Family Focus



Interview by Shelley Bowen, Director of Family Services & Advocacy April 7th, 2020

MEET BEN

How old are you now? I'm fifteen.

What grade are you in now?

I am in the eighth grade

Are you driving?

I have my permit. I like driving.



When do you get your braces off?

Well, I was supposed to get them off in March but with everything shut down I haven't been able to get them off.

What are some of your hobbies?

I like to swim. I like to play baseball and basketball and sometimes football. I can usually keep up with others. Sometimes I have to stop because I get tired. If I stop for a little while I can go on. I also like playing sports video games like Madden and 2K. I like hanging out with my friends, playing sports and just pretty much going with the flow.

You've always been pretty laid back and gone with the flow.

Ben's Mom: Yes, he has. He gets along with pretty much everyone. He has always been easy going.

Is there ever a time when you get grumpy?

When I'm tired, I get grumpy. When there is a lot of stuff going on, like activity or people all around me I get irritated.

What is it like for you to get tired?

My calves will burn. If I stop for a few minutes the burning will stop. It really depends on how long I let it go on. The more I push through or continue going after my calves start burning, the longer it takes for me to recover. It takes more energy to move. It's difficult to stand up straight.

What kind of music do you like?

Hmmm, I like... Country Rap and the 80s.

Who are your favorite artists or groups and favorite songs from those genres? Although I didn't know that Country Rap was a genre.

Laughs, well maybe it's not...

Guns and Roses and my favorite song would be Welcome to the Jungle. And let's see... Post Malone and I have a lot of favorite songs. My favorite album would be Hollywood's Bleeding.

Really? Do you sing in Axl Rose style?

Laughs... Well, not in public.

What is your favorite meal?

Steak fingers are my favorite. I like to dip them in white gravy. I like French fries or really any kind of potatoes. If I had to eat something green, I would eat green beans. I do like cucumbers. I don't know if pickles would be considered a vegetable, but I do like pickles. I like the spicy kind. I like hot sauce a lot. My favorite dipping sauce would be Chick-Fil-A® barbecue.

I like corn on the cob. I'll eat it if I see someone cutting it off the cobb, but I can't eat it out of the can. I like crunchy foods. I cannot do slimy or squishy foods.

Do you have any pets?

I have two English bulldogs. Maggie is eight years old and Sophie is eight months old. We got Sophie in December.

How do you like being an uncle?

I like it. He's a good baby and really cute. I haven't been able to see him since the beginning of March.

What is your favorite subject in school?

Probably science. I am homeschooled. This will be my second year of being homeschooled. I go to co-op on Fridays and take classes there. That is where I generally do my labs and can work in groups.

I really like being homeschooled because it is at my own pace. I can focus better. There are not as many distractions. I have a daily agenda that tells me what I am going to do from day to day.

Do you enjoy reading?

Not really, not by choice.

What was the last book you read by choice?

Let's see, it was a mystery... I don't remember.

What is your favorite part of coming to the conference?

I like being with my friends and seeing everyone. I like learning about the new discoveries from research. I like hearing about the progress being made on treatments. I'm going to miss the conference this year.

We can't replace the face-to-face friend time experienced but maybe we could arrange a virtual meeting for the guys your age to hear an update on the research. Would you like that?

I would. That would be interesting.

Do you enjoy participating in research?

Yes, I do.

What do you want to do for a profession?

I want to be a barber. I like working with my hands. I can own my own business.

What would be your dream car?

A Corvette or a truck.

Really, well that goes right along with your country rap then...

Laughs... I guess so.