

TRANSCRIPTION

cpsi Canadian Patient Safety Institute
iscp Institut canadien pour la sécurité des patients
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[0:00:09] It started with just around 12 years of age, fainting. It looked like a seizure. It was scary to watch. There were times that she would stop breathing and her lips would turn blue. And it was very scary. The ambulance came a lot, but we were referred then to a pediatrician and then to our children's hospital, the IWK. And from there, we saw a neurologist. And within the first year, they felt that it was epilepsy so she was on epilepsy medication.

[0:00:40] But within that year or year or so of being on the medication, and it made no difference, they realized it wasn't epilepsy and she was taken off that medication. And around that time, a couple of years after it started, my mom had brought an article to my attention. And it was about long QT syndrome [ph] and it's a heart arrhythmia. And when I read it, the hair stood up on the back of my neck and I knew this is what my daughter had.

[0:01:08] So we brought it to their attention, the neurologist at the IWK. And they did an EKG and did not find long QT syndrome. And so we were a little frustrated because my maternal instinct and my gut instinct was telling me that this is what she had. So we pushed further with it but didn't get anywhere.

[0:01:28] And a little while after that, she did have another fainting spell where the ambulance was called and at the small clinic in Wolfville, they found the presence of long QT syndrome. So we brought that back to the children's hospital and said, "See, here we go." And they said those little, small hospitals don't know what they're talking about. So again, we're stuck.

[0:01:57] And so Jessica continued through high school to faint, and it looked like seizures. It was very scary to witness. And not long after that, we changed neurologist. We asked to switch because he wasn't listening to us. So we did get the head neurologist at the IWK. And we pushed for more testing and they did a full workup and they did a stress test, an echo, another ECG, and Holter monitor, and they went through that and it came back negative. We were shocked. We thought for sure they were going to find it this time.

[0:02:31] So she is 17. And with the last appointment we had at the IWK, the head neurologist told us – he looked at Jessica and he said, "Jess, you need to go home and

learn how to breathe through this. This is psychological in nature. There's nothing wrong with you." And he looked at me and he said, "Don't waste your money on an ambulance."

[00:02:54] We were very angry and we went home. And within the next few months, Jess would come to me and she said, "Mom, my heart's not right. It doesn't feel right." But I didn't know what to do because we had workups several times. We had been told that that she didn't have it. I wasn't sure where to go at that point either.

[0:03:14] And about nine months after that last appointment, she died of long QT syndrome. It was highly treatable. That was a very, very difficult day. \$14 a month medication, best-case scenario. Worst-case scenario, and ICD, which is a defibrillator. That's it. So with long QT syndrome, I think they knew right away, too, it was long QT because it's a genetic issue, syndrome. And so all of us had to be tested. And it was several weeks before we found out that my husband was a carrier, unbeknownst to him. He'd had no issues before.

[0:03:57] The medical examiner stated point blank to us that there was no reason that your daughter died. She should still be living. There were many difficult days in those months, but these type of days were so difficult.

[0:04:12] The medical examiner's report, we found that the one ECG that was positive for long QT syndrome should have been diagnostic. And so we really wanted to meet with all the doctors again, and they really stonewalled us, the CO's office, and we were unable to meet with them. They would not give us a meeting after the ME's report, with the physicians. Because we had many, many questions. We wanted to know what had happened and why it had happened. And we also wanted a guarantee or reassurance that they were actually taking steps to make sure it didn't happen again. That is how we find meaning in Jess' death. And we were denied that. We were denied that many, many times. And when those meetings were not forthcoming after the medical examiner's report, we decided to sue, because that is the only avenue that's open, the only recourse. No one would talk with us. It was so frustrating. We didn't want to sue. We wanted answers.

[0:05:10] I clerked for the lawyer. I spent a lot of time, word for word, everything through. I found discrepancies. I found mistakes. For instance, when I met with a cardiologist, he had requested four tests. And we had those four tests done. But we found out that one of those tests, he had never even looked at. It was sitting gathering dust in our GP's file. Unfortunately, our rural hospital where we had that particular test done, their policy was to only send results to the GP and not the requesting physician. And subsequently, that policy was changed after Jess' death at our small hospital. And thank goodness, because when you think about it, my daughter died in part because of misplaced paperwork? That's not good enough. That is beyond reproach.

[0:06:09] But all of these tests were looked at post mortem for the medical examiner's report and found to be positive. They were misread. There was a study done with the study

done with the cardiologist, GP's, and electrophysiologist top guy when it comes to electrical issues with the heart. And the study shows four ECGs; two have long QT syndrome, two do not. And the study gave these four ECGs to about 1,000 physicians, cardiologists, GP's, and electrophysiologists. It was found that cardiologists correctly diagnosed from the ECG long QT syndrome less than 50% of the time. The study concluded that until such time that cardiologists were retrained, only electrophysiologists should be diagnosing long QT syndrome.

[0:07:04] Litigation was an extremely difficult process to go through. I produced a video about Jess' story, and when that was picked up by the media and the IWK was asked for a comment, it was at that time, 18 months after litigation, that they finally granted us a meeting. And in that meeting, we asked the CO, "How many times before litigation did we request a meeting?" And she hedged a bit. And we said, "Was it more than five times?" "Well, yes." "Was it more than ten times? More than 12 times? More than 20 times?" And the physicians' jaws dropped open. They had not been told that we had requested meetings with them. And I knew what they were thinking. They were thinking, "If we'd actually spoken to this family, we may not have needed to go through litigation."

[0:07:55] One physician was very forthcoming, and we certainly could see the remorse in his eyes. When he realized that the changes that he made, how he practices differently now because of Jess' death were gifts to us, he was tripping all over himself trying to show us how he had changed, how systems had changed, how he was diagnosing differently and what he'd done differently to prevent this from happening again.

[0:08:20] A few months before we had that meeting, five years after Jess' death, I applied to become a member of Patients for Patient Safety Canada, a program of Canadian Patient Safety Institute, and I was accepted. I felt that Jess was tapping on the shoulder and pushing me forward. Because Jess, she was a champion of the underdog. Social justice was her thing. But she loved people. She took care of people. If that was said once, it was said 100 times at her funeral by her friends, "She was always there for me. She took care of me. She needed me. She knew just what to say." And she was actually just about ready to graduate from high school when she passed and she was enrolled in a program for child and youth counseling, which she would have been fantastic at.

[0:09:10] But there's always a cloud. As happy as I can be in the rest of my life, there's a cloud over me and over my husband that most people don't understand, most people aren't willing to accept because of their uncomfortableness with our pain. This Jessica-shaped hole will always be here. Doesn't mean that I can't live well. But it's a part of me. It's a part of my story, my husband's story, my family's story.

[0:09:44] Physicians need to listen to us, really listen to us. We know our children best. And they need to continue to look for a diagnosis instead of prematurely stopping. They need to know that they're human, that they're going to make mistakes. And it's what they do with those mistakes that is important. It's a cultural shift within medicine. And it's going

to take a lot. It's going to take a leap of faith for physicians. It's going to take great courage on health care's part, but I believe it is so worth the leap.

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