

NMOSD WON'T STOP ME: UNSTOPPABLE VIDEO TRANSCRIPT

Christine: Hello, hello!

Christine: Welcome to Houston.

Christine: I'm excited to have all of you at my restaurant. So thank you so much for taking the time and coming here and having a chat with me today.

Christine: Shall we go inside?

Everyone: Yes.

Christine: All right.

Christine: All of our lives are probably very different. You know, we're different ages. We have different paths in life. But we all share this common thing of having NMOSD.

Christine: I just would be curious to know what your story was like and how you felt once you did find out you had NMOSD. So let's start with Kim.

Kim: So mine started with optic neuritis.

Onscreen text: Kim's NMOSD journey began in 2020, when she woke up one morning unable to see in one eye.

Onscreen text: In 2021, Kim had an attack, leaving her feet, legs and chest numb. After months of going from doctor to doctor, she was finally diagnosed with NMOSD.

Kim: He came back with this diagnosis that, "We think you have this, we're going to start testing you with all the Aquaporin-4." And they came and eventually did all the things that I needed to do, you know, from PLEX to everything from a spinal to all, which came out positive.

Kim: It was really hard. It's been very interesting but, you know, I'm still going.

Christine: What about you, Kayla?

Kayla: In March of 2020, I had a tingle in my right leg.

Onscreen text: Kayla's NMOSD journey began in 2020 after the tingly sensation in her right leg progressed until she was unable to walk without assistance.

Onscreen text: After several hospital visits over the course of seven months, doctors finally diagnosed her.

Kayla: Within a couple of months, I went from walking to using a cane, then using a walker. I am now numb from my waist on down. It's very frustrating, but I felt a relief when I actually had a diagnosis because I went seven months with, "What's really happening to me?" And then I had to kind of relearn how to advocate for myself because it was, it was just a really rough time.

Ireland: I'm a childhood diagnosis. When I was six, I started having really bad pain in my spinal cord. And every night I would just scream all night long because it was the worst pain I've ever experienced, worst pain imaginable.

Onscreen text: After two years searching for answers, Ireland was diagnosed with NMOSD at the age of eight.

Ireland: After age ten, I started not having flares anymore. And so it's been around a decade since I've had a flare.

Kayla: Awesome.

Doug: And I started out with vomiting, nausea and then hiccups that were hard hiccups and really painful.

Doug: I have a brother and a sister that have MS, and I figured this was just my time.

Onscreen text: In 2016, Doug began experiencing a variety of neurological symptoms that caused him to collapse while walking and break his elbow.

Onscreen text: Three months later, he was temporarily paralyzed from the neck down.

Onscreen text: He was later diagnosed with NMOSD.

Doug: You know, the thing that helped me through this a lot was the fact that my wife was with me all the way.

Christine: I think it's interesting, Doug, that you said, you know, you got through this because your wife is around. So it kind of brings me to the next point, I want to talk about is the support network. When I was diagnosed, it was and it still kind of is considered a rare disease. I felt like my first health care team failed me, so it really forced me to become my own patient advocate and advocate for myself and be an educated patient. It's very isolating and lonely, I think, experience. But I think it does help, especially when I found other people, patients that are even living across the world or across the nation, and we somehow connected. And I think that was helpful.

Ireland: For me, I felt very isolated when I got sick. Everybody was a stranger to me. All the school house drama just was so worthless to me when I was going in and out of the

hospital over and over again, and I had gained a lot of weight from steroids. My entire self image was destroyed, and it was worsened, I think by, you know, the taunting of other teenage girls.

In third grade, I spent 58 days out of school going to the hospital to the point where we had to drop out to do homeschool that year.

Oh, girl.

I dreamed and prayed every day that I would just wake up one morning and instead of going blind in my right eye, I'd still be able to see again just overnight. And like, maybe that flashy miracle didn't happen. But then there is this slow miracle of being alive a decade later, being well, a decade later, as well as I possibly can be with this condition. And I'm just grateful.

Christine: What would all of you say as a piece of advice to people who are newly diagnosed or first experiencing symptoms?

Kim: I would tell a new person, you know, just continue the answer. You know, continue to push forward.

Kayla: I'm 35 and I was 32, when I was diagnosed. So I'm still here. And even though there's really overwhelming days, try to stay as positive as you can.

Doug: All of us will have NMO until the day that we die. But I think what it means not to let NMO define us is to live beyond that and to look beyond that and, in my case, where there are things I can't do now, look for new things that I can do.

Kim: Also, believing in yourself, you know, and knowing where I come from. I'm strong. I'm a strong individual. I do Taekwondo. I am a second-degree black belt in Taekwondo and at the time, the doctors are saying, "We don't want you to do Taekwondo anymore." I was like, "What? You're taking this away? This is what also has grounded me."

NMO has not stopped me from dreaming and having big dreams and now making them come to fruition. I've got to advocate for myself. I got to do it now, I've got to ask questions. That's what my mantra is. I am my own Wonder Woman.

But it's helped me as well with my journey, learning through people, like Doug, that I met who's, you know, a patient advocate and Ireland and all that. We're in it together and there's not a cure for autoimmune diseases but we've come a long way. Christine, you've come a long way since you've been diagnosed, and I keep continuing to think that, you know, I will be all right.

Kayla: NMO hasn't stopped me from living life. I've had to figure out how to change ways of doing things. Getting out to my parks. Parks that I used to hike or go down the

path. I can't go down those trails anymore, but you can definitely still get out a different way. So any of them with a sidewalk or flatness, I can roll down those and still enjoy.

I always just tell myself, "little steps." And then as it turned out, I'd be like, "little steps lead to big steps." And "better days are ahead" was always something I'd tell myself. If you're having a bad day, it's okay. That's just that day. But tomorrow there's a new day.

Christine: It's so interesting and fascinating for me to hear all of your stories and to be able to relate to a lot of it and to have all of you relate to mine as well. I find this experience empowering. Finding people to be able to have a very raw, honest conversation like the one we're having at this table is a really good connection.

Thanks for coming here and sharing your story and for being very honest and open with each other and myself. It was very much a pleasure to host this conversation with all of you.

Ireland: Thank you for having us.