

TRANSCRIPTION

cpsi Canadian Patient Safety Institute
iscp Institut canadien pour la sécurité des patients
Sabina Robin
Patients for Patients Safety Canada

[0:00:06] In April of 2004, I lost my fourth child, Mattea, at seven months and 23 days old. She suffered from an intracranial hemorrhage less than 40 hours after being admitted to a Calgary hospital. Four days later, we disconnected the life support and held her as she took her last breaths, a lifetime's worth of love and laughter silenced because someone wouldn't listen.

[0:00:28] It was a typical Sunday at the Robin household. I'm rushing around like a mad woman trying to get four children and a husband off to church. And I go and get the baby, Mattea. And I see that she's got what I think is an ink spot just below her nose on her cheek. And so I kind of do that quick little dap and, you know, it's not coming off. And I noticed that she had quite a bit more bruising. So she had bruising not just on her knees, but she had bruising on her abdomen, on her back. There was a little bit of bruising on her ears. And I just knew, you know, just being a nurse, that this was not good.

[0:01:15] And I was on the road phoning the doctor. He was just like, "No problem. Meet me at the clinic. We'll see her as soon as we get there."

[0:01:22] We learned that Mattea had ITP. ITP is idiopathic thrombocytopenia, so in short, it means bleeding from an unknown source. So it was a huge concern. He was sending us to see a pediatric hematologist in Calgary, which is an hour away, within the hour. He's willing to admit her onto a pediatric ward. And now she really wasn't nursing and she wasn't eating at all, which was rare for her because she was a very good eater.

[0:01:57] So then the resident came up – it was probably about 45 minutes later – and kind of assessed her and looked her over and she goes, "No. She's all good. There's nothing wrong. She's fine. Just carry on."

[0:02:13] And she started violently vomiting and she was just becoming more and more lethargic. She was starting to whimper and whine and cry, like, when you touched her. She wanted to be held, but as soon as you held her, she would cry.

[0:02:30] So I rang the nurses and I said, "Listen, I need to see the attending." And they're just like, "Well, you know, we can send up the resident." And I said, "No, I don't want to see the resident." I was just, you know, upset that they, you know, they weren't really listening to me. They didn't do any more extra monitoring.

[0:02:51] They did call the resident in. she basically doesn't want to do anything. She says, "You know what? She's got gastro. We realize that she has this ITP, we're not going to do anything more than what's ordered," which was the prednisone. "And no, we will not start a line. She does not need it." I said, "I think we need to do something more." I was pushing for it. And she was just like, "Well, you can discuss that with the specialist in the morning." And I said, "I think that's going to be too late." And she just promptly left.

[0:03:35] Whatever I said just was not sinking in, was not, you know, seemed to be computing with anyone. And it was sort of a long night. She still was just very lethargic. She was becoming more and more unresponsive.

[0:03:52] And so I rang for the nurses and I was just like, "You guys, you need to do something for her. She's dying." And they were just like, "You know what? Mrs. Robin, you know, you're tired. You know, you really should try and get some sleep." I said, "You need to call the attending, like, right now." And they were just like, "You know what? If you think that you need to see the resident again, we will call the resident, but we are not calling the attending. We're not calling anybody else." I was just like, "You know what? This is crazy. I'm done here."

[0:04:32] And so I was going around the room and I was like, starting to pack up all my stuff. The resident comes in and she said, "Where do you think you're going?" And I said, "I'm leaving." I'm like, "We're going." She was just like, You know, Mrs. Robin, you're getting out of control here. We are really doing the best that we can for your daughter. There is nothing really wrong with her at this time. She is sleeping." She is unresponsive. She is dying. I said, like, "Look at her." And she goes, "I am not waking her up to do an assessment on her."

[0:05:06] After weighing my options, I decide that perhaps that it is in Mattea's best interest that we stay. And she started to cease. I called the code in room and they all came, coming into my room, the resident that was there previously, all the nurses, but it was like a gong show. I was just like, "It's too late. It's too late. Like, we got to go." And he's like, "Where do you want to go?" And I was just like, "We got to get her to the children's hospital." And he's like, "We need to get a CAT scan. We need to know what's going on." And I'm just like, "I know what's going on. I told you guys, like, 12 hours ago what was going on. She's bleeding and we're waiting." And literally, it took over four hours for them to transfer her out from the Peter Leahy to the children's hospital.

[0:06:00] But once we got to the children's hospital, there was like literally, there is a team of 13 doctors and nurses and they just they took her and they worked on her as the hours ticked on. Her intracranial pressure was creeping higher and higher. And they had already put a tap in to drain the extra fluid, but it didn't really seem to make a difference.

[0:06:25] Then they wanted us to remove her off life support.

[0:06:32] I just wanted to have my daughter's life mean something more than just her death.

[0:06:38] I worked with three other physicians, and together we developed an order set for ITP. And so an order set is something that comes up when there's a diagnosis. And so it automatically comes up on the computer and it says, "Okay, this is what ITP is, first of all. And so these are the things that you're looking for. This is what it looks like. And these may be some of the medications that they may be on or need to be on." We developed a guideline for ITP for when children were to be admitted to a hospital. Before, it just seemed like there didn't seem to be any sort of checks and balances for medical residents when they were learning how to practice.

[0:07:29] What it's led to is now, residents have that sort of safe space to feel like they can call in the attending physician without feeling chastised or feeling like they're being incompetent. I went from there to the Patient Safety Council to becoming a WHO member to working here with Patients for Patient Safety Canada. And it sort of has become sort of my daughter's legacy.

[0:07:59] It is important for organizations to recognize that they can inflict a second type of harm onto patients and families when they don't step up and acknowledge the responsibility and the accountability that they've had in an adverse event. I just think it's important for them to sort of recognize the importance of taking on that accountability, responsibility. It just promotes that healing. And it also it provides that opportunity for lessons to be learned. And I think at the end of the day, for families, that is the most important thing, the lessons to be learned. They just want to go forward with their lives, but they want to know that they've done everything in their power to make sure that it doesn't happen to another family.

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