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Nora Guthrie: we’re all ‘hoping machines’ in the fight against Huntington's disease

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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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Nora Guthrie: we're all 'hoping machines' in the fight against Huntington's disease

The cause to defeat Huntington's disease came full circle at the recent HD Therapeutics Conference, where keynote speaker Nora Guthrie recalled the brave struggle against the disease by her father, iconic folk singer Woody Guthrie, and the groundbreaking advocacy of her mother Marjorie, the founder of the Huntington's Disease Society of America (HDSA).

"We are the hopers and the changers," said Nora, 68, quoting her father, to the audience of 350 scientists, drug company representatives, and family advocates gathered at the 13th annual meeting in Palm Springs, CA, in late February. "The note of hope is the only note that keeps us from falling to the bottom of the heap of evolution, because about all a human being is anyway is just a hoping machine."

The conference was sponsored by CHDI Foundation, Inc., the nonprofit virtual biotech dedicated to developing HD treatments. Like a number of past keynoters, Nora preferred not to have her presentation recorded. She interweaved her father's music – he wrote "This Land is Your Land" – with the family's struggles against HD.

However, Nora agreed to an interview with me in which she reflected on the early days of HDSA – started in 1967, the year her father succumbed to HD, when she was 17 – and the progress towards treatments.

Nora Guthrie (right) being greeted by Sarah Tabrizi, FRCP, Ph.D., with Blair Leavitt, MDCM, FRCP (left) and Gregory Suter looking on (photo by Gene Veritas, aka Kenneth P. Serbin)

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International Huntington Association

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A vast HD 'tribe'

I was thrilled to meet Nora. Watching and interacting with her helped me connect with a giant of American history as well as with what she called the vast HD "tribe" that Marjorie had started.

Before our formal interview, in conversations with Nora, I also relived key moments in my personal journey with HD.

After her keynote, filled with emotion, I hugged Nora, telling her that my mother had died of HD.

Nora was at first befuddled by my pseudonym, "Gene Veritas." I explained to her that it meant "the truth in my genes," a reflection of my condition as an HD gene carrier.

During one dinner, I told how, in the late 1990s, my efforts to get background on the disease and the cause led me to study Woody's life and watch the 1976 film *Bound for Glory*, based on his autobiography and portraying his early phase as a drifting folk singer. Nora recalled her personal impressions while on the set.

"I feel a spiritual connection with you and your family," I told Nora at the outset of our interview. "Thank you for being here, and thank you for speaking out for us, just as your father spoke out for so many people."

Impressed with the research progress

As I proceeded to my first question, Nora interjected: "Not just speak out, but speak up."

In that comment, and many of her other responses during the interview, Nora quoted her father or echoed his singular eloquence with her own plays on words and unique phrasing.

I asked Nora what it was like to speak to the scientists.

"For me, it was like a sci-fi movie, because coming from my early years with Huntington's with my father in the late 1940s and early fifties, when there wasn't *one* person you could talk to, not one doctor that knew anything about Huntington's, not one social worker to help you get through it, not one support group," she said. "Our family was kind of inventing how to deal with Huntington's in those days. There were no pamphlets. There were no guidelines. So, we were going day to day, day *by* day, inventing – trying to be creative, trying to be helpful, trying to figure out even what the symptoms were."

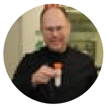
Nora recalled the first HD benefit concert Majorie organized at Carnegie Hall in New York City in 1968, with Woody's musician friends

Today, Nora said, just at events like the CHDI conference, hundreds of "young, energetic, and smart" people are focused on developing treatments – all descendants of Marjorie, the "Eve" of the HD movement. To Nora, they represent hope for the community.

Devoted to preserving her father's legacy, Nora still seeks to combine music with HD advocacy. She described the concert she organized last summer in Berlin, gathering musicians and HD families and organizations.

"For me, the music and the art and the sciences are one group," she said.

You can watch the interview in the video below.



Nora Guthrie: In the Fight Against Huntington's, We're All 'Hoping Machines'

from **Gene Veritas**

18:51

A cure: when, not if

Like all children of an HD-afflicted parent, Nora was born with a 50-50 chance of having inherited the genetic defect. In her talk, she did not broach the issue of genetic testing. We also did not discuss it in our interview. For many in the HD community, that is a private matter.

At age 68, Nora has passed the age of typical onset. She looks to be in excellent health. According to Woody biographer Ed Cray, Nora declined testing. So did her famous brother Arlo, a musician born three years earlier. Their brother Joady tested negative for HD in the early 2000s. (Two half-siblings died of HD.)

I wished Nora and her extended family the best of health.

Finally, I wanted to know what her parents would say about the advances in HD science, if they were alive today.

"I think the most impressive thing for them is an affirmation of their belief in humanity," Nora said. "That people are interested. That people do care. That a cure is down the road. It's just a question of when, not if."

Posted by Gene Veritas at 12:07 AM

Labels: Arlo Guthrie , CHDI , cure , genetic testing , HDSA , Huntington's disease , Marjorie Guthrie , Nora Guthrie , research , scientists , tested negative , treatments , Woody Guthrie

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