TRANSCRIPTION
Audio time: 0:07:24
Claire inspires change after her passing.mp4

[00:00:06] Claire was born with a genetic condition known as trisomy 13. So you have three number 13 chromosomes. She had severe developmental delay. She did walk. She required 24-hour care. She communicated through the use of pictures. Ninety-five percent of these children die before the age of one. If they live beyond that, they're considered a long-term survivor, which Claire was.

[00:00:36] In March of 2008, my daughter, who was then nine, was diagnosed with a malformation in the back of her head, which was causing her spine to disintegrate. We needed to do surgery, and the surgery was a very planned event. It involved surgeons, neurosurgeons and intensivists and anaesthetists and us as Claire's parents. Claire had her surgery to correct the defect in the back of her head, which was definitely needed. If we didn't do the surgery, she would become paralyzed. Her spine would disintegrate over the course of the year. So we really had no choice. It was an urgent thing.

[00:01:17] The plan was she'd go to ICU or the PICU, the pediatric intensive care unit, and she would stay there for seven days. She would remain on a ventilator in a very deep sleep. After an apparent successful surgery, she went to ICU. We enjoyed about 12 to 24 hours of good readings on the sensors and some relief on our part. But by the time we got into day two in the ICU, we were in trouble.

[00:01:44] Claire initially developed pneumonia, probably from the endotracheal tube being very high in her neck and some secretions getting into her lungs that should not be there. That pneumonia was appropriately treated, but it did set her back a little bit. That in and of itself probably wouldn't have been a problem. Claire remained in the ICU for 16 days after her surgery, and at that time, we consented to withdraw the ventilator that kept her alive and she died.

[00:02:15] Initially, we thought Claire's care in the ICU was as it should be. But after the dust settled, we came to realize or I came to realize something didn't sit right. So I did some research and realized that Claire may not have been cared for in the manner in which I had wanted or needed her cared for.

[00:02:38] The Eastern Health was very receptive to a discussion with my husband and I. They listened, they wrote, they went away and they thought about it, and within 24 hours we were notified that there would be an external review into Claire's care.

[00:03:01] The review of Claire's chart and chatting with the people involved by those from SickKids revealed that the ventilator management fell below the accepted standard in a pediatric intensive care unit. Her death was precipitated by an abrupt rise in carbon dioxide. And what I had found out, which led me to bring the issue to Eastern Health and what the reviewers confirmed, was the most common cause of an increase in carbon dioxide is a blocked endotracheal tube.

[00:03:31] What do you do when you have a blocked tube? You pull it out; you replace it. The reviewers questioned as to why that was never done with Claire. The review found Claire's death to have been preventable, and that finding was accepted as such.

[00:03:47] The period of time leading into the review process and during the review was a very challenging time in the pediatric hospital within Eastern Health. Tensions ran high. They were very hurt that I had questioned their care of Claire. They were devastated when Claire died. It was one of their own. They felt that they had done everything they could. They were frustrated with me that I didn't see that side of things. As the mother, I needed the answers. My husband and I both needed the answers as Claire's parents. But as a nurse, I needed answers as well. I still worked in the same critical care division in which Claire died. I needed to feel comfortable that we had done everything we could for Claire.

[00:04:41] Once the review was launched and the review findings were back, everything fell apart. The ICU was devastated with the review findings. We were devastated with the review findings. It was the worst possible result. I stayed for a year. I gave it one full year after the review findings. And the frustration, the sense that I was ungrateful, it was palpable at times, so I left.

[00:05:26] There was a change in senior leadership within Eastern Health during this process. And Vicki Kaminski took over the new role. And she became the point person, the contact person within Eastern Health for questions, comments, concerns, and moving the review recommendations along.

[00:05:53] She was great support to Dave and I, my husband and I. She listened. She heard us out. She offered her thoughts. She probably heard things she didn't want to hear. But she listened to them anyway and took it all in. She met with the ICU staff. She had a forum with them, you know, “Tell me what the problems are. Tell me what your concerns are,” was very much her approach at the time.

[00:06:18] Vicki is a nurse by background, and she did apologize for Claire's death. And it wasn't, “We're sorry Claire died”; it was more along the lines that, “Claire died because of us, not in spite of us. And for that, we really are sorry.”

[00:06:29] One of my apologies came from a front-line nurse who spent many an hour at Claire's bed working very hard to keep her alive. And her apology was, “If I have done something that unknowingly has contributed to Claire's death, I am really sorry.” And for me, it's so important because I sat there thinking, “Wow, I am so privileged to have had this nurse look after Claire.” This was about reviewing the case, seeing if everything was or was not done as it could and should have been, and then learning from. It was never about blame. Would I do it all again with Eastern Health? Yep, I would hand Claire over to the same people.

END OF TRANSCRIPT