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Dr. Reckling interviews Olivia, a 15 year old, about the challenges of living with mito as a teen and how she stays active and connected to her friends

Anne Reckling: Hi Olivia. I’m so glad that you were able to take the time to talk with me today, so we can learn more about what the experience is. Olivia you can share what you what it has been like for you to live with mitochondrial disease. What sort of things, how does mito affect you?

Olivia: Well, it affects my energy levels, I have a very hard time controlling my energy levels. I also, for a very long, while had a hard time controlling my weight and my body temperature. My blood pressure also, my vision has actually gone up and down a lot. I’ve had kidney issues, it’s a very long list.

AR: You’ve had a lot then. You’ve had a lot of involvement.

O: Yeah, you get used to it after a while, but you do get a new thing every once in a while that freaks you out, but with family and everything it makes it a lot easier.

AR: Your family helps you a lot?

O: Yeah

AR: That’s great. It took a while for you to get diagnosed? It took 9 years?

O: It was about three months after my ninth birthday. It took nine years. I was failure to thrive until I was about three. *(Mom in the background adds in.)* Oh, I was apparently failure to thrive until I was about nine when I got my diagnosis.

AR: Wow, okay. So that was when. Do you remember finding out about what was going on?

O: You know, I actually remember being diagnosed with Kawasaki’s disease. I’m not exactly sure when I realized I had something else wrong with me. I remember going on medications. I was actually on about two or three medications, and I was confused because the Kawasaki’s was over, why am I still on medications? I think that’s when it really hit me that there was something else going on. I had heard my parents talking about it, but I thought it was still just the Kawasaki’s, but I caught on and started to take more control of it myself.

AR: How do you take control of it? What do you do?

O: I take medications daily, about nine medications. Other than that I try to keep myself warm. I actually have to keep a good monitor on my energy levels while I am at school. I have to use a

CPAP machine at night, it actually helps me breathe better. I also have a one-on-one aide with me while I'm at school, and she can help me realize when I am not at my...

AR: When you're not full of energy?

O: Right.

AR: How can she tell that you're not? What do you think she notices?

O: I usually begin to look very pale, my lips can turn blue, I'll start to rub my eyes. I think I've only passed out twice at school because my aides do a very good job of monitoring me. Every once in a while I won't realize when I'm not well. I also start to shake a lot, too.

AR: Okay. What do you do then? Let's say that your aide says that you are starting to look like you're getting tired. What do you do? Do you go home, to the nurse's office?

O: Well, I usually have two options. I go to the nurse's office, and lie down for about a half an hour. When I get up, if I don't feel any better, or I don't look any better, I will call my mom. Then she'll come pick me up.

AR: Sounds like you guys have a good plan and it helps.

O: Yeah.

AR: And you have to stay warm, so it sounds like temperature is an issue.

O: Yeah, mito seems to differ a lot, even between siblings. My brother and I don't have many of the same symptoms, other than fatigue. Our eyes are very much the same, but other than that. He has mostly eye issues and respiratory issues. I have mostly cardiac issues and fatigue issues, with all that other stuff.

AR: What's it like having a brother? I know you have different symptoms, but you are sharing a disease.

O: Harry and I have a pretty close relationship because of it. We understand what each other are really going through even though we don't have many of the same symptoms. We've only known that Harry has had mito for three years, and before that he was the guy who was trying to learn more. He was a great big brother, and now I just think that we've become closer.

AR: You're probably able to support each other.

O: Yeah, a lot of the time.

AR: And, like you said, understand each other in ways that other people don't. Now, did you go to school all the way through?

O: All the way through my diagnosis?

AR: Well, it sounds like you probably missed school just being in the hospital, but did you ever have to school at home? Did you stay in school most of the time?

O: I get totally supported for most of my courses at home, but whenever I'm able I try to get in school as soon as possible. So it's like I go to school and I'll audit some classes, I'll go home and I'll actually get the real lesson in that class. That way I really get the social-emotional aspect of school, without having to have the pressures of all the classes and I can stay longer.

AR: That's neat. That's great that you figured out a way to work it out. How is it then with friends?

O: My friends get it somewhat. They've been extremely supportive, they get very nervous when I'm not in school. Actually in eighth grade I was out for 2-3 months, and there were a couple of rumors that my friends got back to me as soon as possible. One rumor was that I was terminal, I was dying of cancer, and the other was that I was hit by an 18-wheeler.

AR: (gasps) Oh, my. Some days you might feel like you've been hit by an 18-wheeler. (laughs).

O: My friends are actually really great. I appreciate their support and I have kept a lot of really great friends.

AR: That's neat. It sounds to me like you and your family have worked a way around to make sure that the social part stays an important part of your life.

O: Yeah, it's a guess-and-check really. We've tried this a couple times and it hasn't worked and this is the first year that we've been able to keep it pretty constant.

AR: It sounds like you are pretty busy taking care yourself and then also the social and academic. Are there other things that you are able to do?

O: I really enjoy fencing. I fence when I am able. I enjoy a lot. I also am very artsy. I draw a lot, and I work with clay.

AR: It sounds like you have a very full life.

