



MEET JACOB

How would you introduce yourself to someone?

Normally when I introduce myself to someone, they are surprised to learn my age. If they don't come right out and ask about my size, it's clear they are wondering why I am so small for my age. For that reason, it seems like one of the first things I have to tell anyone about myself is that I have Barth syndrome.

I'm pretty quiet. It's funny, I know the people I see through the Barth syndrome community. Even though I know many of these people, I still wait for someone to notice me before I jump in. Like at the conference, I've known many of these people since I met them at my first conference ten years ago. I still have to hang around them for a little while before I can just open up. It's not easy for me to just jump into a conversation. I have to warm up a little bit first.

(Laughs) I don't know when I changed to be like this, but it doesn't seem to be getting any better.

How old are you now?

I'm nineteen

And how tall are you?

Five-two (158 cm)

How do you describe Barth syndrome?

It pretty much varies depending upon who I am talking to.

What are your interests?

I like watching movies and being with friends. I enjoy cooking. I tried something new the other day. I combined chicken, buffalo wing sauce, cream cheese and shredded



cheese and croissant rolls, rolled them together and baked them. It turned out pretty good.

I like hunting but I haven't been in a while. It's hard to hunt. It takes a while to get out in the woods and by the time I get out there I'm tired.

When I was in school, I read a lot of books. If I really get into a book right off, I will read it every spare minute I have. If it doesn't get my attention right off, I put it down. It feels good to be able to do that now. When I was in school, I didn't have a choice. I had to push myself to get through a book that was on a reading list. Sometimes it was really hard because I was really tired. Now, I mostly read shorter stories or news articles.

Who is your favorite author?

Stephen King.

Are there foods you really like?

Hot sauce and peppers are definitely a big thing with me. Mom gets onto me for eating too much of them. I crave sour foods, like salt and vinegar chips, dill pickle chips and pickled sausage. I love those red-hot pickled sausages. I love pickled eggs, they are amazing. Franks and Louisiana hot sauces are the best.

I like chili peppers. Jalapenos are my favorite. They are good! We have pepper plants. I'll pick them and eat them fresh. The ghost pepper was the hottest pepper I have ever tried. I don't ever want to try it again. It's like everything burns. Worse than wasabi where your nose feels like it's on fire.

My favorite sandwich is turkey, mayonnaise and mustard.

Is there any food that you can't eat?

There aren't many foods that I can't or won't eat based on flavor. My food preferences are really based upon consistency preference. If something is too grainy, it makes my mouth feel weird. I can't eat anything that is too sweet or too soft. I can eat uncooked onions but if they are cooked in a food like in spaghetti, I can't do it. Same thing with tomatoes. I'll eat them but I don't like them mixed in with anything or cooked. It's got to be raw.

Can you mask the foods you don't like with hot sauce to be able to eat them?

I'll be honest with you. I slather everything down with hot sauce. I'll dip food with every bite. Hot sauce is a staple in my diet.

How is your stamina now that you are out of school?

If I have a regular sleep schedule, I am okay. When I can't sleep, I am worn out by around six o'clock. When I lose sleep, I can feel my heart racing... A LOT! I can tell when it happens. It happens throughout the day and it wears me out. Sometimes it happens when I am in bed and I feel wide-awake even though I am tired.

How do you know when you just have to stop?

My feet start to get really heavy and I start stumbling over my own feet. I start tripping. I will lose my balance. That's my first sign.

I'll get headaches if I keep pushing myself. When I get to that point, I sleep heavy. I'm not waking up, not even to eat. I've learned the importance of not over-stressing my body. If I stop to rest when I notice I am getting tired, I can generally go on after taking a brief break. The further I push beyond my limit the longer it takes me to recover.

Weren't you having issues with headaches and pain?

My migraines seem to be improving but I am having problems with my back. The doctors aren't sure what to do about it. The problem seems to stem from my hips being inverted but the only way to fix that would be major surgery. I'm dealing with the pain because the surgery would take eight weeks of recovery. Because of the neutropenia there is a pretty significant risk of me getting an infection. Surgery doesn't seem like a very good option.

I also have sciatic nerve pain. The worsening curvature in my back seems to be making the sciatic nerve pain worse. I've been to the pain clinic, but no one seems to know what to do with me. I was taking this gel that was super expensive. It's supposed to target the pain source. If I rub a little amount on my back where it hurts it does offer some relief after about an hour.

Are you working?

Not now. I liked working and earning some money, but it was too much. I was on my feet way too long. I would come home and crash until I had to work again. I felt like I could never recover. I could never get enough sleep. I never knew from one day to the next how I would feel. On my good days, I felt I could get through it but

then there would always be the bad days. I tried, but it just didn't work out. That's important to me. I know that I did my best. I know I tried.

What didn't I ask that you that you would like others to know?

After high school, there was a shift in my life. I had graduated from school and the next step for me was to try to get a job. When I couldn't do that it really hit me hard. It made me consider things differently. It affected me in a way I couldn't have predicted. I wasn't a kid anymore. It was difficult. I was really struggling. I felt like I didn't have control of anything in my life.

I went to therapy and therapy helped. It (therapy) isn't something that anyone should be ashamed of seeking. I would suggest that anyone who is struggling consider seeking therapy, it helped me. I'm in a good place now.