
MEET RAPHAEL

How old are you now?

I'm eleven.

Tell me about school.

I am in grade six. I enjoy eating with my peers most of all.

What foods do you like?

Hamburgers, chicken nuggets, French fries, potatoes, pancakes.

Raphael's mom: He hates fruits and vegetables. He won't even try different foods. He will pretty much eat meat with potatoes and pasta, and will add pesto and parmigiano to everything! He will eat yogurt because I beg him.

I'm sure you miss seeing your friends at school.

I do miss going to school. I do my schoolwork with my mom and see my classmates on the computer. I have many friends in school. They are understanding and willing to help me if I need help.

Do you tell your friends you have Barth syndrome?

I don't mind talking about it. When we are playing sports, I may need to stop. I would tell them I have a disease that prevents me from doing sports too fast or push myself too much.

Raphael's Mom: He started a new school this year that goes from grade six through grade ten. He is friends with everyone. He doesn't have one particular person that he is friends with. He has one friend who is bit taller than him. She would carry him on her back if needed.

Are you still playing the piano?



As I am practicing more, I enjoy playing more. I started playing three years ago. I also started to play the guitar in September, after Travis came home and began to show me how to play.

What do you really enjoy doing?

I like swimming, biking, sleeping and I like playing video games. Our family went biking this past weekend. I was on a tandem bicycle with my dad. We got the bicycle about two years ago, but this was the first time I was big enough to ride on the bicycle. I loved it but I was really tired at the end of the day.

How would you describe what it feels like to be really tired?

When I get tired it takes more energy for my body to move.

What did it feel like after you went out on the bike ride?

It felt like I was in a fog. I kept forgetting things. I had to lay down on the sofa. I couldn't do anything. I felt dizzy and felt like I had to throw up. My head was pounding. I got cramps in my legs, they were really burning and felt very heavy.

Do you enjoy coming to the conference?

Yes! I love it, especially when I go with my brothers, because I still do not speak English very well.

What do you most enjoy?

Seeing the other people with Barth syndrome, playing with them, since we don't see them very often.

What is your favorite memory from any of the conferences?

I loved it when we went on the outing to see the dolphins, but also when we go to the swimming pool and play with the other boys.