

“What is too much? At the same time you don’t want too little, because if you don’t use it you lose it... yes, it’s the same for people with mito, but for us, if you use it too much, you also lose it.”

In this interview, Dr. Anne Reckling talks to 15 year old Morgan about what it is like to be a teenager living with mitochondrial disease, advocating for herself and keeping a positive outlook.

AR: Hi Morgan, my first question would be, how does mito affect you?

M: Hi. Well, my issues include muscles and the GI track, and those are the two main ones, but also energy. I fatigue, and when I get fatigued, I get brain fog and can’t move, and also, lots of pain. Actually one of my issues everyday is chronic pain that they can’t really figure out or help. I’d say it affects me in that my human body doesn’t work like everybody else’s does, even though it looks like it should, because I walk around and I’m not in a wheelchair and so they think, “Oh, Morgan, she’s a normal girl. She can try out for sports, she can come play jump rope with us, or whatever it is, and wouldn’t have any reason not to be as good as everybody else”. The fact is, my body just isn’t as strong enough the other people, even if I would like it to be sometimes. Sometimes more than others.

AR: So, you don’t look sick, and other people expect you to be just like a regular teenager.

M: Yes

AR: What’s that like for you? How does that work with your friends and people that you meet and school?

M: Well, I’m home schooled, but I do get out almost everyday. I have a scouting program that meets every week and a fine arts academy that I attend also once a week. With the fine arts academy, there’s a drama club that I do, which meets anywhere from one to three times a week. Then the week of the show it will meet everyday for hours at a time.

AR: Wow. How do you work that? That sounds like that takes a lot of energy.

M: Yeah, I know with my scouting group, there are only five girls in the high school/eighth grade unit, so most of them understand a little bit because I’ve known them for quite some time. They understand a little tiny bit. They understand that my body has some sort of energy thing and muscle thing that they might not see. They know something’s there, but they don’t really understand what it is. I know in the fine arts program and the drama club some of my closer friends know that it’s there, but in general I don’t walk around with a sign, “Hey, I’ve got mitochondrial disease,” because that would look really silly for one thing (*laughs*). They just think of me as Morgan, the girl who might not be able to dance as well as everybody else in the big dance number during the musical. I know I complain that I’m tired. I don’t mean to complain, but I’ll say, “Whew, I’m tired today”. I sometimes wonder if some of them just kind of automatically think, “Oh, yeah Morgan’s tired a little bit more”.

AR: Are you thinking that they don't know the significance of what it means to be tired for you?

M: Yeah, or if one of them says they have a headache, and I say, "Yeah, my head was hurting or my back was hurting," or whatever. I don't think they know really how bad it is, but I don't want to sound like a whiny little brat who's selfish and wants to talk about herself all of the time.

AR: How long have you had the symptoms?

M: The symptoms have been noticeable since birth. We didn't know; we were misdiagnosed with something that we were told wasn't a big deal and it was something I would grow out of until I was ten years old.

AR: Until you were two?

M: Until I was ten.

AR: Ten, okay, wow.

M: That was when we learned it was something neuromuscular and that was when the word myopathy popped into the picture.

AR: Then the metabolic piece, the mitochondrial disease piece, came later?

M: Yeah, we started to notice the symptoms. My four brothers and sisters and also my dad have the same mitochondrial disease. So, for me, one of my brothers, or my little sister would just get sick out of the blue, and we wouldn't really know what caused it. We just thought we got GI bugs and ear infections a lot. After the word myopathy started popping into the picture and between the testing that they did and noticing that they might be "out of the blue", but some of those "out of the blue" might be because they had a strep infection already or because they ran around with their scouting group.

AR: So, they started to connect it with other things that were going on. What was it like for you to get the diagnosis?

M: Well, I've only been diagnosed with mitochondrial disease within the past year. I know I had a biopsy. In 2002, right before I turned ten, that's when we saw a different doctor who said, "Oh, I think this really is something and it's neuromuscular". I was still so young and didn't really pay attention to the doctors at that point. I just noticed a lot of extra blood tests and extra testing and I didn't really think too much about it other than "another blood test", because I've never liked needles because they always have a hard time pricking me. Then in the fall, I had a muscle biopsy in my arm and my leg. Obviously before that, my mom explained a little bit about how they think it's a muscle problem. I think somewhere in the back of my brain I thought, "Yeah, maybe my body really doesn't work quite like everybody else's". Up to that point I'd believed my body was normal and if I'd just try harder then I'd be a better ballet dancer or a faster swimmer, or whatever

it was. Or maybe I'd be able to go out for sports, because that was one thing I could never really do at all.

AR: So it sounds like there was a change in your thinking from feeling like you could just try harder to realizing that it really wasn't about effort; it was about the way your body is.

M: Yeah, and that is still a big process and it's really within the last couple of years that I've realized that, no, I can't go out for sports, but that's more about the way my body is, not because I didn't try hard enough. In a way, that's almost been a relief because sometimes I thought, "Well, if I'd only tried hard enough I would have been able to stick with the swim team and might not have always been the last person to finish the lap".

AR: So before you might have blamed yourself, or your spirit, your willingness or determination. But this time you have an understanding of why, and that it's not something that's your fault. It just is.

