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MEET BRYN

How old are you now?

I'm three-thousand-years-old.
Bryn's Mom: He's eight years old

Tell me about school.

I am in second grade.

I saw your pictures of you and your family on an outing in the country. Where did you go?

Bryn's Mom: There is a lake near our house that we go visit a lot.



At this point Bryn exited the scene because every three-thousand-year-old boy needs to play with his pet bunny (Weekend). The interview continued with his mom.

What is Bryn's biggest challenge with Barth syndrome?

His biggest challenge right now is with remote learning (COVID-19). He does not like getting in front of the camera. When I told him this interview was going to be online, he didn't want to do it. He does get to see his classmates a couple of times a week through online school but that's about it. He does the school-work but he wants nothing to do with the computer. He doesn't type and was just beginning to learn keyboarding. He did do very well in the one week when we were able to get the WiFi down to the treehouse.

What is the age difference between Bryn and his younger brother?

Five years. There is a big difference between the two in terms of their size and frame. Bryn is thin and his brother is bulky.

Is Bryn noticing any differences between himself and his classmates or his brother?

It's starting. He is noticing it at school. He has quite an imagination that he uses to compensate. Like, he's three-thousand-years-old and he's a magician. He doesn't compete a whole lot with his brother. I think that's because of the age difference but he does notice the difference between himself and his peers at school. He is noticing that he can't keep up with his peers. He knows why but it is starting to bother him a little bit. His way of showing it is through frustration or anger. He doesn't get physical, but he does get frustrated.

Do you think fatigue plays a factor in his frustration threshold?

It does. He definitely gets cranky when he is tired. At 8:00 pm he is totally mister cranky pants. Even though he is exhausted he still wants to stay up. Since so much has changed in his routine due to the COVID quarantine it's hard to tell if he is just being crabby or worn out. It's probably a bit of both. By dinner time it is pretty noticeable. By 8:00 pm he is finished.

What does Bryn like to eat?

He likes cheese (particularly mozzarella sticks) and peanut butter. He loves grilled cheese, mac and cheese, anything with cheese on it. His big thing right now is peanut butter toast. He hates pickles, ketchup and any kind of sauce. He likes rice but he doesn't want anything on it other than butter and salt. He does like salt. He loves watermelon and any citric fruit. He doesn't like the texture of oranges and will suck on them until the juice is gone, discarding the pulp. He loves green vegetables. He will just gnaw on broccoli and eat spinach, dill and basil. He really likes strong herbs. He will eat rosemary and mint right off the plant. He is still on a g-tube. That really reduces the stress because I know he is getting proper nutrition.

What are his interests?

He likes fishing. We just got back from our little stream. He created a javelin out of sticks with one being used as an anchor to hold himself and the other one to catch fish. The fish are about 2 inches long but we have to take bait so he can catch them. He also really likes engineering things out of Lego sets. We invested heavily in Legos for him to have something to do. He is really good at it. He has mastered sets that are for 16+. He can do an advanced kit in about three days. He likes playing in his treehouse with his brother, especially now that his brother can get up there on his own.

He's really the engineer with the design and putting things together.

He's really into science. That's the one thing we can get him into with his schooling. They had some weekly Mystery Doug segments. He sat down and watched all of them in one sitting.

Bryn came back to tell us a little bit about Weekend, the bunny.

He is a lovable bunny. He has a litter box that he uses to go to the bathroom. Sometimes he sits in his litterbox to eat his hay.

What else should we know about Bryn?

"I know enough magic to turn myself into any animal. I am a Hogwarts student. I am only three-thousand-years-old."