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In this interview with Annalise, Dr. Anne Reckling hears the perspective of a young adult and how her teen years were changed by a mito diagnosis. She offers insight for teens and parents of teens living with mito.

Anne Reckling: Thank you so much for much taking the time today. Now how old were you when you were diagnosed?

Annalise: Hi. I was about thirteen.

AR: Do you remember what symptoms you had or what it was like?

A: Specifically, since I was a little kid, I had attention deficit hyperactivity, and I went from being up all day, active all day, to the exact opposite. Sleeping all day, I couldn’t really do anything and that’s when something clicked that something wasn’t right. That’s the first thing that I can remember that something was wrong.

AR: Do you remember how old you were?

A: I think I was about eleven or twelve.

AR: Eleven or twelve. Then, as it usually does, it takes a couple years to get a diagnosis. How does mito affect you now?

A: Well, it depends on the day. Sometimes I can be fatigued, real tired, or my muscles hurt. It really depends what’s going on. It affects a lot of things.

AR: So muscles hurt, pain, fatigue.

A: GI tract, trouble digesting food.

AR: My seven year old has a tube. He’s fed by a G-tube now.

A: I don’t have one

AR: Have you ever?

A: No, I used to have problems keeping things down, but I’ve never needed one. My friend has a G-tube, in Canada.

AR: Oh, she has mito?

A: Well, we think she does. She's never been formally diagnosed. Oh, my mom just said has.

AR: So it sounds like fatigue, muscle pain.

A: I get a lot of migraines.

AR: Do you have a sense of when it's coming?

A: No, not really. I've had migraines since I was eleven, so over ten years.

AR: What was it like to get a diagnosis of mito?

A: I don't really remember. I never really knew what was going to happen, so I didn't know how to take any of it. When I got to Cleveland the first time, it felt like more or less the doctor knew what he was talking about, so I felt better talking to him than the other doctors because they didn't seem like they had the time, or knew what was going on with me.

AR: It must have been frustrating with doctors that you felt didn't know what was going on, or take the time. But when you got to the Cleveland you found somebody, at the Cleveland Clinic, that knew and understood.

A: Yeah.

AR: What do you remember from being a teenager about what it was like? How did it affect you then?

A: Well, it made it hard for me to do the same things that my friends did. It made my friends more protective of me. They didn't really want me doing the same things that they did because they were afraid I would get hurt or I'd get sick or something would happen. Which was nice, but I'm not a porcelain doll. I'm not going to break.

AR: So they kind of overprotected you. Did they then in a way, by trying to protect you, exclude you from things? Did they still ask you?

A: Well, not exclude, but it's more like they went into hyper protective mode. It wasn't exactly that I ever felt excluded, but it made it harder to relate, because I couldn't really tell people how I went to the doctor. The only person I can really do that with is the girl from Canada. She'll be like, "I was so sick yesterday, it threw up all afternoon". She doesn't have to worry about me freaking out, because I've been there.

AR: So it sounds like they were really overprotective and in that way made you feel a little different, instead of just treating you like yourself.

A: Well, I have a couple of people who did that, too. It just depended on who you were talking to. Whether or not they've ever been really sick in their life, or who freaked out easily.

AR: What sort of things were you, and are you interested in?

A: I'm interested in a lot. I like to read, I like writing, I like watching cartoons. My friend got me watching Japanese cartoons called Anime, so I watch that now. I watch that with one of my friends, because she is the only other one I know that likes them. So, reading, I like to write, and I like to take walks.

AR: That's great. And, did you do regular school, were you home schooled, or how did that work?

A: I went to regular school until mid-junior year of high school.

AR: Wow, you made it a long way. What made you go into home schooling?

A: Yeah, the public district didn't believe that I was sick.

AR: The same thing that your sister struggled with.

A: We don't really look sick. I sort of agree, we look healthy, and it's sort of a double-edged sword. Because we looked healthy, are able bodied, and can walk and do these things, it's a blessing because we can do all these things, but it's also not. People are less apt to believe that we are in bed because we can't move because we went for a walk with our friends the other day that we really can't move. They just think we're being lazy...

AR: Because they can't see it.

A: Yeah, they think we are milking it or something.

AR: Right. Now, you have a service dog, too. What does the service dog do?

