

MEET CHRISTOPHER

How old are you now?

I'm eleven but I'll be twelve in a month.

What grade are you in at school?

I'm in fifth grade, going into the sixth-grade next year. I was held back a year when I was in the first grade.

What is your favorite subject in school?

Math but I also love science.

You look just like your dad.

Yeah, I get that a lot.

What are some of your hobbies?

I play Fortnite. It's a video game that I can play online with my friends.

I like art. I don't draw as much as I used to, but I do still draw a lot.

I went through a phase where I liked learning about survival kind of stuff.

I like fishing. I'll fish anywhere there is water. I have my favorite spots. I go with my mom to work and have a spot that I go fishing while she is working.

I go hunting every year. My dad taught me how to hunt.

Do you have dogs?

We have seven working dogs. They are all different sizes and breeds. They all have different tracking skills. Some breeds are better at certain skills, like bloodhounds are good at sniffing and baying. Baying is when a dog alerts the owner that they have found a deer. My dad taught me what I know about that. I can't really go out with him because when you go out with the dogs you have to keep up with them. My Barth syndrome



keeps me from doing that. Even my dad has a hard time sometimes in keeping up with the dogs. He has GPS tracking collars on the dogs. That helps.

What else do you like?

I like cooking. Well, I wouldn't say I like to "cook, cook". I like to make pickled stuff. I will cut food up and put it in vinegar.

What do you put in vinegar?

Garlic, cucumbers and carrots. The thinner you slice the food, the quicker it takes to pickle it. I'll usually cut food really thin and it's ready the next day. I'll put a little salt with the vinegar to help the flavor. I love vinegar, I'll drink straight white vinegar right out of the bottle.

Is there anything that is too sour for you to eat?

Yesterday I got some malic acid. That's the white stuff that goes on sour patch kids. I tried that straight up and it was too sour for me. I couldn't eat that straight out. I do like Sour Patch Kids.

Anything else?

I like to play football.

Do you ever get super tired where you just can't play?

You mean like in real life?

Yes, like in real life.

Oh yeah, all the time. Like yesterday I about passed out when I was in therapy. I was so tired and out of breath.

Will you stop or do you push yourself?

I'll stop when I feel it in my body that I need to stop.

What does it feel like when you need to stop?

It's hard to explain. I give out of breath and it's hard to walk. My legs feel like they are falling out from under me or like I don't have control over them. I definitely get out of breath if I keep trying to go on. It's not a sleepy tired. It's more like a worn out tired where I need to stop to take a break tired. I don't get sleepy during the day where I need to take a nap. But I do get worn out. I do get to the "I need to take a break tired" during the day a lot. Anytime I have to do a lot of walking or have to go for a long time, I get worn out. I can go a little bit at a time. I need to take a break and I can go on.

Do your friends understand?

Yes, I have made my friends aware. Last month one of my friends had the flu and I needed to make him aware that he couldn't come around me. If I am playing with friends, I let them know and understand when I have to stop and take a break. I try to try, to keep going and not give up too easy. But I know my limits and if it gets too out of hand, I stop.

Tell me something more about yourself that you want me to know.

I either want to be a vet or a doctor when I grow up. I want to be a doctor because I know how it feels to be sick all your life and understand what a patient is going through.