M: Yeah, back when I was trying that hard, I felt like it was my fault, but at the same time I really felt like I was giving it my all, and trying my best. It was harder for me to understand at that point, but as the years have gone by and I've had all the diagnoses—if I've heard one diagnosis, I've heard a million. It's only in the last year that they've said something more than congenital myopathy or metabolic myopathy for sure.

AR: So it sounds like its made it a little more clear and less confusing. Which is hard to think about with mito because it is a little bit confusing, too. It sounds like it made you experience clearer, and what was going on with your body.

M: Yeah.

AR: So, besides mito, what are your interests, what do you love to do?

M: I know when I was little I loved ballet dancing, but partially because the mito and the way it affected my muscles, I wasn't able to keep that up past age twelve. Even then I was the slow dancer. I still like to dance, but my body's not quite strong enough to do as much as I would like to. I definitely like to read, that's something I do quite a lot. I love with the drama club you get to do that acting and the singing and the dancing—even though I think I'm a horrible singer, and a horrible dancer. But its still fun, you get new experiences.

AR: You have a good time.

M: Definitely a good time.

AR: Have you found a way to work around any of the mito symptoms? Have you found a way to know what you need to do to be able to do some of the things you want to do?

M: Yeah, I know kind of explaining it to, like, my scout leader. I went on a camping trip a couple of weeks ago. We had already talked about it some, but my mom, especially, and me, talked to the

scout leader about when I'm tired, that I need to eat regularly and drink lots of Gatorade and be sure to get rest. We were all going to be sleeping in sleeping bags, and because of the size of the tent and the car, it turns out the tent was huge but the space in the car was small, she didn't want everyone to be bringing foam mats or air mattresses or anything. But my thing is, that I already hurt pretty badly everyday for no particular reason that we can find. If I sleep on hard ground for two nights...and maybe taking a hike and going fishing during the day—which turns out we didn't do because it rained the entire time! But I would be a lot more sore sleeping on the ground than sleeping on the air mattress. So my mom talked to her, and I ended up bringing the air mattress and it ended up being okay.

AR: Good, good. So it sounds like part of the key is letting other people know what you need, and being clear about what you need.

M: And not just suffering in silence, which is a thing I tend to do more than I should sometimes.

AR: Do you?

M: Yeah, I don't explain to people. Back in February, I missed the drama rehearsal because I was in the hospital, and it was hard to explain, because they had seen me the Tuesday before and I had looked mostly fine, maybe a little under the weather, but all and all, pretty good. So, to hear that I'm in the hospital the next night, I don't think most of the people understood it at all because they've never heard of the term mitochondrial disease, except from my mouth.

AR: Right, and most kids and teenagers who do get sick don't end up in the hospital.

M: They just get sick and get better.

AR: Right, it's different with that. So, not suffering in silence, communicating what you need, making sure you get enough rest, drinking a lot. I hear that from a lot from kids, that fluids seem to be really important.

M: Yes, definitely stay hydrated and get sleep. I know they talk about how when you're a teenager you need sleep, but somehow it's the teenage years when you get the least sleep. You really need to try to get sleep, because I know it definitely makes a difference for me. Whether it's because of the time I get to bed or because I just can't sleep well during the night, then it happens over and over again for a couple nights. By that fourth or fifth day, I am definitely more tired than I would be just from not sleeping well, or just not getting enough sleep, or if I spent too much energy yesterday.

AR: Have you found it helpful being home schooled to be able to plan your rest time or down time?

M: I have. We don't get up at 6:00 am, and part of that is just our family schedule. We get up between 8:00 or 9:00, and get up and do school work then. On those sick days, I've been known to bring my biology book to the hospital, and they just look at me funny, but I don't really mind it. As long as you're feeling good, do your school work and then maybe on those days when you're

feeling pretty good, and you didn't get as much school work last week because you were sick, you could do some of that to catch up for next week. Rather than just saying, "Oh, I'm behind now, oh well".

AR: You sound motivated and determined to work with your schedule to do the things that are important to you. Do you have dreams of what you want to do when you grow up yet?

M: I'm still trying to figure out what sort of career I want. I am currently definitely thinking a lot about being a nurse of some kind, or at least something in the medical profession. Right now my dream is to graduate high school, graduate college, and to have a job of some kind, even though I don't know exactly what it will be yet. If I meet the right guy, then getting married and having a family.

AR: Just living a regular life, right?

M: Yeah, just living a regular life. Just, faith in God, and living life to it's fullest potential and not just sleeping on the couch saying, "Oh, I've got mito, if I move I might hurt more or get tired". I don't want to spend the rest of my life on the couch feeling bad about myself.

AR: So you keep pushing yourself, but you find a balance to make it work so that you don't hurt yourself.

M: That's something that within the last two years that I've been playing with. What is too much? At the same time you don't want too little because if you don't use it you lose it. And I talk about that not just with mito, but with everybody. Yes, it's the same for people with mito, but for us, if you use it too much, you also lose it. So, you end up breaking up the muscle, and normally people can build it back up, but I can't as well as other people do.

