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## JULES

### Interview with Jules' mom (Valerie) during COVID-19 quarantine

#### How old is Jules?

He is eleven.

#### Is he back in school?

School is scheduled to begin next week. The experts are optimistic but as his mother, I'm not really quite sure what to think. We'll see. It's mentally exhausting to work and teach your child at the same time. He often tells me *"You are a bad teacher, but you are a good mama."* What we are learning is the need to go back to school is more for the psychological well being of the child. It isn't good for them to be so isolated. I am concerned that it will be difficult for him if school doesn't soon return.



#### How does he do with school?

It's difficult for him to pay attention. He suffers with dyslexia. Handwriting is difficult for him. He enjoys reading. Right now, my greatest concern for him is his education. His health seems stable, he seems to struggle with some subjects in school.

#### How was he with school before quarantine?

He liked it because he liked the socializing. His teachers have never said that he doesn't do well in school. He has a small circle of friends at school that he enjoys spending time with. He has kept up with his friends from school through video meetings, but it doesn't take the place of face-to-face interaction. He is going to go to secondary school when he is twelve. We will have to select courses such as mathematics and science. That is very much on my mind.

#### Is he still using a feeding tube?

Yes. We considered the surgery for him to have a G-tube, but he prefers to have the nasogastric tube. He doesn't feel hunger. So, he still needs to the tube. A couple of

weeks ago we had to increase his enteral feedings because he was not gaining weight. His appetite fluctuates quite a bit. He will eat tiny amounts of food but not enough of what he needs to thrive. It is quite a problem.

I would be nervous if he didn't have the tube. I think it is better for him to have his four feeds through the tube every day. I know he is getting the nutrition he needs. He has energy to do things that I don't think he would have otherwise.

When we are home and go to places where people know him people are aware that he has the tube. No one asks questions. When we go elsewhere, people stare, and little children will comment about it. It bothers him. I think next year he will be ready to go through with having the J-tube before school starts.

### **Is he small statured?**

He is a little smaller than his peers, but he isn't as small as most of the children with Barth syndrome. He always followed along in the growth curve. I would say his greatest challenges with Barth syndrome would be feeding and neutropenia.

### **Are you noticing he fatigues with school now that you are working with him from home?**

That is difficult to say because he will yawn a lot when we are doing a lesson but after we are finished, he seems to have more energy. But I read somewhere that yawning is the body's way to restore oxygen to the brain. He does seem to be in a fog quite often. I do notice there is a difference if we take a break and come back to his lesson. He will work on a lesson for a short while then he will take a break and then come back. He does well with these short breaks.

### **What does he enjoy doing for fun?**

He enjoys reading. He enjoys reading Harry Potter. He enjoys reading The Adventures of Tintin, a comics series by Belgian cartoonist Hergé. He enjoys watching movies in the evening. We have Netflix. He enjoys selecting a movie to watch in the evening.

He enjoys listening to music. He really likes a French group called Kids United. He also likes the Beatles. He enjoys reading and listening to music at the same time which is interesting because I can't do that. We recently went to a concert. We thought he would enjoy that because he likes listening to music at home. It didn't go well. As soon as the music started, he was ready to go home. The music was too loud. He plays the video game Minecraft.

**What else would you want others to know about Jules?**

He is eager to learn. He likes to go to museums. He likes learning about civilizations. He is a happy boy. He doesn't like talking much about Barth syndrome.