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An 'electric,' inspiring Thanksgiving for the Huntington's disease community

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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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TUESDAY, NOVEMBER 26, 2019

An 'electric,' inspiring Thanksgiving for the Huntington's disease community

Thanksgiving is my favorite holiday. I've reflected on it many times [in this blog](#). For me, rather than the commercialism and stress associated with the holidays, it's truly a day of relaxation, the warmth of friends and family, and gratitude.

This year, the Huntington's disease community has bountiful reasons for thanks. Several clinical trials to test what might become the first effective treatments are in progress, and the community has demonstrated spirited participation.

The historic [Roche](#) gene-silencing program successfully started its crucial third and final phase, GENERATION HD1, earlier this year. The program includes an open-label extension of all 46 participants in the first phase, completed in December 2017, all of them receiving the drug RG6042 via a monthly injection into the cerebrospinal fluid (CSF).

“Two years ago, we showed for the first time – about 25 years after the discovery of the gene –the ability to lower CSF levels of mutant huntingtin [protein] in patients with HD, which was a very exciting first-in-human accomplishment, and that was really the springboard that allowed us to proceed to our global development program,” Scott Schobel, M.D., M.S., Roche's associate group medical director and clinical science leader for RG6042, [reported](#) at the 26th annual [Huntington Study Group \(HSG\) meeting](#) on November 8. “So these heroic 46 volunteers were the foundation of that.”

GENERATION HD1 is “recruiting incredibly well,” Dr. Schobel said. “It's been absolutely electric.” Total worldwide enrollment in GENERATION HD1 and related studies has surpassed 800. “It's been a huge response from the community,” he added.

Several other programs provided updates at the HSG meeting.

Although much work remains to develop effective therapies, HD families and their supporters can feel proud for helping further the progress achieved in 2019.

Priscilla's inspiring fight and peaceful paintings

An HD-stricken woman I know from Brazil, Priscilla Ferraz Fontes Santos, embodies the life-force of the HD cause. I saw Priscilla in 2013 at the sixth [World Congress on Huntington's Disease](#) in Rio de Janeiro, and got to know her at #HDDennomore, Pope Francis' [special audience](#) with the HD community in Rome in 2017.

Brazilians don't celebrate Thanksgiving, but Priscilla's words, paintings, and photos help us feel the peace and hope of our quintessentially American holiday.

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Priscilla was stricken with juvenile HD as a teenager. She had played soccer, pursued acting, and completed her journalism degree, but the disease prevented her from finishing a second degree in tourism.

Many juvenile patients do not live past 30. Priscilla is 36. She takes no drugs to control her involuntary movements and other symptoms but instead relies on alternative and spiritual approaches, including yoga. However, she also follows HD clinical trials and hopes for a cure.

Starting November 22 and ending December 10, Priscilla and her art teacher are staging an exhibit of Priscilla's paintings in Serra Grande, a town in the state of Bahia. They have called it "Colored Atmosphere."



Priscilla with two of her paintings (family photo)

"The past two and a half years, I have been taking painting and art classes, and I have discovered for myself the pleasure and well-being that painting brings," Priscilla wrote in an introduction to the exhibit. "As I await the cure, I have gained the courage to overcome many difficulties and meet challenges with the ever-present support of my family, friends, and health professionals who care for me."

Priscilla ended with this wish: "I hope that you enjoy my paintings and that they awaken in you all of the strength, beauty, and joy with which I painted them." (I translated the text from the original Portuguese.)

Priscilla is an "inspiration of strength and positive thinking" for all of us, Priscilla's mother Lúgia wrote in a message in Brazilian WhatsApp group dedicated to the HD cause.



Priscilla practicing yoga (family photo)

Symptom-free, but awaiting treatments

As always, I am profoundly grateful for not having yet developed any of the inevitable classic symptoms of HD, which struck my mother in her late 40s and ended her life at 68.

I turn 60 next month – an age at which my mother had full-blown HD and could no longer care for herself.

Last week, I presented my new book on Brazilian history to an audience at the University of San Diego. I had never imagined I would still be able to write at age 60.

Even more importantly, I'm able to continue supporting and loving my wife Regina and daughter Bianca. A sophomore at the University of Pennsylvania and HD-free, Bianca will spend Thanksgiving with friends in Connecticut. However, in a few weeks she will be home for winter break.

I am crossing my fingers that GENERATION HD1 and other trials can produce an effective treatment – and that I can hold on long enough to benefit and share more precious time with my family.

Posted by Gene Veritas at 4:52 PM     

Labels: art , clinical trials , cure , GENERATION HD1 , Huntington's disease , juvenile HD , painting , Priscilla Ferraz Fontes Santos , RG6042 , Roche , Scott Schobel , spiritual , symptom-free , Thanksgiving , volunteers , yoga

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