AR: So you have to work to try to find that middle point, that middle ground.

M: Yeah, just a daily general exercise program that's definitely gentler than most people would think aerobics would be, but it works for me.

AR: That's great. One of the things I want to ask all of the teenagers that I'm interviewing is if there's anything that you have learned that you wish that you'd known earlier? In other words, is there anything helpful for a teenager who is newly diagnosed to hear or learn from your experience?

M: I'd say there are two things. One is just to pay attention to those doctor's appointments and ask your parents what the diagnosis means exactly. If the doctors are prescribing a new medicine, ask what it does. Even if the question sounds really stupid to you, go ahead and ask them. Don't be afraid and think, "I'm actually really curious about what that is going to do for me, but I don't want to sound like a baby and ask a really obvious question that all the other adults know the obvious answer to". Just go ahead and ask, because I've found it's important to know what you're dealing with know more about mitochondrial disease than that it's just this energy thing with muscles. Know what it is. You don't necessarily need to become a PhD and know that

mitochondrial disease is when your complexes don't work, and exactly how they don't work. Know how it affects you, what it is, and what you can do to work around it.

AR: So becoming knowledgeable in your own illness and also in the medicines and the medical interventions. I imagine that paves the way to becoming an advocate for yourself as you get older.

M: Yeah, and you can't advocate if you feel depressed all the time. Even if you don't plan on being any sort of advocate for mito, other than just living day-to-day life, just remind yourself that no matter how bad it is, there is always—always—somebody out there who has it a lot worse off than you do. So don't be depressed. Everybody has their bad days. I've certainly had mine, nobody's perfect. Just remind yourself that it could be a lot worse and you should be thankful for what you do have. I've got the ability to walk around, to get up and get a glass of water and drink it without choking. There's the age old question, "Why me?" and the answer is, "Well, why not me?" It can certainly be extremely hard and can seem like you can't go on. It's like, "Why should I? Nobody cares, nobody understands". Yes, it's bad, but it can be worse, so do what you can with what your body can do.

AR: Has it helped meeting other kids with muscular issues? Seeing the variety?

M: Yeah. I went to the camp for the Muscular Dystrophy Association. It's ages 16-21 and all the campers there have muscular dystrophy of some kind. I started going when I was 10 or 11 years old and I've been going every year since then, and I'm planning on going this year again in July as well. One of the things that's a perspective changer for me is that I go around in my day-to-day life, and in my drama club with my peers I'm one of the weaker ones, even if I don't look like it. I just feel like I can't go run and have a race around the building like my other classmates but at least I can still walk around the building. Then to go to camp and see that I'm really one of the strongest people there, and the fact that I can get up, take a shower, brush my teeth, and dry my hair without needing help. You don't realize how good you have it until you see people who have it worse off than you. I know some girls who are sweet, sweet people and really fun to be around, and they can barely clap their hands. They've got great personalities. To see how happy they are, and even if they aren't happy are the time, but I can see that you can be a person who is fun to be around and barely able to move your lips. Just be happy and have a good outlook on things, and look at yourself, and realize I can do all these things, and here I am feeling bad because I can't be on the soccer team.

AR: Sounds like it gives you some perspective, and helps you see, correct me if I'm wrong, what's important in people. That it's not necessarily about being on the soccer team, but its about the joy and connection they can bring to other people.

M: Yes, they always say pay attention to how a person acts, and how they look, what sports they are in, or if they are in any advanced math class or anything. The personality is really what you are going to like, or not like about a person. It's not so much about how Austin is a great soccer player or he's the quarterback on the football team, but that Austin's got a great personality. I'm actually thinking about an Austin that I know. He a funny person, he's hysterical, he's actually got a lot of

wit, and fun to be around, but he's in a wheelchair and he can't move. He is definitely a really fun person to be around.

AR: One of the things that I get amazed by the teenagers living with mito is the perspective that I find that you have on life that is different from other teenagers. Almost having a perspective that is more mature, being able to see what is important.

M: I think it's one of those things, like a natural disaster, that might tear apart your house and then you get a different outlook on things, obviously, because it's so sudden. People think of those as the big perspective changers, and that it's what taught you what is really important, like if somebody broke in and set fire to your house. Yes, those things definitely do, in a way, change your perspective, but also having some sort of physical condition that you have to live with everyday, even if people don't see it. It's definitely more important to be a good person, and to talk to people. There's more to life than just being the quarterback of the football team, or being the cheerleader.

AR: Well, thank you so much for talking with me. Is there anything else that you are thinking that you would like to make sure that other people know before we stop?

M: As far as coping goes, there's the whole, "Everybody's got it worse off than you do", but how I end up dealing with my day-to-day life is through my lord and savior, Jesus Christ. He has definitely helped me. It doesn't really make much sense until it happens to you. In my weakness, he is strong, and he has definitely meant a lot to me in my life. I don't think I would be nearly as optimistic and happy as I am on my good days if it weren't for Him.

AR: So you found that to be a comfort and a solace for you?

M: Yes, definitely a comfort, and he makes he is definitely stronger than I will ever be, even if my body was stronger.

AR: I am so glad you spent time talking with me today, thank you.