

“We don’t let the disease control our lives, we live through it and we make sure we give ourselves time to do what we want to do.”

Harrison is 19 years old and talks to Dr. Anne Reckling about having mito while attending college, focusing on his dreams and dealing with frustrations.

Anne Reckling: Hi, thank you so much for participating. It’s very helpful to other teenagers who are recently diagnosed, or are living with the disease, and even helpful to the older people, and the parents to hear your stories. I wanted to start first with how you were first diagnosed, or how long have you been struggling with the symptoms and how it affects you?

Harrison: It started at the end of my sophomore year of high school. I was sixteen and it was the last few weeks and I started out with what we thought was a virus. We went to the doctor several times, couldn’t shake the virus, couldn’t get rid of it, and eventually just before I graduated I walked downstairs, and my dad told my mom that I looked just like my sister did right before she crashed. So then we started the whole process, and it took us about a year and a half to get the diagnosis. I ended up being out of school my junior and senior year.

AR: So you were homeschooled?

H: Yes, we set up a 504 with the school and I took all of my academic classes at home and was exempt from gym. I had tutors for math, writing, science, and history.

AR: So you didn’t have any symptoms until you were sixteen that you can look back and see?

H: We look back and prior to sixteen, we don’t really recognize anything, aside from maybe an extra hard cold or getting really tired. That could have been a symptom. I was perfectly fine.

AR: Gosh, that must have been scary to be doing fine and then to have it crash on you.

H: Yeah, it was tough because I was used to being able, I’d get a cold, be sick for a day or two, and I’d be back on my feet doing everything I was used to doing, everything I liked. It was a tough adjustment. It was real hard to all of a sudden realize that when I did have a crash, I’d be down for weeks. I couldn’t go out, couldn’t do stuff with friends, couldn’t hang out.

AR: Right, right. In the beginning when you say crash, what’s it like for you? Because I know that it’s different for everybody, or for people.

H: Most of my crashes involve getting debilitating migraines, and I end up sleeping usually 17-18 hours of the day for a week or so.

AR: And that makes it pretty hard to be a teenager.

H: Yeah, Can’t go out, can’t really have any friends over, because we don’t want to be exposed to any sicknesses that have been going around. So, it’s kind of like I’m being secluded.

AR: Yeah. You're sister was already diagnosed at the time?

H: Yeah, she had problems since birth. I believe it took 9 years for her diagnosis. It actually ended being a fluke. She was in the hospital for Kawasaki's disease, which is totally unrelated. There just happened to be a doctor who was specializing in mitochondrial disease at the time at the hospital who saw her, and put two and two together.

AR: That's amazing. Wow, that's really amazing.

H: It was real lucky for her.

AR: Yeah, and in a sense for you, too, in the sense, that if you have one at least they know to look for it if you have a sibling, or a parent with the disease. Now, you're 19 now, and your mom mentioned in the email that you're in college. What kind of stuff do you like to do? What's going on with college? How do you make it all fit?

H: Right now I'm taking four courses for full time course load. I take an algebra course, I take a writing course, I'm taking biology, and sociology. It's Science-D track the Community College of Rhode Island. It's geared for getting you ready for a four-year pre-med program. Eventually, I'd like to get all of this under control and be a heart surgeon.

AR: Wow, that is amazing. That is a great goal.

H: Right now being the freshman year, the first semester, I'm getting used to a lot of adjustments, realizing I need to be super careful about how I manage my time. This past week and a half I actually missed several days, because I didn't manage myself well, and I ended up having some migraines.

AR: How do you manage? You say manage yourself, what do you do?

H: I basically, for me, its not too, too difficult, I just have to rest a lot. I can't go out, I don't go out and drive around and see movies. I stay at home, I sit down, I watch TV. I also monitor to make sure that I am eating and drinking enough.

AR: Okay, that seems to be what I hear a lot of the time. Not only the rest, but particularly eating, and particularly drinking, getting enough water. Getting fluids seems to be important. You're able to eat okay? You don't have any G-tube or any of that?

H: No, I have no digestive problems. My main systems involved are my eyes, and muscles. I actually have a little bit of a hard time keeping weight on due to metabolism, but that seems to be working itself out right now. I'm in pretty good shape. My eyes—actually without my contacts, I'm legally blind. I believe its 20/800 in one eye and 20/400 in another.

AR: Wow, now is that related to the mito?

H: They believe it is, because it happened in the course of a few months.

