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'Let's Talk About Huntington's Disease': 2019 HD Awareness Month kicks off

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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](#)

FRIDAY, MAY 03, 2019

'Let's Talk About Huntington's Disease': 2019 HD Awareness Month kicks off

May is Huntington's Disease Awareness Month. As in past years, the [Huntington's Disease Society of America](#) (HDSA) is encouraging HD families to share their experiences in a social media campaign, [#LetsTalkAboutHD](#).

Other HD advocacy groups are also marking HD Awareness Month.

As a presymptomatic HD gene carrier who lost his mother to HD in 2006, I kicked off my own participation as a guest May 1 on [Help 4 HD International's](#) podcast [Help 4 HD Radio](#) ([click here](#) to hear the program.)

I recalled my family's struggle with HD in an interview with podcast host and HD gene carrier [Lauren Holder](#), the [Help 4 HD Radio](#) producer and the 2014 HDSA Person of the Year.

"We need to continue telling our stories," I said in response to Lauren's question about how to promote HD Awareness Month, emphasizing the need to attract those unaffected by HD to our cause.

I also highlighted the "real hope" for the first effective HD treatments with clinical trials such as the [Ionis-Roche project](#). These trials are "really unprecedented in the history of HD," I noted. In the mid-1990s, when my mother was diagnosed, there had been "zero hope," I recalled.

The next day, I posted HD Awareness Month flyers on my office door at the [University of San Diego](#).

I'm ready for [#LetsTalkAboutHD!](#)

[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](#)
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[Heather's Huntington's Disease Page](#)



Gene Veritas, aka Kenneth P. Serbin, at his office at the University of San Diego (photo by Yi Sun, Ph.D.)

A painful silence

My conversation with Lauren stirred up painful memories – but also provided fresh insight – about my own path from refusing to talk publicly about HD to exiting the “terrible and lonely HD closet” in 2012 with an essay, “[Racing Against the Genetic Clock](#),” in *The Chronicle of Higher Education*.

Regarding my “coming out” about HD, Lauren wanted to know: “How did it make you feel? Was the process hard? Did you feel a sense of relief?”

“Deep down, I knew that someday I would need to go public, in some way or another, because it’s very hard to be an advocate without telling people about your story,” I said.

I recounted one poignant dilemma – discussed in public for the first time in the podcast – in the early 2000s. Back then, HDSA-San Diego was joining other chapters around the country in hosting the organization’s first fundraising galas.

“I would volunteer for the galas,” I told Lauren. “I was writing the newsletter that we would distribute at the galas. But I would never tell anybody my story.”

I was known in other San Diego circles for my work as a scholar of Brazil, and once I had given a local public talk on that country.

“I had met this one couple [at my Brazil talk],” I explained to Lauren. “And then, a year or two later, they showed up at one of our galas. So it was like, ‘Wow!’ They were wanting to know what I was doing at this gala here. And I said, ‘Well, this is my personal commitment to charity and making a difference.’”

“And I didn’t tell them my story,” I explained. “It’s that kind of situation that was very difficult for me, because I was afraid of being outed, because nobody at my work knew my status. I was worried about losing my job and losing my insurance, and, if I were ever to switch jobs, could I get health insurance again? All of the concerns that people in our community, and other communities, have.

“I really just felt bad that I couldn’t – and wouldn’t at that point – share my story.”

Becoming an open, honest advocate

Going public “allowed me to be a much, much better advocate, an honest advocate,” I told Lauren. “I can talk openly about HD and my family situation.”

My essay “Racing Against the Genetic Clock” shocked my colleagues at work and around the country, I recalled.

However, I believed that the article was necessary because I “wanted to take away the fear of talking about Huntington’s disease” for others.

“To this point, I have not, to my knowledge, suffered any discrimination,” I added “And, of course, I’m still asymptomatic. Who knows what will happen if and when I become symptomatic? Things could change.”

However, until now, “I’ve been treated with respect,” I said. Living outside the “HD closet” has “been a very positive experience.”

The prohibition of insurance discrimination for people with pre-existing conditions in the Affordable Care Act and the passage of the Genetic Information Nondiscrimination Act have further encouraged me, I added.

#LetsTalkAboutHD!

Going public about one’s HD story is a “personal decision,” I observed.

Those unready to tell their stories openly can still participate in #LetsTalkAboutHD by starting with relatives and close friends, I said.

In the HD community, we *all* have important stories.

As I’ve told Lauren and so many others, “Together we will defeat HD!”

Sadly, HD and juvenile HD patients continue to die. HD Awareness Month provides our community with the opportunity to renew our energies and tell the world of the urgent need for treatments.

Posted by [Gene Veritas](#) at [11:55 AM](#)      

Labels: [#LetsTalkAboutHD](#) , [clinical trials](#) , [discrimination](#) , [Gene Veritas](#) , [HD Awareness Month](#) , [HD closet](#) , [HD gene carrier](#) , [HDSA](#) , [Help 4 HD International](#) , [Huntington's disease](#) , [Lauren Holder](#) , [presymptomatic](#) , [treatments](#)

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