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*In this interview with Jamie, the 18-year-old Florida native talks about growing up with mito, learning what schedule works best for her, and gives some great advice to younger kids.*

**Annie:** Hi this is Annie, I’m a member of MitoAction, and I’m here with Jamie, who is a teenager living with mito. She is 18 years old and she is here to tell us what it is like day-to-day, things she’s learned throughout the process, and some advice she might have for teens who may be experiencing similar obstacles in their life. So first of all Jamie, I’d like to say hi how are you?

**Jamie:** I’m fine thanks. How are you?

**A:** I’m good. So Jamie why don’t you tell us a little bit about yourself. You’re 18, so are you going to school right now? Are you working? What is a typical day like for you?

**J:** I am going to school. I’m in college so I got to FCC. I go two days a week, well three days if you count Wednesday night. I don’t currently have a job, but I babysit a lot.

**A:** Oh, okay, that’s a lot of work. So are you going to school part-time then?

**J:** I’m enrolled full-time.

**A:** Oh okay.

**J:** But I chose to have all my classes on Tuesdays and Thursdays.

**A:** Oh, that’s nice. So what kind of things do you like to do besides going to school and babysitting?

**J:** I’m on the computer most of the time, and just hanging out with my friends, and my boyfriend and stuff.

**A:** What kind of things do you like to do on the computer, listen to music?

**J:** I listen to music all the time. I talk on AIM, and I have a MySpace. I get on email, I like to play computer games like World of Warcraft and Grand Theft Auto. My boyfriend has a band so I go to a lot of shows.

**A:** Oh, that sounds like fun. So, you have mito, and I was wondering if there’s anything that you’d like to share about how that affects your ability to do some of these activities you enjoy.

**J:** Since I have mito, it’s the reason why those are the only things that I do, because I used to love

to play basketball back in middle school. It was a lot easier for me, but it's gotten a lot harder, so I don't really play as much.

**A:** So you try to focus on things that don't take as much energy?

**J:** Yeah, and at school, since getting from class to class...by the time I get to the next class I am just ready to sit down. It takes a lot of energy.

**A:** So I'm guessing that you set up your schedule like that so that you have just two days of school.

**J:** Yeah, it's a lot easier than going every single day. That way, I get to rest and focus on being able to do my homework the other days, and just hanging out and stuff.

**A:** Do you feel like that is working for you? Having those days off is enough of a break?

**J:** Yeah, I think it does help.

**A:** That's good. Can you tell us a little bit more...you said in middle school you used to play basketball, so when did you get your diagnosis of mito?

**J:** I've had it since I was born.

**A:** Oh okay. So, when did you first notice the symptoms?

**J:** Well my mom and my brother both have it, so I guess when I was born they noticed it from the beginning, that I had low muscle tone and everything. I've noticed since I was really little that I was different and I couldn't run as fast or do things that other kids could do. It's just progressed, as I've gotten older.

**A:** What kind of symptoms do you have besides not being able to run as fast?

**J:** It's a lot of fatigue. Something I might be able to do today, I won't be able to do maybe tomorrow. If I went to Disney or something, I would be really tired the next day and not able to do a lot of stuff. And I'm really weak, and a lot of my friends who don't really know that I have it, that I haven't really cared to tell them about it, they don't realize that and they might be rougher on me, and not know what's going on. Or if they push me or something, and I fall and they don't understand what happened. They'll be like, "Oh, I didn't push you that hard".

**A:** Do you usually tell your friends, or just your really close friends?

**J:** Normally just I tell whoever. I don't really care who knows. If I don't get around to telling someone...

**A:** So you don't really see a reason to tell them, it doesn't really matter. It doesn't really affect anything.

**J:** Yeah.

**A:** So you mentioned that if you were going to go to Disney, you would be really tired the next day, or you wouldn't be able to do something like that the next day. So when you do go on vacations or plan going out, do you have to plan ahead so that you know you'll have some down time?

**J:** I don't really usually. Sometimes we'll make sure that we'd go to Disney or something on a Saturday. Well, this was back in high school, we would make sure that we went on Saturday instead of Sunday since I had school on Monday. But now I'd just make sure I wouldn't have to wake up too early, but that's not really a problem because I don't start school until 11, so normally I can sleep in.

**A:** So you planned your schedule like that on purpose, so you can wake up a little bit later?

**J:** Yeah.

**A:** That's a great idea. I've heard some of the other teenagers say that they drink a lot of fluids. Do you find that helpful?

**J:** I haven't really noticed.

**A:** Well, everybody's different, so it's good to hear the variety of things that could be helpful. So, it sounds like you have your schedule custom to you and your needs, and I think that's a really good point to make. You need to know what works for you, and what works for you might not work for someone else. Sounds like you have found that balance and that's great. Going back to school, when you were younger and you couldn't make your own schedule like you can in college, how did you deal with that?

**J:** Well, in high school I got sick a lot. So, I think it was in tenth grade I got put into Hospital Homebound. I took two classes at high school and then the rest of it was at home, and that wound up being even harder with keeping up with all the schoolwork. So they tried that for me so that I wouldn't get as sick, and I didn't get as sick because I was at home, but the schoolwork was just too tough so then I wound up going back to school full time. So those were some of the things they tried.

**A:** Was it harder because the work was just split up in two different places?

**J:** Yeah, because Hospital Homebound students usually only have classes two times per week, and so they have a lot more homework because they have a lot more time to do it. So I had all that homework that I would normally have for Hospital Homebound, and they gave it to me as if I only had class two days per week, and then I had classes every single day at high school—regular high school.

**A:** You found it easier just to go to your regular classes?

**J:** Yeah.

**A:** How did teachers react when you were sick? Were they pretty understanding about your absences and things like that?

