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Annual Huntington Study Group meeting reveals an HD community energized to aid families, develop treatments

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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

TUESDAY, NOVEMBER 03, 2020

Annual Huntington Study Group meeting reveals an HD community energized to aid families, develop treatments

Moved online because of the COVID-19 pandemic, the [27th Annual Huntington Study Group Meeting](#) nevertheless revealed an HD community committed to aiding affected families and developing cutting-edge treatments.

Originally scheduled for Atlanta, GA, the virtual conference took place from October 29-31, with more than 800 scientific and medical participants from around the world. The meeting featured two days of presentations concerning care of HD-afflicted individuals, as well as updates on key clinical trial programs, aimed at producing drugs.

On Family Day, which drew an estimated 180 additional people, the affected, caregivers, and advocates heard both expert presentations on coping with HD and highlights regarding research.

Research moving full steam ahead

Martha Nance, M.D., a long-time member of the Huntington Study Group (HSG) and the director of Family Day organizing committee, kicked off that event with a reflection on the “highlights and lowlights” of 2020 so far. A neurologist and frequent sounding board for this blog, Dr. Nance is also the medical director of the Huntington’s Disease Society of America (HDSA) [Center of Excellence](#) at Hennepin County Medical Center in Minneapolis, MN.

We all know the lowlights, Dr. Nance said: the COVID-19 pandemic, the death of George Floyd in Minneapolis, the 2020 election with its uncertainty, and climate change.

“For me, a highlight of this entire year was this meeting,” Dr. Nance said, referring to the great progress in HD research. “The last two days we heard about more things than you can shake a stick at.”

Dr. Nance listed the important developments detailed in the scientific talks, including several innovative ways to potentially block the harmful effects of the mutant huntingtin gene. Both the scientists and family members got updates on

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

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[GENERATION HD1](#), the historic, in-progress gene silencing clinical trial by [Roche](#) aimed at reducing the amount of toxic huntingtin protein in the brain.

At the conference, several speakers referred to temporary slowdowns in research programs because of the new safety protocols resulting from COVID-19. Dr. Nance also noted difficulties in accessing some HD community members because of the pandemic in the U.S. and abroad, although she also has observed a helpful “explosion” in telemedicine.

However, despite the uncertainty about overall scientific research funding because of the COVID-19 crisis, “research is alive and well in Huntington’s disease,” Dr. Nance stated. “If what happened at this meeting continues, research in Huntington’s disease is moving full steam ahead.”

“I found the meeting to be energizing,” Dr. Nance concluded in an e-mail to me on October 31.

For detailed reports of the research presentations, see HDBuzz’s coverage by clicking [here](#) and [here](#).

For the next year, HSG is providing access to on-demand recordings of the conference talks and other events. [Click here](#) to register for access.

‘Heroes,’ and a thank-you for me

Dr. Nance devoted most of her Family Day introduction to counterpoising the difficulties of 2020 with the stories of “heroes” who have stepped up to assist others in the HD community by exercising their unique skills.

“We need to hear about some people who’ve done good things,” she explained. “I hope that you can emboldened, empowered by some of these heroes.”

Dr. Nance – to my surprise and appreciation – began with the example of me, Gene Veritas (aka Kenneth P. Serbin), the author of this blog, now in its sixteenth year. Dr. Nance recalled how she and I had worked together on our college newspaper ([click here](#) to read more). She said that I use my journalistic skills to help inform the HD community, and to be “very up front about my struggles and fears” as a carrier of the HD mutation.

I write in this article about myself because Dr. Nance stressed how important it is for the HD community to be informed about its social ramifications.

‘I can’t breathe’

Dr. Nance recalled my September 2014 report on Jeffrey Bane, a West Virginia man arrested because the police misunderstood his HD symptoms to be the result of narcotics abuse ([click here](#) to read more).

Dr. Nance replayed the video of a bystander who had filmed Jeff suffering injuries as the police held him to the ground, thinking that, with his involuntary, HD-

caused movements, he was resisting arrest. "I can't breathe," Jeff said desperately as he asked the officers for help.

Jeff only received the help of paramedics after the police had held him to the ground for almost ten minutes, Dr. Nance pointed out.

Then she asked the attendees "to just take a deep breath, pause, and think for a minute."

After 54 seconds elapsed, she resumed her presentation. "Hopefully you took a deep breath," she said. "I think probably you felt anger, hate, sorrow, sadness, fear, anxiety."

She continued: "We can't change something that happened six years ago. What we *can* do is try as hard as we can to keep events like this from happening against in the HD community."

Dr. Nance noted that HDSA has a toolkit for educating first responders, police officers, and fire personnel about HD. The organization provides other resources (such as a special HD ID card) to help HD-affected individuals and their families prepare for potential encounters with the police, she added.

(I have explored these crucial themes in other articles. [Click here](#) to read more.)

'Your life matters'

In examples surely moving to the audience, Dr. Nance presented the stories of several other HD "heroes."

Inducted into the Minnesota Auctioneers' Hall of Fame in 2005, Joe, whose wife and daughter died of HD, took "his grief, his sadness, his sorrow" and raised money and bought electric toothbrushes for hundreds of HD-afflicted people, Dr. Nance recalled.

As a ten-year-old watching his mother face HD, B. J. Viau started an annual basketball hoop-a-thon that over the years raised some \$750,000 for HD research. Among other things, B. J. went on to become one of the founders of the highly active international Huntington's Disease Youth Organization.

Diagnosed at ten with juvenile HD, Elli started kickball tournaments to support the cause. She became an internationally recognized HD advocate.

Dr. Nance also recognized the 791 "heroes" who are taking part in the GENERATION HD1 clinical trial.

With HD, she said, it's easy to become angry, sad, and depressed. However, people can also "stand up tall" to help others. We need more everyday heroes, she added.

“Your life matters – not to take away from anybody else whose life matters,” Dr. Nance said in closing. “What you do makes a difference.”



Dr. Martha Nance (left) praises the advocacy of juvenile Huntington's disease-affected Elli Hofmeister (in images at right) at the virtual 2020 HSG Family Day (screenshot by Gene Veritas).

Posted by [Gene Veritas](#) at [11:02 PM](#)      

Labels: [B.J. Viau](#) , [clinical trials](#) , [COVID-19](#) , [Family Day](#) , [gene silencing](#) , [Gene Veritas](#) , [GENERATION HD1](#) , [HDSA](#) , [huntingtin](#) , [Huntington Study Group](#) , [Huntington's disease](#) , [Jeffrey Bane](#) , [Martha Nance](#) , [police](#) , [research](#) , [Roche](#)

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