

Dr. Anne Recklingsits down with Reed, a 13 year-old living with mito. He is part of our series of interviews of teenagers living with mitochondrial disease and will be sharing his outlook and advice for young people living with mito.

AR: Hi Reed. How are you?

R: Hi. I'm good.

AR:How does mitochondrial disease affect you?

R: Well pretty much it just makes me get tired quicker and it has made me drop out of a couple sports I liked.

AR: What sports were you in?

R: For a long time when I was younger I was on a swim team, but that really tired me out a lot. Then more recently we tried karate, but the gym we were in was really hot and it zapped my energy, too

AR: When your energy gets zapped what does it feel like?

R: I generally get hot and tired, nausea and headaches.

AR: Was it hard to have to quit the sports?

R: Yes.

AR: What kind of stuff do you do to help with the mito symptoms?

R: If I get a headache I lay down. I like to drink a lot of water and Gatorade.

AR: Your mom said that you just went to Six Flags. Do you like to ride the really big roller coasters?

R: Yes I do.

AR: You do! They scare me. I think Six Flags has some of the really big ones that twist around and everything. How did you feel after that day?

R: That day I felt pretty good except at the end when there was no line I went on one of the roller coasters called the Scorcher. I went on it seven or eight times straight and I got nauseated.

AR: I think I would get nauseated probably on one of them. So you drink lots of water and lots of Gatorade, and if you get a headache you lie down and it sounds like you had to change some of your activities in terms of getting out of a couple sports. Are

there any sports that you can do?

R: There are not really any sports I'm doing right now.

AR: What kind of stuff do you do?

R: We do scouts and last year we did a robotics team for FLO and we may be doing another team sometime soon.

AR: And you're home schooled?

R: Yes.

AR: Were you ever in a regular school?

R: No.

AR: So does that help also? Are you able to pace yourself so if you get tired you can stop for awhile?

R: Basically all I do is sit down and study my stuff.

AR: You do okay then. Your hands don't get tired from writing? Sometimes I hear kids who get tired.

R: My fingers do get tired after awhile.

AR: Do you work with a computer?

R: I use textbooks. The only thing I really use the computer for is for my math.

AR: So it sounds like you're used to doing a lot of handwriting and everything. So water and Gatorade before and probably during, lay down if you have a headache. Any thought afterward? Lets say if you have maxed yourself out and you didn't stop when you probably should have. What helps?

R: I usually drink Gatorade for relief.

AR: It sounds like fluids are the big thing.

R: Fluids and food.

AR: Do you try to eat during the day all day sort of thing, little bits?

R: I take snacks.

AR: So fluid sounds like it helps a lot when you're not feeling to well. So, how did you find out you had mito?

R: I don't know...it was a while back.

AR: Is it hard to remember?

R: We always felt there was something wrong with us. We probably got it about a year ago.

AR: How does it feel to have a diagnosis, to have a name for this?

R: The name didn't make much sense to me so it didn't feel different.

AR: Have you learned more about it? Does it make more sense now?

R: Well, we pretty much knew the symptoms by then.

AR: And you still know the symptoms?

R: Yes.

AR: So it sounds like not much has changed for you just by knowing the name. How does it work with friends? Is it difficult with friends knowing about mito or that feeling you have to do activities different. Does it make a difference for you?

R: It doesn't really seem like it makes a difference. I don't meet people at school who have a big interest in sports. I meet people at church and at home school groups we go to.

AR: That's great. So you have some friends that it really doesn't matter for. What, if anything, would you tell somebody that just started having symptoms of mitochondrial disease and then they just got a diagnosis at age 13 or 14? What might you know that you want them to know? Is there anything you wish somebody had told you that you had to learn for yourself?

R: Not really. I have shorter legs so when I run I get tired faster. I've tried lengthening my stride, focusing more on throwing my leg out, and things like that.

AR: The different ways of trying to get faster but conserving energy maybe? Is there anything you can think of or anything that keeps you from getting frustrated when you're tired or not able to do sports that you want to do? What keeps you going and what keeps you happy?

R: I like to read books and I program computer games and stuff. I'm not a physical person.

AR: So it helps you have a lot of other interests besides the karate and swimming that

you had to stop. It sounds like all your siblings and your dad have mito. What is that like?

R: It just seems normal.

AR: It sounds like you don't think about mito a lot.

R: No really.

AR: You just live your life.

R: Pretty much.

AR: Thanks for taking the time. We're letting other teenagers know all the different ways it can be like to have mitochondrial disease as a teenager.