**J:** Yeah, plus I went to a technology school for high school, so I could access everything online and they could just send me emails and let me know what I needed to do.

**A:** Oh, that's great. So, your teachers were really understanding, it sounds like. Did you have to approach them, or did they already know what was going on?

**J:** Some of the teachers I just told, and the ones that didn't know, at the beginning of each year we had a 504 meeting, and all of the ones that hadn't known about me got told at the meeting.

**A:** Oh, okay. Is it hard sometimes having people not know that you're sick, because they can't tell by looking at you?

**J:** Yeah, that's what I really hate. Sometimes I talk to my mom about how it would be easier to be in a wheelchair, because then people would know that there's actually something wrong with me. Like, parking in a handicap spot, because I have a handicap sticker, and when I get out of the car, people just look at me, like, "okay...?"

**A:** Like, "why are you parking there?"

**J:** Yeah. So, sometimes I think that it would be easier [to be in a wheelchair].

**A:** Yeah, that's really hard. Do you find yourself explaining what mito is? I know a lot of people don't know what it is.

**J:** Yeah.

**A:** Have you found a good way to explain it?

**J:** I just wind up telling them that it affects my muscles, and the way I do things. I'll just be tired a lot. I probably explain it differently every time I tell someone.

**A:** Right, because it's complicated, and it can be hard explaining to someone if they had no idea.

**J:** Yeah, I mean, one time, it was actually one of my boyfriends that I had a while ago, and I told him I had to tell him something, because I felt that I should tell him. He didn't know about it, I mean, he had no idea that there was anything wrong with me. So, I was on the phone with him, and I told him what I had, but I didn't really explain it to him much. So, he went on the internet and looked it up. He came back to me completely worried that I was going to die tomorrow, because there are many ways that it can affect you, in different ways, like it can be so much worse than it is.

**A:** Right, everyone is different, and if you go look online, you can find all kinds of stories.

**J:** Yeah, so I had to re-explain it to him, because I guess he was looking up the worst cases.

**A:** Well, that's interesting, because now we can Google everything. It's important to explain it to people, and maybe say that it affects everyone differently. That's another little thing you have to add on to the end so they don't worry.

**J:** Yeah.

**A:** So, what kind of goals do you have after college? What are you studying?

**J:** I want to be a nurse.

**A:** Oh, that's great!

**J:** I think maybe a pediatric nurse, or a midwife.

**A:** Oh, that'd be nice. That's a great goal to have. So are you taking a lot of science classes right now?

**J:** Right now I'm just taking the general classes so that I can get into the nursing program.

**A:** I'm sure you'll be a great nurse, because you'll be coming in with this background of what it is like having to deal with medical issues, and having been a patient yourself.

**J:** Yeah, like I'm in medical terminology class, and a lot of the different words, I already know from going to different doctors.

**A:** Right, you've heard it all. When you go to the doctor, are you more involved, now that you're older, with your appointments and things like that?

**J:** A little more than I used to be. Sometimes I'll just go by myself now that I'm older, but a lot of the time my mom will still come and talk to them instead of me.

**A:** To help you understand, and be there for you. You said that your mom also has mito?

**J:** Yeah.

**A:** And your brother, too?

**J:** Yeah, my little brother.

**A:** So, do you find that's a good support system you have because you can all relate to each other?

**J:** It definitely helps seeing that my mom is how old she is, and that she is still mobile. When we were talking before about how everybody's different, all three of us are completely affected in

different parts. Like, my brother has more neurological stuff, and then my mom has other types of stuff that is affected with her, and then I'm other stuff. It's interesting to look at.

**A:** What sort of things do you find helpful if you are having a particularly bad day, or you're tired, or you just feel bad? What can help you get through that time?

**J:** Just, all I can do is rest, I guess.

**A:** Do you talk to your family about it? Or try to take your mind off of it? Anything like that?

**J:** I don't really talk to them about it, if I'm having a particularly tiresome day. If something bad happens where I'm with another person, that made fun of me or something, I'll go talk to them, and my mom will share something that happened in her past. That helps, but that's about it.

**A:** Is there anything that you want to share with a teenager who might be having a hard time? Anything you've learned, or anything you wish you'd known as a younger teenager? Something you might tell that person?

**J:** Actually, I more like to share with a younger child. When I was younger, in elementary and middle school, is when I mainly got made fun of, because little kids can be really mean. I remember once when I was in 6<sup>th</sup> grade, and he was probably in 6<sup>th</sup> grade because he was in the same class as me. We had to run laps in P.E. and of course I was slower than everyone else. I used to have a friend that would stay back and run around the block with me. This kid came up behind me and was like, "why are you running like that?" Of course I was crying and everything, and my coach was really nice, and of course, yelled at him. Things like that happened all the time, I got made fun of when I was little. As a teenager, like, when I got to high school, things changed, and everyone was understanding of it, and they could care less that I had this disease. I just want to tell younger kids that it gets better, if you're getting made fun of. Older kids aren't really as mean.

**A:** That's good. I'm sure there are more activities that you can get involved in, maybe more as you get older, that you can't do when you're younger. Like you said, you like to go on the computer, and go on AIM, and MySpace, and you can't do that when you're younger as much. That's good, that will give younger kids some relief that as they get older people become more understanding.

**J:** Yeah.

**A:** Well, that's great advice. It sounds like you've really learned a lot, and been able to set up your schedule so that it works with you. I just want to thank you so much for talking to me today, and we really appreciate it. I know all the teens reading this really appreciate everything you've said. Thank you so much, Jamie. Bye.

**J:** Bye, thank you.