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## MEET DEREK

### How old are you now?

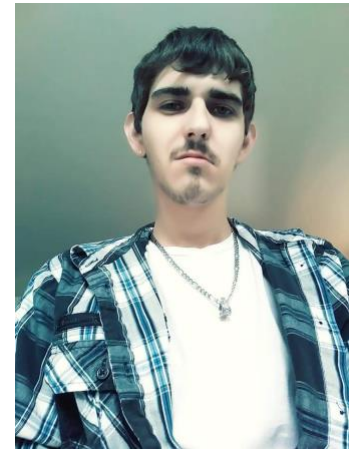
I'm twenty-six

### How are you holding up with the COVID-19 quarantine?

I'm doing pretty good. I'm keeping up with friends. I play PS4 and X-Box. Healthwise I am doing good.

### Do you have pets?

We have a cat in the house. I wouldn't say it's my pet though.



### How would you describe yourself to someone who doesn't know you?

I like to spend time with my family and friends. I enjoy being with other people. I check in on the people I care about. I live with my dad and my brother in the Saratoga Valley area in NY.

### Have you been to see the horse races?

Yes, we had passes when I was younger. It's fun. There are concession stands where you can get something to eat and watch the races. The food is pretty good. You don't have to bet to watch the horses run.

### Are you still into music?

I used to write rap, but I don't do that as much as I used to. I still do write. I stopped because it made me think too much. It takes time. I need to have something going on in my life for the inspiration to write. My dad plays the piano, but I don't play an instrument.

I like hip hop, R&B and rap. I enjoy listening to artists that I know. I watch them on YouTube. Each person has their own style or rap about certain situations. They rap about emotions. I can relate to the music. They use their art to purge their emotions out in the form of music. There's a message in rap. Many people think rap is nonsense but it's not. If you listen to the words you will realize it's relatable. It's like modern poetry.

I'm not into slow songs, love songs or sad songs. They make me think too much. I don't want to listen to get depressed. I want to listen to music as an escape not to make me feel worse or dwell on sadness.

### **Do you read?**

It's not like I don't know how to, but I wouldn't say I enjoy reading.

### **Do you stay in touch with the other people your age who have Barth syndrome?**

I do stay in touch. I keep up with Travis, Darryl and Jeremiah the most. I talk with Darryl and Jeremiah on the phone. I keep up with the other guys on the Facebook. I was looking forward to sharing a room with one of the guys who was coming to the conference alone this year. Of course, we aren't doing that now since the conference has been postponed. I really look forward to seeing everyone during the conference. It makes me sad to think about that not happening this year.

### **Do you remember a time when you weren't a part of this organization?**

No not really. I was five or six years old when we all got together for the first time in Baltimore. The people in this group are a lot like family but in some ways closer than family. I mean, these are the members of your family who really get it. These are the people who just know what I'm going through. Our conversations aren't limited to Barth syndrome. I'm always comfortable when I talk to my friends in this group. They know what it's like to get worn out. They just understand that the mental exhaustion that goes along with it (Barth syndrome). I mean, I get tired when I push myself physically, but I get mentally exhausted too. There's no judgement.

### **Do you exercise?**

I exercised in the past. I participated in Todd Cade's study. I was able to build muscle up. It's amazing how quick I could build muscle. It seems to breakdown just as quickly. You have to workout every single day to maintain the muscle. I will say, I certainly had more energy when was exercising.

### **Do your friends outside of the group understand your fatigue?**

Yes, they understand I have limitations. They know I need to take breaks. They are pretty cool about it. I couldn't really walk the entire distance of a mall without taking a break.

### **When do you know when you need to take a break?**

My legs will feel like they are on fire and I have to stop. I mean they literally feel like they are on fire. I only have to stop for a couple of minutes for the burning to stop. I don't have to walk very far my calves to start burning. If I push too hard it becomes difficult to

lift my feet. They get really heavy. If I don't stop, my legs get really heavy and hard to lift. I'll start tripping and fall.

It's like I have no control over my own body. If I push myself too far it affects me mentally, like the way I think. I don't push myself to that point very often, to where it affects me mentally. I get physically worn out everyday, many times a day.

It's not like cramps that I got when I was a little kid. It's a different sensation. The cramps I got when I was a kid were like very sharp pains. It felt like someone was squeezing the muscles really hard. This is definitely different.

### **Have you thought about getting a scooter to help you get around?**

I've been thinking about getting one of those motorized bikes to help me get around. I wouldn't want a scooter. I think I would use a motorized bike that isn't as bulky as those scooters. I've seen those Segway scooters, but it looks like you would have to have really good balance to stay upright on one of those. I don't know if I could do that.

### **If you could go anywhere where would you want to go?**

I don't know I've never really thought about it, Hawaii maybe... No, I know. Let's go see Darryl in Philadelphia. If I could do anything or go anywhere, I would want to go see Darryl. I would just want to be with someone that I enjoy being around. We wouldn't have to do anything. Spending time with him would be the perfect getaway.