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How did Paxton's cancer journey begin?

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So we had gone to see Santa in December of 2017, and just a normal day, went and stopped at a restaurant and and I had pulled Paxton's hair behind her ear and thought, oh, that that looks like a bump on her kind of on this, this part of her ear, and that was on a Saturday, and on a Monday, I had called our pediatrician, and she we couldn't see her, but she said, after school, go to a walk in clinic and just let a doctor take a look at it. And so they prescribed an antibiotic. Didn't know what it was. It was probably maybe the size of a pencil eraser in that space, maybe a little bit bigger than that, but yes, so they prescribed antibiotics. And then she called and said, well, we don't, you know, not sure what this is, but we don't really take any chances. When you see something like this on an ear. So I want to get you into see a ENT, and that was set up for like, three days later. So we went and saw that, that doctor, and he he wanted us to finish antibiotics, and he added steroids. He wanted to see us in three weeks. And so over the course of you know, then it's Christmas and you're doing all the things, and it was getting bigger. And so I called before two weeks was up, and said, This is getting bigger, and I think we need to come see you sooner than three weeks. And so we went back in and he said, I've never seen anything like this? In the 26 years I've been practicing medicine, and I think you need to go see a new doctor.

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So so that ENT sent us to go see a new pediatric ENT at TTUHSC, and when Dr. Idicula, we had to work through some insurance issues, but when he finally got to see her, he thought it was a cyst, and he said, the chances that this is cancer are so rare, it's not worth mentioning, but we will, we will test it, when we remove it, we'll do surgery and remove the cyst. And when we went for the follow up visit a week after surgery, he had results that said it was rhabdomyosarcoma. And the next day, we were in Dr. Al-Rahawan office, he's the pediatric oncologist. And from there, it was just a flurry of tests and scans to determine, was this the primary site there, in her ear, or did it start somewhere else? Had it spread just as just to know the scope of what we were looking what we were facing, and they came up with a treatment plan and and then we were busy doing what we needed to do.

Can you tell us about the specific cancer Paxton had?

3:06

Yeah, rhabdomyosarcoma is a is a rare muscle cancer that is typically not found up in your thoracic region. So Paxton's ear, the cancer was found and that were meta, not metastasized, but it started behind her ear. And the good news having a muscle cancer back there is you don't have a lot of blood flow in that muscle, so it didn't have a lot of opportunity to to to go elsewhere. And so that was really a blessing in how it was found and where it was found.

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What and where was the treatment process?

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The first, first thing was, it was they did not have clear margins, so they hadn't gotten it all. So we had a second surgery, and that's when they discovered that it, it hadn't started here. It was actually originated in the muscle behind the ear. So in that surgery, they installed a port so they could deliver the chemotherapy. They did a bone marrow biopsy, and then they removed a little more from her ear. And thought, thought, actually they might have to take most of her ear in that surgery, so they would just cut, test for a clean margin, continue cutting as they went through until they felt like they had gotten it all. So that was the second surgery, and then we were supposed to start chemotherapy. A week after that, they wanted to, they needed to hurry and start the chemotherapy. And they found out they still didn't have a clean margin and wanted they scheduled us for a third surgery. And as we're talking through the treatment with with Dr. Al-Rahawan, one of the benefits to teach you, HSC is part of a National Children's Oncology Group, and that's like 250 50 oncology groups that are focused on childhood cancer, and they all share all of the information, so all of the treatment protocols are the same. If anyone sees that, there's a best practice in some area, it all gets shared. And so I think the only organization that's outside of that is St Jude's. But he said, if y'all want a a second opinion, we went to Cook's children's, and the oncologist we saw there confirmed everything. Dr. Al-Rahawan, told us she had actually just come from St Jude's. She called her colleagues at St Jude's. They aren't doing anything different treatment wise for this kind of cancer and so, and she also, she also said, you don't need a third surgery, because you're never going to get a clear margin. These cancer cells are scattered, and there's no there's no getting it all with surgery. You have to have chemotherapy and radiation, but the radiation will will take care of all of it. And so we came back to Lubbock after that second opinion.

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So that was our second opinion. And all of the care could we could get here in Lubbock, except the proton beam radiation, and there were two places in Texas that offered it.

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Dr Al-Rahawan's preference was MD Anderson in Houston, because they were the they were the creators of that technology. And so anyway, we did 20 weeks of chemotherapy. And in the middle of that, the protocol was, you, you complete 10 or 12 of those sessions, and then they start the radiation at that point in the in the treatment plan. So we moved to Houston for two months to have the radiation, and that was 28 days, five days a week, you do the radiation, and then once the radiation was finished, we came back to finish the rest of the chemo that was remaining. So, so all said we started chemo like March 20, and our last chemo was like August 14. So that was the treatment, you know, is this really short, but it was really just chemo after chemo, really intense.

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How important was it that you all experienced this together?

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I think, like having the people I was closest to was just comforting, like I knew that, like, even though it was like, harder, I would still have people that, like, were willing to, like, sit with me in my pain and stuff.

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Well, I think, I mean, our family is very close, and the timing of having to move to Houston was such that school was out. Paxton hadn't been going to school for two months because of all of the treatment, but our whole family, because the radiation was starting at the beginning of summer, our whole family got to go to Houston and live in Houston together. George didn't have to stay here and maintain family life here for him, for him and Payton and I didn't have to navigate all of the getting back and forth and doing all of the treatment for Paxton by myself, and so that was really a blessing for us.\

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When we were in Houston, we didn't know anybody there. It was just really us four in an apartment and in the hospital, in the clinical spaces where we had to be.