

*Corpus Christi Caller Times*

## **Corpus Christi teen battles rare illness to claim national debate championship**

By David Silva Ramirez

July 5, 2019

In January, Susannah Stearns couldn't have predicted that in less than six months John Henry Stearns would be awarded the title of best high school debater in the nation.

At the time, she frantically tried to decide her next move. She looked in the back of her car to see her teenage son slumped in the seat, unable to move and completely devoid of color.

Susannah had rushed to the Corpus Christi IceRays game, where John Henry had been helped out of the American Bank Center and put in the back of Susannah's car.

His health was at a point where even attending a hockey game could lead to grave consequences.

She could take him to the hospital, but she knew all too well that they would be unable to help. So she took him home. The best that could be done is letting him get some rest.

The action that triggered his situation: he stood for the national anthem.



*John Henry Stearns receiving his First Place Big Question debate trophy at the National Speech and Debate Tournament in Dallas, TX on June 21, 2019.*

It wasn't the first time that John Henry had dealt with something like this, and it wasn't the first time Susannah wondered how her son could ever fully participate in the things he wanted to do, if he would graduate high school or if he would even be able to lead a normal life.

At the time of the IceRays game, John Henry was about a year and a half removed from his diagnosis of erythromelalgia, postural orthostatic tachycardia syndrome and somatic hypervigilance.

He was diagnosed after years of heat sensations and swelling in his hands and feet started to occur during middle school and early high school.



*John Henry Stearns won the National Speech and Debate Association's Big Question Debate championship.*

At first the sensations were written off as allergic reactions, but as time passed, the sensations would come back, the pain would gradually worsen and the duration of the pain would last longer.

John Henry would also get lightheaded from standing up for too long.

The sensations began to get more severe, to the point where John Henry felt like he was being burned alive. The family suspected that he may have erythromelalgia, an extremely rare, incurable disease.

During the last day of his sophomore year at W.B. Ray High School, John Henry passed out in the gym, his body giving in due to the physical activity.



*John Henry Stearns waits to be seen by his doctor at Sunnyside Pediatrics on Tuesday, July 2, 2019. When he was 16, he was diagnosed with several medical conditions, some of which are rare and made him think he may have to give up debating. (Photo: Rachel Denny Clow/Caller-Times)*

That summer, after visiting doctors in Austin, Houston and what John Henry felt like “every doctor in Corpus,” he was officially diagnosed.

The erythromelalgia was causing the episodes of severe burning pain, redness and swelling in his hands and feet. These episodes could happen about 15 times every single day and could last anywhere from 10 minutes to two hours.

The postural orthostatic tachycardia syndrome, or POTS, affected his blood circulation and caused lethargy, fainting and an increased heartbeat when standing up.

The somatic hypervigilance caused bodily sensations more intense than those of the average person, which resulted in sensory overload.

At Texas Children's Hospital, a doctor said that John Henry was living with a radio that no one else had, that had no way of turning off.

The best thing that could be done is find a way to set that radio to a volume that he could live with forever, he said.

"And I thought, you jerk, my kid is 16 years old," Susannah said. "I don't want to turn the volume down, I want it off."



*John Henry Stearns sits with his emotional support dog, Tillman, at his home on Tuesday, July 2, 2019. His dog was named after Tillman Huett-Lassman, who was a privately paid Lincoln Douglas Debate coach for his first National Tournament in 2013. "I always thought I'd want a kid named Tillman," he said. "'It's a nice reminder of that chapter of my life.'" (Photo: Rachel Denny Clow/Caller-Times)*

By John Henry's junior year, his life was completely uprooted.

Immediately he lost his ability to play football and to participate in physical activity.

His pain would tie his stomach in knots, causing him to lose weight. His time outside of his home became more and more limited. He missed school for three months and had trouble being mentally present, his mind too fixated on pain.

He couldn't do common things. He couldn't stand up at church or even sit on the wooden bench for too long. He couldn't stand to wait in line at a fast food restaurant. He couldn't go anywhere too loud or that required too much walking.

The person that he was and the aspirations that he had were no longer at the forefront of his life, if those things were now achievable at all.

