

“I come first... because, who knows? I have the energy now, but I might not have it tomorrow, I might not have it next year, you never know. I have big plans for myself.”

In this phone interview, Dr. Anne Reckling talks to Donovan about his experience as a teenager who is living life to it's fullest despite having mito. Donovan gives his outlook on his friends, teachers, sports, and balancing his energy.

AR: Hi, Donovan

D: Hi

AR: How old are you?

D: Sixteen.

AR: What grade?

D: I'm finishing up my sophomore year so I'll be a junior next year.

AR: When were your diagnosed?

D: I think it was only 2 or 3 years ago. It took us quite a while to get to that point.

AR: Can you tell me about the diagnosis process? When did you first start noticing symptoms?

D: We first started noticing things in middle school. Around 6th grade, teachers were emailing my mom saying I was lethargic, and that she should take me to the doctors be get checked for mono. I got tested for a lot of things, had regular doctors appointments, and was told everything was fine. Then I started to miss a lot of school and get sick a lot. Finally in late 6th grade and early 7th grade, I seemed to have had an allergic reaction. It was like I was allergic to strawberries. My face was red and itchy, my eyes were puffy and I was real tired. It looked like I needed Benadryl or something, but I wasn't allergic to anything. We went to a couple doctors and they suggested that I be tested for food allergies. So I went through the whole elimination diet and had to bring food to school. I spent one whole week pretty much just eating salad, no dressing or any of that stuff. Then we started to work things in little by little. It was terrible. I was starving myself trying to eat the bare minimum. It was real tough to do right in the middle of school. But it wasn't always that bad. Sometimes I would show up to school with a baked sweet potato and all kinds of stuff like that and kids would want to switch meals with me from school food.

The elimination diet didn't work. I was still having these allergic reactions even though I was eating almost nothing. I went and got the allergy shots with all the different things in them, like 100 different shots in my back and arms. I got all those and still

nothing. We went all the way to Portland, Maine and saw one of the best allergy doctors in the state and that's where I had to have all those shots and I wasn't reacting to anything on my back. Then when I was sitting in the doctor's office after I had all those shots, my face started to break out right in front of him. Everybody was confused and he basically said, "I'm sorry, but I don't know what to do," and I got shipped from doctor to doctor. People got confused, discouraged and they would just drop me. It was terrible. I'd wake up some days and my eyes were swollen shut and I couldn't really see. It looked like I got in a bar fight the night before - it was bad. We went from doctor to doctor and finally we hooked up with Dr. Burt Adams. He was a real big push for us, sent us down to Boston and got us introduced to a bunch of people.

First I would go to a rheumatologist because I had real bad joints and lots of joint pain. A couple of them looked at me and one of them checked my joints because my hips were really bothering me. He checked me over, looked me right in the eye, and looked at my mom and said, "I'm going to give you a business card to a psychologist who is just down the road". That happened quite a bit. Everyone was saying, "You should go to a psychologist instead". No one could find anything physically wrong with me. I was healthy, I was on the swim team, had been physically active all the time, I was in good shape, and had good eating habits. It turns out that when he referred us to the psychologist it was the best thing that had happened to us so far. Dr. Elizabeth Spark near Boston diagnosed me. Dr. Adams almost made the diagnosis himself, but he had a lot of ideas and she pretty much solidified them for him. She determined that I had Sjogren's syndrome, which is something that usually elderly woman get. It effects joints, hinders your sleep ability a little bit, and dries the eyes and mouth - which are things I was suffering from already. I had no tear production at all in my right eye and my left eye was barely there. I was on eye drops all the time. So that accounted for most of the joint pain and then she also wanted to follow the lead of mitochondrial disease.

AR: Is she the first one that brought up mito or had that been brought up before?

D: Well Dr. Adams up here in Maine brought that up first. He had the idea and when I got back from Dr. Spark down in Boston. He started me on the [mitochondrial cocktail](#) (Coenzyme Q10 and all that stuff), but just a little bit of it, though, because he didn't want to go full into it. Then we were referred to a genetics doctor down in Boston, Dr. Gorson. He said, "Well, you're doing the right thing here, so let's just amp it up a little bit". He pretty much tripled the cocktail and from there we also went down to Atlanta.

