

Kirkland Family 2/2

Can you share some of the challenges you faced with Paxton during and after treatment?

0:06

I think, probably the biggest challenge for for your child and for taking care of your child well, when they're when they're doing the chemotherapy and the radiation is especially, she was seven. They're so young, they don't understand. And there is nothing pleasant about having to force your child to take the medications that are necessary and and we did not the kind of chemo we had. A nurse always gave the chemo through her pork. So I was never giving her the medications that made her so sick. We were just responsible for giving all of the medications to try to keep her from being so sick. And so there were, there were, there were lots of battles just to get the medications down. If you're so nauseated that you can't, you can't even smell food, and you can't even think about swallowing something, and yet you have to take five or six pills at a time. It's just, it's just a hard that's just a hard every day, every six hours, thing to walk through with a kid.

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1:16

Think the other thing she lost that was harsh is Paxton lost so much weight during all of the chemotherapy that she she was pretty weak, and in the chemotherapies that she was on caused nerve damage, and that led to what they call drop foot so the nerves in her in her feet, wouldn't fire correctly every once in a while and so her foot wouldn't pick up, and then she'd just, she'd just be walking across the floor and just, and just fall on her face. And so we had to be careful about about falls.

Do you remember anything you did enjoy eating at that time?

1:56

In Houston. I mean, that's really the part I remember, is just the pancakes were really like, the only thing I would eat, if I would eat anything, and then the pickles, well, so Paxton. Paxton was writing about it a couple years later, and what she wrote in this, this essay for her teacher. Do you remember writing it? No, I don't know what you're Oh, she wrote that all I would feed her in Houston was pancakes, and she wanted something else to eat besides pancakes, and that's all I would give her. And the real story was she wouldn't touch anything else. Pancakes were the only thing she would eat. And so that's what I I mean, that's what I offered her every time I offered her food.

(continued)

2:37

You're trying to get calories in, she'll say yes to a pancake. You can have pancakes anytime you want them.

Kirkland Family 2/2

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So I forgot what it's like, exactly called, but like, when you're, like, getting your pork flushed, flushed, like, for me, it like, sent a really, like, awful flavor, like, up my mouth. And so I could just, like, like, eating a pickle, since those are, like, so strong that kind of just took it, took it away, took that flavor. And so the nurses that was they she was the only one they'd had who would eat pickles they had. They would offer suckers, but those flavors weren't strong enough to kind of disguise that taste. And so we would take pickles with us every time they had to.

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3:23

Every time we'd go into the hospital or doctor's office or anything, we would show up with our zip lock full of pickles, and she would eat a couple of best maid dill pickles to get ready to have that port washed and flushed.

What are some positive things you've taken away from this experience?

3:39

When you're in the middle of it. And there are times where you feel like it's life and death, and we you know that, hey, tomorrow is not necessarily promised. But when you when you come out of it, and you've kind of walked through that together, specifically with us as our family, there's been a couple of times that, uh, that you look back on it, and we've articulated as a family that, hey, we would never want to do that again. We would never wish that upon anybody. But at the same time, we wouldn't trade it. That's a hard thought to think about that, but you wouldn't trade having gone through that, and for for the closeness that it's brought. And then the other thing is, is the enjoyment of regular life, things, we're able to celebrate some of of Paxton successes, you know, bigger and more joyfully, because you you sometimes can remember that those negative times and and how hard that was, but, but so I would say that we've acknowledged that, that that we wouldn't want to do it again, but, but we're glad we went through it. We've come through the other side and thankful for, for, for the strength that that has given us.

How do you feel about Paxton being too young to remember most of the cancer treatment?

5:00

You know, she was seven when she went through that. And when, you know, if you think back to your life, you don't remember everything for when you were seven, either you you probably have some great memories of good things, and you probably have some memories of some things that were challenges, but, but the blessing of that for Paxton was she, she doesn't relive any of that. And so, yeah, I would say that that really is a blessing that she doesn't have all of those memories. And for when her mom was telling me years after, when she read that thing about the pancakes, that that was kind of one of her biggest memories, we just kind of like, oh,

Kirkland Family 2/2

wow, how great is that? That that's what she's remembering, and she's not remembering a lot of the other things.

What has follow up care looked like for Paxton?

5:43

Once we reach the five year cancer free mark, we go once a year and under the care of someone in Dr. Al-Rahawan's office, who is the survivor part of the survivor group. Up until the five year mark, we would see Dr. Al-Rahawan, the visits, the follow up visits. The first year we went well for a long time, we went once a month to see him, and we would have all the scans done every three months. I think that lasted for a year. It might have been two years, but we had scans for two or three years, and then the the visits tapered off, the further away we get from from treatment. So right now, we're at once a year with Dr. Al-Rahawan's office, and then we go twice a year. The only, the only effect that we have following all the treatment is that the radiation damaged her thyroid, and so she has to take a thyroid medication, which requires going to see an endocrinologist a couple of times a year to manage the correct dosage. That you know that's a small that's a small little inconvenience in the road, there's lots of people who have to take thyroid medication.