



MEET BLY

How old are you now?

I'm fifteen now.

Tell me about your interests?

I like trains. We have a train track that is right behind our house. There are probably about twenty trains that go by each day. I go out there quite a bit. They all know me. They honk when I am out there. I have a trail that crosses a small creek with an old wooden bridge plank that I cross to get there. Sometimes the engineers will throw things out to me when they go by like hats, tee shirts, tape measures and railroad related things. It's really nice.



What is it about trains that interest you and going out to greet the trains?

I like waving at them and to people in general. I like when they honk at me. They will even flash their lights at me sometimes.

Do you have a job, or do you volunteer somewhere?

I'm a security person at church. When people drop their children off and pick them up after service, I make sure that parents receive a code for each child that they have to show to pick up their child. There are about two hundred children. It's to make sure that the children aren't released to the wrong people. I have been doing that for about a year now.

I also mow the neighbor's yard, which is about 5 acres. I use a mower with a 72" deck.

There are several people in our neighborhood that ask me to take care of their animals, usually cats and dogs. I always carry dog biscuits on me to give the neighborhood dogs. They always get excited when they hear my four-wheeler coming.

Tell me about school.

I have been in public school for about a year and a half year now. Before that I was homeschooled. I have eight teachers. I love my teachers. They are awesome. I really like PE.

One of my subjects is You and the Law. I have always been pretty curious about the law. It's interesting because the class covers topics all the way from what happens when someone breaks a law, how they get caught and the trials for the cases. We will also do mock trials.

I really like art. I've enjoyed making cards over the years for BSF donors. I enjoy doing the projects in class but when we aren't working on projects the teacher gives us free time to work on other schoolwork which helps me to keep up with my studies. I enjoy drawing more than I enjoy painting, though.

Are you driving?

I have my permit. I will get my license when I am sixteen. Driving is not bad. I can't say that I absolutely love it. I wouldn't necessarily go out and drive around for fun, with a car anyway. I have a four-wheeler. I use that to go everywhere. It's smaller and more maneuverable than a car. I can use it to get around in the neighborhood. I have better visibility with the four-wheeler. I wear a helmet and a chest protector on the four-wheeler. I like patrolling our neighborhood and visiting the neighbors.

Do you have friends who live near you who you enjoy spending time with?

I like to go visit some older neighbors up the street. I go up there all the time to visit with them for about an hour or an hour and a half. I try to go every day. They have a little dog. I enjoy spending time with them. We talk about school and I get to play with their dog. It's always great to spend time with them. It works out well because we don't have a dog.

I have friends from school who I get to spend time with. Sometimes I get to spend time with Abram¹ but not very often.

Tell me how Barth syndrome fatigue affects you?

It doesn't happen all that often. When it does, it comes on really quick. Like, I'll be going along just fine and then all of the sudden, it just hits. I have to stop and take a break. There are no warning signs. It just comes on. If I was at school and I need to rest, I will for sure rest. It would be actual work to get to the nurse's office. The tired isn't sleepy, it's just like being wore out.

¹ A friend with Barth syndrome who lives nearby

What do you want to do when you grow up?

I for sure want to work for the railroad. I would really like to be an engineer, but a dispatcher wouldn't be so bad either. Johnson County Community College has a Railroad Sciences program. The school isn't too far from our house, about 20 miles away.

Why do you like trains so much?

That is one of life's great questions. I'm interested in the mechanics of a train and everything involved in making them work. Just the idea of what they can do and how they operate is very interesting to me. A question that I get asked a lot is how the crossings and signals operate. For an example, I'd tell them that one rail acts like a positive wire, and the other rail acts like a negative wire. For the crossing to turn on, the electricity goes from one rail through the wheel, through the axle to the other wheel which makes an electrical circuit and gives the crossings power to turn on.

Is there anything else you would like to share?

No, I think I'm good. I had a blast.