AR: So you had a muscle biopsy down there [Atlanta]?

D: I did. I went down to Atlanta and they took 2 ½ inches of muscle out of my left leg. They stitched me up and sent me home the same day. We got those results back about 6 months later.

AR: What did they find with the muscle biopsy?

D: They found that I did in fact have mitochondrial disease. I do believe it was complex; 1

and 3 deficiency, I'm missing 2 complexes in my mitochondria. It's funny because I just finished up college prep biology in school so I'm learning a lot more about it now, and understanding a lot. I contribute to class and talk about myself a lot.

AR: You sound like you are fairly open about what you have dealt with.

D: Everyone knows and if people don't know I say, "Hey, do you want to hear something fun?" They call it the invisible disease because if you look at me nobody would think twice. I definitely don't look sick. I was a swimmer for 3 years from 6th through 8th grade, I was 7th in the state in a couple of my events, and I was keeping up with things. Then I started to fall behind a bit because it was just getting worse and worse as I went along. It would tire me out a lot. Don't ever let anyone tell you that swimming is not a real sport. It takes more out of you than you can ever imagine. You use every single muscle.

AR: How do you deal with it now? You're 16, you're open with people, how are they? How are the kids at school? Do people give you trouble about it? The teachers or anything?

D: The biggest thing has probably been teachers. My friends really don't care. It doesn't affect my social life at all. If I'm hanging out with friends and I just happen to be tired, (usually I'm not because I just push through it because I'm having a good time) I don't let it keep me down all that much. Some teachers have had a problem with it because I have energy pretty much whenever my body wants me to have energy. What I do the day before will most likely effect me three days down the road so there is really nothing immediate about it. The sport that I do now is mixed martial arts. It is the UFC stuff and the cage-fighting thing. That's real brutal sport and it is real fun. I got turned on to it by some friends so now I'm the only kid in the gym doing all the grappling, wrestling, boxing, all that stuff and keeping up with all these big guys. A lot of teachers just don't understand how I show the video on my camera of me in a big state tournament, winning this big trophy just a couple days earlier, but then I was too tired to go home and complete the 75 questions in algebra. It's me trying to endure myself and use energy when I have it to stay fit versus teachers and homework requirements.

AR: Maybe they would want you to just totally focus on school, if you have some energy you should be doing it on school and not living the rest of your life.

D: Exactly.

AR: And you say you don't look sick so it is hard for the kids.

D: No, I definitely don't look sick. I'm in the gym all the time, lifting weights. I go into the gym after school with a couple of teachers. Just a little while ago I lifted 305 pounds and then I just kept going with everything else so people wouldn't realize. I'm not a big kid; I'm 5'7" and weigh 155 pounds. I just try to keep in the best physical shape I can. It's really hard for me to keep up with a normal schedule of school and the flow of things.

AR: So how do you make it work? What do you do? It sounds, like most of the teenagers I talk to, that you want a life. You know you're not just about school and there are a lot of things you would like to do. How do you do it? How do you fit it together? What do you do for your body? Are there certain things you have to do?

D: I come first. School doesn't come first. When I say "me", I don't mean "me" personally, I just mean my time with friends and family, keeping in good shape and all that stuff. There are two major things in life: there are things that I want to do for my own well being, to be happy, have fun, enjoy life, learn lessons and things like that, and then there is school. I would much rather do a bad job in school and have teachers not be happy with me than devote all my time to school work and not go out and live life. Because, who knows? I have the energy now, but I might not have it tomorrow, I might not have it next year, you never know. I have big plans for myself. I'm going to United Technology Center for the next 2 years of school where I will learn to be a mechanic because I'm a total grease monkey. After that, I want to continue in the gym and see if I can make a professional career of mixed martial arts fighting and a lot of stuff, so it's not really based around schoolwork. I'll do what I can, get the best grades I can, continue to learn everything, but I'm not going to give up dreams and give up my time and energy for a report that is due the next morning.

AR: It sounds like your dreams aren't ones that would require the heavy academic background. It's a different type of learning that you will be doing.

D: I'm not saying I totally slack off and stuff, but when I don't have the energy I just limit my activities at home and at school. I try to keep an even balance and usually it works out okay.