AR: Oh, okay. So it's the migraines, the eyes, and the muscle weakness mainly.

H: Yes, now the other thing with the recent migraines, I ended up noticing that I was having some other issues, that I believe were emphasized by the migraines, so we went to the hospital where I recently was diagnosed with epilepsy.

AR: So you started having seizures.

H: Yes. I don't have grand mal seizures. I believe they called them absence seizures, which are its as simple as, I'm sitting here talking to you, I pause for four seconds that I don't notice, and then pick up right where I left off.

AR: Okay. Now did they give you medication to manage that?

H: Yeah they put me on Lamictal.

AR: Sounds like you are taking a full load at school. That would take up time. Before that, were you pretty busy with school or did you have any other activities?

H: Prior to this, I was keeping up with school, getting all my work done at home, pretty much throughout school we were able to facilitate it so that I could have my work done on my schedule. That actually left me with the energy expenditure at a point so that I could get out and go and do things with friends, go out and have fun, see movies. We don't let the disease control our lives, we live through it and we make sure we give ourselves time to do what we want to do.

AR: That's awesome. That's wonderful. And I think that sort of thing is so important for people who are newly diagnosed to hear because you can get on the internet and read very difficult stories, and those are real, and there are also people are living with the disease and going on with their life, not letting it control them, like you guys are.

H: I think one of the most important things for people who are in my particular age group, the hardest things is that you have a greater understanding what is being said. Somebody who was my sister's age when she got diagnosed, she didn't really understand that the disease can take a turn for the worse and end up being progressive, and what that progression is. I think that is harder, but it's also better because it allows you to put what you want to do in perspective and let you decide, "I'm going to do this, because I might not be able to in the near future".

AR: Okay. It gives you a different perspective because you understand what is the possibility, of what could happen. It also must be different, too, I'm imagining the contrast, of feeling good, to feeling bad. Where as kids who are diagnosed early. I can use my son as an example. He was three, but he'd been having problems since he was one and a half. This is his life. This is what he's known. So for him, there isn't so much of that recognition. I think as kids get older, they recognize it in other people, the differences.

H: I actually just had a discussion about that with my mom. That's one of my toughest things, realizing I know that I am capable of doing everything I want to do, and I am capable of achieving the academic status that I want. But then I realize that frustration of physically; I'm not in a place to attain that yet.

AR: Your body won't let you right now.

H: Right.

AR: Now that would be very frustrating. And at your age, it's the age...I'm just thinking of late teens/young adulthood, you're thinking about what you're going to do with your life, what you want to be. It's a lot about your goals and dreams.

H: Yeah

AR: How's it been with friends? What has it been like for you?

H: Actually, I had a few close friends that I had gained through the middle school and early high school years that stayed good friends throughout junior and senior year. Other than that, I didn't really have much of an opportunity to branch out and meet new people, just because I wasn't in a social environment. I wasn't at the high school everyday meeting people, talking to people. I wasn't at the mall with people hanging out. I wasn't out doing everything everybody else was. It was tough to have to rely on a few good friends as opposed to a bunch of people to call up to hang out.

AR: That would be frustrating.

H: My senior prom, I ended up making it to my senior prom. We purposefully set stuff up so I would be able to go. I had a friend who I've known since before I was born, and she flew out, and she went with me. I got home that morning and we brought her back to the airport, and I sort of had a little bit of an emotional breakdown because it was tough being back in the environment, seeing everybody who was hanging out who was friends and realizing that I had missed all of that friendship making, or social networking.

AR: And all those experiences that are sort of typical of juniors and seniors in high school.

H: The one thing that I can say was actually good that came out of it was we learned how we have to manage everything for my sister she that doesn't have to go through all that. We have her at a place where she is attending school as much as possible to be with friends, and do all of that social networking.

AR: Okay. So, in a sense, she's learning from your experience, from what you went through. So other than senior prom you really weren't around the school a whole lot.

H: No, I went in once or twice when there was a field trip for an elective I was taking, or something like that, but I didn't go to school for any academic classes for two years.

AR: That was done at home?

H: Yes

AR: So you rest, you eat, and you drink, and if you do those things you are able to manage. Well, sometimes it may feel like, “Well, maybe I have no energy, maybe I feel like crashing,” and sometimes it feels good? Is that sort of the way it goes?

