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In this interview, Dr. Ann Reckling talks with 18 year old Kristin about coping with mitochondrial disease, school, hobbies, friends, and family.

AR: Hi Kristin.

K: Hi.

AR: First off I just want to ask you a few things. You’re 18 and almost finished with school. When were you diagnosed with mito?

K: It was a suspected diagnosis in 1994 and that was confirmed in 1998.

AR: Did you have a muscle biopsy done?

K: Yes I did.

AR: What kind of symptoms were you having and how did that affect you?

K: Well I don’t remember what kind of symptoms I was having then, but now it tends to make me have a lot of back pain, I get tired easily and I get headaches, and breathing stuff.

AR: That’s an important part. I noticed you have a service dog. Does the service dog help with those things?

K: Yes. Sometimes I used to have seizures, and I don’t have a lot anymore, but she could get my nurses or my mom. I have a ventilator at night and when it went off sometimes the nurse wouldn’t hear it. She would get them.

AR: How long have you had the dog?

K: About 6 years. I got her when I was about 13.

AR: It seems like you have a really good relationship with her. Dogs become so important to people.

K: Yes. She is really, really good.

AR: Breathing, pain, fatigue...it sounds like you used to have seizures. What kind of things have you learned to do so you can do the things that you want to do? Do you go on trips?

K: Not really. Well, I know I don't have as much trouble as a lot of other kids do. I think I can do a lot of stuff that normal, active, healthy kids can do, but maybe can't do it as long or as well. I can't really play sports or going running that long.

AR: You just have to cut things a little shorter?

K: Yes.

AR: Do you have to do anything different with your eating or drinking?

K: Sometimes I do. I don't get hungry that much and I have trouble eating a whole meal, so the nurse has to push fluid and I have to drink a lot.

AR: I hear from other teenagers that is one of the things that is important. So you don't have a G tube or line?

K: No.

AR: Have you ever had one?

K: No.

AR: What kind of things do you like to do?

K: I think my favorite thing to do is to write. I don't feel like walking. I like taking pictures, watching old movies, and I really, really like music, mostly rock music. I want to learn how to play the guitar. I have one, but I haven't learned yet.

AR: That's great. So it sounds like you have a lot to do. It doesn't sound like mito has held you back at all.

K: Well, maybe not as much, but sometimes a little because I don't go to public school so I have a little bit of trouble making friends. Usually I write pen pals. I have a lot of friends on Facebook now.

AR: So you don't have many friends that are right there?

K: And my one friend went to college.

AR: Oh, that's hard. With your friends and the friend that one went college, do you talk to them about mito?

K: Well, we do. I don't generally talk about it right there, but he was really accepting, he never made fun of me for it. A lot of them who do live close by know because they have

known me since they were kids.

AR: Did you ever go to public school?

K: Until 6th grade.

AR: Did mito have anything to do with the fact that you stopped going?

K: Mostly from the people who worked there who were giving us trouble. They didn't think I was sick because I didn't look sick, so my mom thought it would be best to home school me.

AR: That's something I hear a lot with this disease. I have a son with mito and he doesn't look sick and it is a struggle.

K: I don't really look sick. I have a pacemaker scar but that is about it.

AR: So the school didn't believe you and wouldn't make the accommodations.

K: Some people thought I was lying.

AR: That's terrible.

K: I don't think a lot of people do.

AR: You're almost finished with your senior year, what are you going to do? What is your next plan? What do you want to do?

K: I'm not quite sure yet. I know I want to probably be a writer, probably write books but I'm not sure about college or anything else.

AR: You want to be a writer? What do you write now?

K: Well, I know these little girls and their mom. I started writing these mysteries once a month when I was 15. I have been doing it every month ever since. I'm going to end that this year because I think they might be getting too old. My sister and a couple of my nurses read them and someone said I should send it in, but I don't know. I might look into doing that. And I write Sci-fi.

AR: That's great that you're so disciplined to write a mystery every month.

K: It's a lot of fun. I feel like the characters are real. There is this one who I think of as me as the character.

AR: It sounds fun, and it sounds like you enjoy it a lot. What kind of things keep you going when you get frustrated with mito?

K: When I get upset about something usually I'll just write or sometimes I will talk to my sister, but I really don't get frustrated that much.

AR: It sounds like the mito affects you, but it does not have one big effect at one point, but slows you down a little bit.

K: Yes. I will be fine and then I will develop a problem. Recently, my back has been getting worse, but then I'll take a pill and it will help. Right now I'm probably going to start doing therapy, so that will help. Then I will get better for a while and then something else will happen.

AR: So it sounds like even when a new symptom develops, it doesn't feel like it is not being treated. You will be able to find a way to deal with it with physical therapy or medication and it will go along okay for awhile and then it might crop up again. Your writing and talking to your sister is helping you through this also.

K: Yes.

AR: I think your sister understands probably better than a lot of people.

K: Yes. She is like for real on that. She has it too. We'll talk about what the doctors said together.

AR: So it sounds like it is important you have that relationship with your sister that you have.

K: Yes.

AR: Is there anything that you would like to tell a teenager who was just diagnosed with mito? Can you think of anything to tell them that you wish someone had told you?

K: I was diagnosed as a kid, but my sister wasn't and people are like, "Oh, I feel so bad because you have always been sick". I actually think it is easier just to always have had this because you don't know any other way. For people like my sister it is a teaser. They live their whole life normally and they suddenly are diagnosed. But, it is not the end of the world because teenagers can be so dramatic; it is not the end of the world. There is treatment. I would probably tell them not to give up or anything.

AR: That's great. It's more like living with a chronic disease, it's not the end of the world, and it's not going to change.

K: I can't change some things, but as long as you don't let it, it's not going to ruin your life. If you're like, "This is so horrible," then it probably will be more horrible than it has to be.

AR: That's really important to learn because I think because mito is not well known. I think sometimes when the diagnosis is given some stories are kind of scary and sometimes you seem to focus on those instead of other things that you can do with your life. That's one of the things I really like about interviewing all the teenagers with mito because you are all living the life, maybe with some modifications but everybody is pursuing their dream. Thank you Kristin.

K: You're welcome. Thank you.