O: Yeah, I try to make it as full as possible, to make up for the time I am sick.

AR: Yeah. What keeps you going when you are sick? What inspires you?

O: Well, I know it sounds weird, but when I am sick, for the first day I pull look at the tv guide and I schedule all the tv shows that are going to be on. So I know that if I am pretty bored right now, let's go watch tv. I try to get up and walk when I can, but that's not always an option. I'll sit up and

I'll work on some art, or I'll finish homework. When my friends aren't at school I'll call them they'll talk to me for a pretty long time. I was out for 124 days last year so...

AR: That's a lot.

O: Yeah, and I was on bed rest for three months because I was diagnosed with congestive heart failure. I tried to keep that pretty under raps, though. I didn't really tell my friends all the details until it was over with because I didn't want them to worry.

AR: Yeah, you wouldn't want to scare them. It's hard to be on bed rest when you are fourteen, or fifteen, huh?

O: You know, I was very upset. I was extremely bored. It just seems like you've done everything you could possibly do, over and over. You get pretty bored, but you try to get through it by thinking of all the good things you are going to be able to do when you are better.

AR: Okay, and you were able to do it. You got through it. If you met somebody, let's imagine, who was fourteen, and they were just diagnosed. What kind of things would you want them to know? What would you tell them?

O: Well it is a pretty rare disease, so I would want them to know that they aren't alone, and that there are ways that you can manage it. It's going to take a while, but you'll get used to it. You have to live through it, you can't survive it. So, you can't just let it be that thing that you life revolves around, because if you do, it just consumes everything in your life.

AR: That's beautiful, that's wonderful. I think, I was also saying this to your brother; I think it is just such a gift to interview a lot of teenagers who are dealing with this because it's awesome the way that everyone who is dealing with this has found a way to live their life, and to enjoy their life, and to live it to the fullest. I think you all have very inspirational thoughts for the others.

O: Thank you very much.

AR: You're welcome. So for the other teenagers, but also for the parents, like I am, of a younger child with this disease, I think that you all have words of wisdom to pass on.

O: I really hope I can help those younger kids because there weren't really a lot of people that could help my family and myself out when my brother and I were diagnosed because we'd never heard of it. It wasn't something like cancer, which people know about. It wasn't like heart disease, or something like that, that was well known. Which I'm sure is still extremely hard; it's just that it's something that nobody's ever heard of. You don't know what the symptoms are, you don't know what the ramifications are, and you have to live through it, kind of like, "Oh, what's gonna happen next?" until you get a good handle on it.

AR: Right, and even the doctors don't know what's going to happen next.

O: No, I was actually in a stress test and my blood pressure decided to hit the floor. It was like 58 over 40.

AR: Did you hit the floor?

O: I didn't actually. The doctor hit the code button and an entire floor of doctors came into the room and started rubbing paddles together. I was like, "You can't shock me! I'm not in cardiac arrest!" (*laughing*) Of course, I've seen all this on tv, watching E.R., and I'm having a heart attack? My mom is just standing there, saying, "Sit her up, lay her back down and then sit her up and she'll be fine".

AR: You probably surprised the doctors when you said, "No, you're not going to shock me". They weren't expecting you to speak.

O: Nope, they were pretty sure I was passed out by then. (*laughs*)

AR: With the disease being unknown, have you felt that you've had to explain it to more people in the community that you live in or the school?

O: You know, I've got to say, that is probably my least favorite part of the disease. I mean, I know what it is, I know how to handle it, but when it comes to explaining it, and educating other people on it, it gets so complicated. Even though it sounds simple to me and my family, it's so complex to other people. It's nobody's fault; they don't live it everyday and barely anybody knows what it is. When it comes to it, I just end up describing myself as a battery that needed to be charged. It sounds silly, but it's the only way I know how to get it across.

AR: Yeah, and yet it's so much more complicated than a battery but how do you get it across?

O: I basically start at mitochondria. So, "Did you know that the mitochondria is the powerhouse of the cell, and it's in almost every cell in the body? Well, mine don't work." I try to make it sound funny, because if I don't, it sounds incredibly scary and don't want people to start "kidding" me, or being scared for me. I'm trying to educate them.

AR: Have you had to educate people?

O: I have. I've helped to educate my teachers, my friends—that was definitely interesting. They actually took it pretty well, though. My mom helps me a lot trying to get across everything. I find that I have to put a lot of things into layman's terms, but it's so much easier to explain it using all the medical stuff, because that's what I've heard.

AR: Right. It's a funny story; I had to explain to my son's kindergarten class, what a pic line was, because I didn't want them to pull on it, and they wanted to know why he had this thing in his arm. I went in there with this idea that I would tell them that it was like an IV. It was funny because I was standing in front of the class, and I said, "Now how many of you know

what an IV is?” and they all look at me. They didn’t have a clue. You get conditioned to know all of these medical things.

O: It gets to be second nature.

AR: Right, and it isn’t to other people. It is different. I’m so glad you were willing to speak with me.

O: I’m actually really happy that you called.

AR: Oh thanks! I do think that those of you who are living with this, it’s beautiful that you truly are living and not just surviving, which is awesome.