H: Yeah. Right now with the college schedule and everything, we are trying to push the envelope a little bit to see what I can do to see what I can do to make myself feel even better, so that I’m not as tired as much. I’m trying not to sleep as much during the day. One thing that we have contemplated switching so that I am on a normal, but awkward sleep schedule, is I might take night classes next semester, so that I can sleep during the day and then function at night. That is sort of the schedule that I’ve been on.

AR: Okay. So you like functioning in the evening. So you stagger the sleeping?

Yeah.

AR: Does it help? Is that working? Or you are thinking of that for next semester?

H: I’m doing a little bit of an experiment right now. One of my professors is allowing me to attend one of his evening classes, but stay registered in his day class. So, I’m going to be attending that later at night, and I’ll see how that works out, being able to rest during the day and then go back at night.

AR: That makes sense. It sounds like for what you are talking about you have to be very flexible to try new things. How did you end up deciding to be a heart surgeon? That is very specific.

H: It was actually my junior year one of the few things I did attend, my teacher made it so I could go in afterschool hours and just with him, it was a dissection lab. It was the dissection of a heart, and it was one of the coolest things I had ever done.

AR: That’s great.

H: Also, that same teacher, he also in my high school they have what’s called a senior project. It is basically a thesis paper and fieldwork that you do, and it’s a project that you pass or fail to graduate. He got me into a program at Rhode Island Hospital, in their research lab where I was able to volunteer and help out with the care of the animals, and watch some surgeries.

AR: Oh that’s amazing. That must have been so fascinating. Wow, that’s really neat. You’ve let me know what works to cope and how to get through things. What would you say isn’t helpful?

H: Eating a lot of junk food (*laughs*), anything that is sort of normally mad for you is multiplied tenfold for kinds my age with mitochondrial disease. You have to eat. Eating constantly, as opposed to, as most people would say you are supposed to eat three good meals a day, graze. Graze on good things, like if you find a vegetable that you like and just keep that, so you are eating five servings of that a day. Have a lot of water. I have a water bottle that I fill it up, I drink it, and when it's empty I fill it up again.

AR: So you keep yourself really well hydrated.

H: Yeah, and its not eating a lot of stuff, it's just to constantly have something good for you that you're putting into your body. I'm starting to find out that the more doing a little bit of exercise here and there, isn't bad. So, in the school, there are elevators, but I'll take stairs up and down. It's as simple as two flights of stairs, but it's walking that and walking out to my car. But it's also not overextending yourself and doing four flights of stairs.

AR: Finding that balance, which I think is a challenge at any age, but I think it's even more a challenge, at least it would have been for me as a teenager, to reign myself in, and to know what I could do. Not even to know what I should do, just to get myself to stop.

H: I've encountered that a few times. I have felt absolutely fine when starting the activity and I have extremely overexerted myself, and I have come to about an hour after the activity being crippled. Either from getting a headache, or a muscle cramp.

AR: Right, and I guess that's how all of us learn. We overextend ourselves. If you think back about what it was like to go through this, and it's been fairly recent since you have been diagnosed, is there anything that you wish somebody had told you, that you want to pass on to someone else who might be walking in your shoes.

H: Is there anything that I would want to pass on...I think that the doctors I've encountered have been really good. I can't think of anything that I wish the doctors had told me. The biggest thing that I would pass on to other people is it's a disease and it can be dangerous, but it can't identify who you are, and you can't let it control you. You need to realize that whatever point you are at, there's somebody worse off than you. You have the ability to do whatever you want to really. With the seizures, I have my motorcycle license, and with the proper medication, I go out and drive the motorcycle with my dad every once in a while.

AR: Wow, that's great. So realizing those dreams, and not having it limit you.

H: Living the disease, not surviving it is the key.

AR: That's a great quote, we should have that up on the site.

H: I believe that is from a book called *The Secret*. The book is actually a scientific based book, based in quantum physics, the real simple idea around it is that your emotional aura that you put out will be returned to you at some point. So, if you put out good vibes, and you are nice to people

and you have a positive outlook, that will come back to you. If you sit down and seclude yourself and put out negative vibes, then that will come back to you.

AR: That makes a tremendous amount of sense. I think one of the things I've enjoyed most about interviewing all of the different teenagers is that I hear that from them. All of them are finding ways to still live their lives. They live their lives and they may have to do things a little bit different, they may have to change things, but they're still able to realize dreams. That's an inspiration for other teenagers. I think it's also an inspiration for those of us, those parents who are raising young children, when we look to the future for them. Thank you so much for talking to me today. I really appreciate it.