



The
**Ehlers
Danlos**
Society™

The Ehlers-Danlos Society

P.O. Box 87463 · Montgomery Village, MD 20886 USA
Phone: +1 410-670-7577

The Ehlers-Danlos Society - Europe

Office 7 · 35-37 Ludgate Hill · London EC4M 7JN UK
Phone: +44 203 887 6132

ehlers-danlos.com | info@ehlers-danlos.com

A Patient Perspective

Larry Constant, Jr.

The EDS Global Learning Conference 2019 Nashville

Video https://youtu.be/ljjM_g_8fl4

[00:00:00]

[00:00:10] **Larry Constant, Jr.:**

So, this is my first time ever speaking in public. I was walking around at 3 a.m. last night, writing the speech and editing it, you know, you get insomnia, right? So, good way to burn it off. So, let's see how I do.

Hello, my name is Larry Con— What?

[00:00:25] **Offscreen:**

You got this!

[00:00:26] **Larry Constant, Jr.:**

Okay. All right. Maybe.

Hello, my name is Larry Constant, Jr. I'm 34 years old and have the kyphoscoliosis version of EDS. I'm from New Orleans, Louisiana. I received my diagnosis about eight or nine years ago, at 26 years old. In adolescence, my mother noticed my chest and spine were abnormal and deforming. I was extremely thin, had very loose joints, and so started our very long journey for answers. She was told, "He'll be fine! He seems normal. It's just growing pains"...*et cetera*, as we all know...so, as a result, I grew up with a pretty normal life. I played a lot of sports, got injured a lot, although I was extremely, terribly uncoordinated, easily fatigued, and generally weak. My parents often recount stories of me walking around in the outfield of baseball games, picking up grass, and looking at it in the sunlight, while balls, while balls just rolled right by. I broke bones, I got into fights, I skateboarded, and I played guitar in punk rock and heavy metal bands.

[00:01:27]

In many ways I'm grateful for this because it prepared me for the tough road ahead. After high school I began to get worse. My spine deformity became much more profound, fatigue became relentless, and pain became unbearable. At this time, I realized something had to be done. My mom and I restarted our medical quest. That's my mom right there. Ack. Sorry.

[Applause]

[00:01:54]

We saw a doctor after doctor. Clinic after clinic. I did muscle biopsies for muscular dystrophy, ten EMGS, tons of spinal myelograms, and countless procedures to find an answer. Seven years later, I finally found my answer with a geneticist at the Hayward Genetics Center at Tulane Hospital in New Orleans. He spent a lot of time with us that day and explained EDS to both of us. My mother cried at the joy of an answer, but also at the reality that I was really sick. Johns Hopkins was sent my records, photos, and multimedia, and had many discussions with the geneticists. Two years later, at 28, I now had a version. The kypho version had very minimal information on Google, so I decided to live by trial and error to figure out my limitations.

[00:02:35]

Now, I was really lucky for most of my working life. I have been a freelance audio engineer and an AV consultant for 17 years. I run conferences just like this every day. A job that I have continued to do for over a decade, with this month being my last and final month. This career was very conducive to my lifestyle. I could work like a maniac one week and stay in bed the next. But as I age, 15-hour days standing, running to breakout rooms to fix presentations, and lifting all of this equipment that you see

here has become impossible. I have made wonderful friends who have protected me, forced me to take breaks, and love me for who I am. So, I thank the A/V world for giving me a purpose and life of love and lessons. I would also like to thank the A/V crew here, as they are the unsung heroes of these events and don't get enough thanks. So, thank you.

[Applause]

[00:03:29]

So, now I will tell you about the most amazing lottery that I could ever win. My wife Carly is in the crowd today. My wonderful life has been possible because of her. We, we were together before my diagnosis and have been for 14 years. She's a registered nurse. So, not only does she provide amazing and precious care to me every day, but also to patients and families. I do not know how she does it, but I am so grateful that she does. In a letter I wrote for the society last year for rare disease day, I wrote that I would live in eternity with this illness, as long as I could live with Carly. These words still ring true today. Thank you, Carly. You are my PIC, my partner in crime, and I love you.

[Applause]

[00:04:14]

Over a year ago, we adopted our furry son Winston. Winston has changed my life. He is our half Basset-half Dachshund mix. He had a rough, rough early life. He has PTS—PTSD and severe anxiety from being abused and neglected, but we have helped him to heal and in return, he has helped heal me. He takes very good care of me on my worst days and has no problem with snuggling in bed all day. We could not imagine our lives without him.

[00:04:42]

I am the only person in my family with EDS, but my family chooses to live this illness with me, and I cannot do it without them. My father and I build guitars as a hobby and he does so much work on our house, to keep it going. My mother is my rock and we are extremely close. My brother-in-law, sister, and nieces all chip in to help when needed. We all know the battles: depression, pain, insomnia, dislocations, anxiety...constipation for breakfast, diarrhea for lunch, and vomiting for dinner.

[Laughter]

[00:05:09]

I could go on for hours. Those battles seemed so impossible to beat, but the story I just told you is about the war, my wife and family are soldiers on the front lines, right beside me. I hope this story makes you look at the soldiers in your life. In fact, look around this room. We are a strong

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powerful army, and I'm proud to be in this fight alongside all of you. My mother has never given up on me and it is thanks to her, I got my answer. My father has taught me to be tough and given me strength. My wife has shown me happiness and shines the brightest of light on the darkest days, and all of you give me hope. Thank you.

[Applause]