"That was depressing," John Henry said. "Because I couldn't do anything. I felt trapped."

John Henry now had psychologists, counselors, pain management doctors, physical therapists, neurologists, rheumatologists and hematologists.

The Stearns household was in a state of survival. His mother fixated on John Henry's health, his father John working to keep up with doctor's appointments and physical

treatments, and his brothers Christopher and Laird consequentially left with dealing with school and their obstacles on their own.

But John Henry and his family remained persistent.

He continued to attend doctor's appointments, seek treatment, participate in pain management and closely watch his nutritional intake.

And John Henry never gave up debate, despite missing several tournaments during the worst times of his illness.

He had debated since the sixth grade and found success and appreciation for it from the start.



*John Henry Stearns won the National Speech and Debate Association's Big Question Debate championship. Debate has always been a big part of his life, so much so that his graduation photos included debate he'd won throughout his school career.*

"Debate has helped me understand a multitude of perspectives," he said. "There are so many different ideas on every topic, no matter what it is... so you really have to understand everyone's opinions, not just your own."

John Henry and Christopher were debate partners in high school, and ranked as a top team in the nation.

But John Henry's illness did not allow him to stand up during debates, and his episodes of pain clouded his ability to keep up with the fast-paced style of debates.

"It felt like I was disappointing Christopher," John Henry said. "We would get into the round and he would get up and give his speech and it was super prepared ... and then I would get up and give my speech and I would forget what I was supposed to say because I was in so much pain."

Despite his setbacks, John Henry qualified for the National Speech and Debate Tournament every single year he was high school.

His senior year he switched schools, going to Tuloso Midway High School and benefiting from their unique schedule that includes intervals of time off.



*John Henry Stearns was diagnosed with several medical conditions at the age of 16, some of which are rare, and made him think he may have to give up debating. He said he's been debating, or arguing, as long as he could talk, and began competing in the sixth grade. (Photo: Rachel Denny Clow/Caller-Times)*

He still had trouble with common things that required him to stand up, so one of John Henry's therapists suggested that he get a wheelchair.

In John Henry's mind, a wheelchair would be a defeat. It would mean giving up a sense of independence and normality. He rejected the wheelchair.

And so, during that January IceRays game, he walked around, took in the arena's loud noises and stood for the national anthem.

Soon after he sat back down, his body gave in.

His mom took him home. He got some rest and realized what he needed to do.

“I got the wheelchair the next week,” Susannah said. “When we went to get the wheelchair, it was a very emotional day.”

Contrary to the initial idea of defeat that it represented, the wheelchair became a tool, one that helped him focus in life and in debate.



*John Henry Stearns was diagnosed with several medical conditions at the age of 16, some of which are rare, and made him think he may have to give up debating. He was diagnosed with Postural orthostatic tachycardia syndrome, erythromelalgia and somatic hypervigilance. He can't stand for extended periods of time and his hands, legs and face often feel as though they are on fire. (Photo: Rachel Denny Clow/Caller-Times)*

“It was such an awakening for him,” Susannah said. “He has accepted the boundaries that his body is capable of doing, but in that journey he’s figured out what his mind can do, which is so much more than most people.”

He also got a therapy dog, Tillman, and learned to manage the best time to use his wheelchair.

The culmination of his journey began in March, when he started debating with his wheelchair.

He found that he no longer had to focus on the pain that standing caused, he could fully put his mind to the topic at hand.

He participated in the National Speech and Debate Tournament's Big Question debate format, focusing on complex societal topics.

At the nationals, John Henry dominated, going undefeated in 13 rounds en route to the championship and a \$10,000 scholarship.

“To finally find those balances in his life physically and emotionally to get him to reach that number one spot is just the cherry on top on all of the work,” Susannah said. “Not just in debate, but in life, to really realize that not only can he be the top in debate in the nation, but that he has learned so much about himself, gone through so many obstacles and can be the best person he can be with the right tools.”

John Henry, and his dog, are set to go to Washington and Lee University in Lexington, Virginia this fall, with a national championship in hand and much different perspective on life than a year ago.

“(All of this) has helped me pursue as much of a normal life,” John Henry said. “And as much a happy life, far more than I could've believed before.”