliant ideas regarding the improvement of Brazil's health system. The term “synapsis” has to do with “link,” “connection.”

*GV: What did you say as you accepted the prize?*

MM: I thanked the sponsors for their initiative in stimulating discussion about the Brazilian health system, which is essential in a country with such social inequality in all areas. I also thanked *Piauí* magazine for having invested in a theme still little known, and for having sent me to the Vatican and Ervália to cover different angles of the subject. But I especially



thanked the HD-affected, their relatives, and the health professionals, all of whom deal with prejudice, the difficulties of being diagnosed, and the hitches that have occurred in the search for treatments, all of this unfortunately also very common in other rare diseases. Lastly, I remembered the theme of the audience with Pope Francis: "Hidden no more!"

*GV: After the ceremony at which you received your trophy, many people greeted you and said that they had not heard of HD but would now take an interest in it. What explains this reaction?*

MM: I think the fact that a prestigious magazine like *Piauí* took interest in the subject is already a reason for reading the article. Another point is that this disease can be present in a family or friends without anybody knowing about it. Or, even if people know about it, they might lack detailed information. So, there's curiosity about learning more about HD. One couple present at the ceremony said that they knew about the disease because a relative had symptoms. They called it "Huntington's chorea," as it is still sometimes known in Brazil, and praised the fact that the magazine had addressed the subject.

*GV: It's been a year since the publication of "Dancing in the Darkness." Beyond your prize, what has been the article's impact in Brazil?*

MM: When it was published, it drew praise from various quarters, from apartment doormen to Brazilian celebrities, besides the subjects themselves.

*GV: What was it like to cover the affected families in Rome in May 2017?*

MM: It was a very rich experience! I understood much better the anguish of the families, the factors that accentuated or eased that anguish, and the determination to diminish the silence on the matter. Everybody was very kind to me, answering patiently my endless questions!

*GV: What led you to study bioethics?*

MM: I think bioethics combines perfectly with journalism in the sense that the guiding concept is "it depends." Central questions of human existence can't be viewed just from one angle. It's necessary to turn the prism and observe the effects that has on the light. It's necessary to understand the context of a matter, people's wishes, the internal and external pressures, and, from that point, try to register things with sensitivity. Bioethics showed – and continues to show – me the profound dilemmas of life and death that are still far from being answered with a single response.







*GV: What has most impacted you regarding Huntington's?*

MM: Huntington's is a hereditary disease that leaves families on hold. Questions hang over them: "Do I carry the gene? Does my child? And my mother? And my nephew?" Despite the existence of a predictive test, very few undergo testing to learn their status before the actual onset of symptoms – which is completely understandable, because there is still no cure. At the same time, there are cutting-edge research projects that could block the genetic trigger and, as a result, help to treat and/or cure this and other diseases.

*GV: What message would you like to transmit to the Huntington's community in Brazil? And beyond?*

MM: I would like to say that I understand very well all of the suffering encompassing the disease and how, sometimes, people feel like hiding it in the closet. But I think the prize confirms the main point of the papal audience: we must speak about Huntington's. Shedding light on things hurts. However, it helps to make people aware of alternatives and of the

partners to be found on this journey. The disease does not affect my family, but my empathy – and that of so many other individuals – is not a question of blood, but of soul. I'm with you!

Posted by [Gene Veritas](#) at [6:56 PM](#)      

Labels: [bioethics](#) , [Brazil](#) , [Brazilian Federation of Hospitals](#) , [Ervália](#) , [health](#) , [hereditary](#) , [Hidden No More](#) , [Huntington's disease](#) , [journalism](#) , [Mônica Manir](#) , [Piauí](#) , [Pope Francis](#) , [predictive testing](#) , [Prêmio Synapsis](#)

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