A: He responds to any fire alarms and seizures. Well, he isn't actually trained to respond to seizures, he just started doing it after I got them.

AR: Wow, he just did it. That's wonderful. So I imagine that if you look healthy and you are walking with a service dog, that people don't always assume that it's yours, or wonder why you need one.

A: Yeah they do. I get stopped a lot. People are really interested in service dogs.

AR: What have you learned to do, so that you can do the things that you like to do? The reading, the writing, and the walking.

A: Well, it's sort of a planning thing. I do try to take a nap before I go someplace. Well, it just sort of happens, anyway. My sister says I'm like a scheduled narcoleptic (*laughs*). I just try everyday around 4:00 to fall asleep. Like, last weekend I couldn't because my friend's birthday party was

early in the day, so I woke up early, and I had to go. So, it was just all day and then when I came home, I was tired and I'm still tired from that.

AR: You are still tired from that. That was when?

A: Sunday

AR: So it sounds like it affects you afterward for a while.

A: Yeah, well, one thing I will say to people who have kids or teenagers with mito is to let them do it, unless they are going to crash hardcore. Let them do it because they are going to resent you if you don't let them have fun.

AR: Did you also learn your own limits? I was wondering if there was a way that you learn your own limits and what you needed to do.

A: Yeah, even when I was out I would get tired, so I would sit down while they were doing stuff. I would still be listening to everything while I was sitting.

AR: Yes, that makes sense. What gets you through dealing with the daily struggles? What inspires you, what keeps you going, what gives you hope on those cruddy days?

A: I don't know. Just trying not to focus on "poor me" because that is not helpful for anyone. I just think about what is happening now and if I do have one of those days, I'll talk to one of my friends, or I'll talk to [my sister] Kristin about it, or I'll just deal with it as it happens.

AR: That's nice that you have a sister who can relate. It's a double-edged sword, too because you wouldn't wish it upon your sister, but you can relate to somebody in your family. Have you met anybody else, any other young adults with mito.

A: Well, besides the one girl in Canada, I know some other people who we think have it, but I don't really know them, I just know them through my mom. So, not really, but one of my friends has chronic fatigue syndrome, so she sort of understands. She's the one that watches the cartoons.

AR: So maybe somebody else with a disease that makes them tired and fatigued.

A: Yeah, she gets the tired thing. It was her birthday party that I was at on Sunday, and afterwards we just sat on her bed the whole afternoon because we were really too tired to do anything else.

AR: It's good that you recognize it. That's another thing that I think is hard, because you have to learn to grow up, in some ways, sooner. What I'm hearing from other teenagers is that you have to learn to plan. Sometimes teenagers really need a chance to be spontaneous to do stuff, but what I've learned from talking to people who are dealing with this, is they have to plan. If they want to do something tomorrow, then today they better do this. Do you have to change the way you eat, drink more fluids, or anything like that?

A: Yeah, I have to drink a lot of fluids and I've had a very similar diet since I've started seeing him. It's the same food that we had to change. It's not actually a specific diet, but it's just what I've been eating since I saw Dr. Cohen. I think it's a low fat, low calorie, high-carb diet.

AR: Oh, that makes sense. Each person I think with mito, from what I hear, is that it's a little bit different. You just have to do things a little bit different. You were saying, the one thing you would tell the mom's dealing with teenagers with mito, to go ahead and let the kids do it and find their own limit unless they are going to crash hardcore. What would you tell someone that you met that is fourteen and newly diagnosed? What would you say to them? Is there anything that you would want them to know that you wished you had?

A: Probably find a good support system. That one of two things is going to happen. You find that life goes and you'll find out who your friends are, because I had a lot of people leave me leave me and not be friends with me afterward, and I also had a lot of people who stayed through the positive and negative. Also, life will go on after this and not to be upset because sometimes it can get really...when I first sat down and thought about what was going to happen, I got really angry. I got really angry when I was diagnosed, but it got better afterward because time heals problems.

AR: It sounds like you have adapted well, and that you are enjoying your life. Thank you so much for taking the time. I think it is really important that all of you who are younger and dealing with this have a lot to offer the teenagers who are dealing with this, and you also have a lot to offer their parents, to know that there is life with mito and life after mito. That it all isn't, as you said, the end of the world. You have bad days, but things do go on and you get to do some of the things that you want to do.