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May 30th, 2020

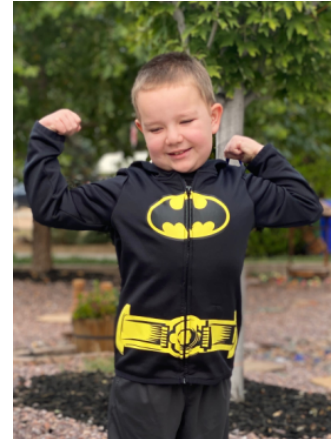
Isaiah

How old are you now?

I am seven.

What grade are you in?

I am in the first grade. I am going to go back to the first grade again. I will have the same teacher. The school is right next door to our house. But school is out now. I still do some schoolwork to practice.



What kind of shows do you like to watch?

I like superhero shows. I like the Hulk.

He then showed me all of his superhero pillows.

What do you like to do for fun?

I like to do stickers. I like to play Nintendo. I play Mario Party and Super Smash Brothers. I play with my mom and dad and Gramma and Papa.

Have you learned how to ride a bicycle yet?

I have one at my Gramma and Papa's house, but it still has training wheels. I get to go see them a lot. Gigi (great-grandmother) lives next door to Gramma and Papa's house.

Talking with Leah (Isaiah's mom)

How is health now?

He is doing very well. He just goes in for routine visits now. His doctors are also being very cautious with his sister. They did a fetal echo, and one before she was 24 hours old. They want to do another follow up before she is a year old. She is now 8 months old. Because the hospital is so far away, I am trying to schedule both of their appointments at the same time. In terms of stamina, he seems to pace himself very

well. He doesn't wear himself out. We haven't had any issues with neutropenia since he was a baby. We are very fortunate to have such a great team of doctors at Phoenix Children's. His geneticist is wonderful about connecting me with parents when their child has been diagnosed with Barth syndrome.

Have you met other families there?

We did meet one family once. Life is just crazy right now with COVID-19. I am hoping this craziness will be over soon so we can get connected. We text each other very frequently. I am glad I have had a chance to be there for the other mom as she gets accustomed to the diagnosis. It is very overwhelming and scary at first. It's good to have someone you can call upon when you need them. I am glad to be that person. We also know another family who has three boys who have been diagnosed with Barth who live nearby. I'm not sure if they are followed by the same doctors that we see. But I do hope that we can get together sometime.

What would you tell a new mom?

I realize I can't say everything is going to be okay, but I can offer experience. It is scary. You second guess everything you do at first. You don't know what you don't know. For example, when Isaiah was a baby, we were told he had to eat so much food. When I look back at his pictures now, I realize he was being overfed and now know that isn't good for a child with Barth syndrome. But I didn't know. I remember feeling so guilty about that, but I didn't know. I think it is important for a parent to be encouraged and given some insights about questions they should ask. It's nice to offer leads to other doctors when a parent is in need. I can't imagine what I would have done if it wasn't for BSF when I was just learning about Barth syndrome. It was such a blessing. And that is what I have told the other family that I have been talking to. Right now, it is scary. That will pass. But this is the community you need because these are the people who can help you. Hang in there.