AR: Do you go full day to school?

I go every day. My 8th grade year I missed 45 days of school in a year and I still passed with high honors.

AR: Congratulations!

D: I still made honor roll even though I missed more days than a lot of my friends who were in school.

AR: Do you have to change the way you eat or drink? Do you have to make sure you have more fluids or does it really affect you?

D: I'm supposed to drink over 90 ounces of water a day, which is a lot. It is real tough because in school we have 80-minute periods, so if I get up to go to the bathroom and I come back, I miss a big chunk. I go to a school that is very big in academics; it's a very tough school. It's a normal public school but the rest of the state has done away with the common assessments and our school decided to keep them. There is a lot of work involved. I just finished up yesterday a 17-page college-prep bio final with 105 questions.

AR: Are you guys out of school for the summer or hasn't school ended?

D: School hasn't ended. I get out on the 16th.

AR: You sound very upbeat.

D: It's getting towards the end of the year and we have half days now so I'm pretty happy.

AR: You sound positive. It's neat to hear you sound positive about a future and what you want.

D: Well, if you can't be positive, you're not going to go anywhere. I have lots of friends who are completely healthy and they don't do anything. They're in terrible physical shape just because they're too lazy. I say, "Hey, look at me".

AR: You sound clear in what you want and I think one of things that I have noticed in talking to teenagers around your age who have mito is that they have very defined ideas, may be more defined than I'm use to hearing from teenagers...more defined ideas about what they like and what they want to do with their life. What I hear from this is what you said, which is you don't know what tomorrow is going to bring. You don't have that sense of invisibility I think a lot of times teenagers do.

D: You never know what's down the road, so just make the best of what you have while you have it and always give it 110%.

AR: Is part of keeping your self as healthy as possible part of also your desire to fighting mito?

D: Very much so. If I don't get out there and exercise and keep my body as fit and as efficiently running as possible, then I'm not going to go anywhere. It seems kind of almost backwards because mito is zapping you of energy. Your body can't take other materials and turn them into all the chemical components you need to use energy properly, but the more you go out and exercise and the better you keep yourself in shape, the better your body will be able to manage on its own. What the doctors told me was if I lift weights and keep my muscles physically strong and fit, then crucial energy can go to other parts of my body and the muscles can hold their own. I'm in the gym lifting weights. Even in gym class I'm putting in over half the effort the other kids aren't. They just don't feel like doing it and a lot of people say, "Hey, aren't you sick? Don't you lose energy real fast?" and I'm like, "I have energy now and I'm going to use it to enjoy my time".

AR: That's a wonderful way of thinking, a wonderful way of approaching it for anybody- whether you have mito or not.

D: Everybody should be proactive in that way. Life isn't always fun and everyone always gets down about certain things. I figure I'll throw all the positive energy into my disease

and situation that I can.

AR: One of the things I have been asking people is if you were to meet another teenager who was just diagnosed with mito, is there one particular thing you maybe want to say to them?

D: The biggest thing for me when I got diagnosed was I was more relieved than I ever have been. Just to know what I had, because I had been going for almost 4 years looking for what I had, going from doctor to doctor, and everyone was telling me it was all in my head when it wasn't. So once I got over the fact that I have this, I was relieved to know what I have. I actually got to focus on what the real issues were. Probably the biggest thing I would have to say to someone is: Don't let it control you, you control it. It is very much real; it is not in your head. Don't let it keep you down. Even if I'm tired, I rest for a little bit, I still go to the gym and I will get my energy probably half way through my work out and I start feeling a lot better. Sure, I'm tired after, but I go home, take a nap, rest, eat lots of carbohydrates and of high-energy foods, and I'm good to go the next day. I don't look at it as a disability, it's something I have, get over it, live with it, and move on.

AR: It sounds like you're all about living. Yeah, you have mito and yeah, there are ways it affects people differently and they have to find a different way to compensate but everybody I have talked to is working to figure out a way to live and do the things they love to do.

D: I have a disability and half the people I know don't even know about it. If they don't know about it, I'm not ashamed to tell them about it or anything. I don't use it as a crutch. I just tell them how it is, and I don't let it put me down. Just do the best you can and be proactive.

AR: Thank you so much.