KAWASAKI DISEASE Olivia's story

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I'm Olivia and my Kawasaki Disease story started in 2018 with my son Luca, who was three at the time.

He'd been complaining of feeling unwell after a bonfire night, and he had a very high temperature, and he was generally just not himself. He spent a day just very unhappy and eventually his breathing started to get quite erratic.

So we went off to hospital and I stayed with him waiting for another seven hours, to be seen to be told that he'd probably got an ear infection. So we got some antibiotics, went off home and were told by the doctor that if he had another high temperature, to go to our GP. We were home, two or three hours, and his temperature had gone back up again. So I took him straight to the GP, who actually told us that there was no sign of an ear infection.

So she said it might be a viral infection and just to keep an eye on him, give him Calpol, ibuprofen, everything that they say to give children and he seemed okay.

Then the next day, which was a Wednesday, he still had high temperature. He started to have a rash over his chest and he generally looked unwell. He had a red tongue and the most obvious sign was his bloodshot eyes, they were so red. I started Googling it and the first thing that came up, you know, three year old child, Bloodshot eyes, Kawasaki Disease, which I'd never even heard of.





So I went back to the GP and this was a locum doctor. Looking back, he probably did save his life because he could see that he was unwell and he thought he had meningitis. He phoned up the hospital and said, I've got a three year old here that needs to come in because he's unwell.

So we got to the hospital, eventually got seen by a consultant. He was in hospital overnight, and the consultant the next morning was like, it's Kawasaki Disease. We need to treat him.

I think, when they'd set him up for the ECG, it was at that point that I then realised there was this potential complications with the heart, which I'd not really read about. That all came back fine.

They started the [IVIG] drip, and everything was fine. I sent my husband off home. It was quite a strange thing how quickly the antibodies kick in and makes them look and feel better.

And it wasn't until the Monday evening that they were like, do you know what, we can send him home, his temperature is fine.

The next day, Birmingham Children's Hospital phoned us up and said, can you come in, like within the next couple of hours, we're going to do an echo [echocardiogram]. So we went in and luckily, there was no damage. His arteries were just slightly enlarged, which they said was normal.



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He had to spend six months on aspirin. Trying to get aspirin in a child that doesn't even like Calpol was, pretty difficult, because it's trying to find things to hide it in. Eventually, we realised that hiding it in apple juice was the way forward. So anybody with fussy kids, apple juice is the way forward on that one!

And he had an echo every six months, which was fine, then it became a yearly thing. And then by last Friday, we had a two yearly check-up, and everything was fine.

So he has to go back in three years time when he'll be 10. He will have a CT [scan] of his arteries, and then heart stress test, just to make sure that everything's okay. If it's okay, then he will finally be discharged.

I think with Luca, it's shown that he's come out the other side of it, and he's gone back to being a normal little kid. He has the odd day of aches and pains.





But Kawasaki Disease is not the end of the world. And I think that's important to stress. Because if you get seen by your doctor, then you can carry on living a normal life which Luca has done for the past four years. And you could meet him today and you wouldn't think he's affected at all.

And I think if we hadn't had the locum doctor to say, you know what, something's seriously wrong with this child and he needs to go to hospital, then maybe the outcome could have been much worse. So, it's not the end of the world, because it does get better.

If you'd like to listen to Olivia's family story podcast you can do so here.

