Dysautonomia with Miss Chile Ambar Zenteno

Speaker Key:

VO	**Voiceover**
CB	**Chantal Boyle**
AZ	**Ambar Zenteno**

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VO Welcome to The Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

CB I'm Chantal, and joining me today is Miss Chile, Ambar Zenteno, who also has dysautonomia. Is that how I say it, Ambar? Have I said that correctly?

AZ It's fine, dysautonomia.

CB Thank you. Ambar is heading to Miss World this year to represent Chile. Beauty with a Purpose started in 1972 and is the heart of Miss World. Each country chooses a project close to their heart and then presents their projects at Miss World. Amber is shining her light on dysautonomia, a term used to describe any disorder of the autonomic, which is automatic nervous system, and is also an advocate for the Hidden Disabilities Sunflower in Chile. I'm very excited to welcome you to The Sunflower Conversations, Ambar. How are you?

AZ Thank you very much. I'm super happy and honoured to be here. I'm excited for this interview. I hope to let you know a little bit more about me and what I do. I'm really happy to be part of the Sunflower group.

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CB We're happy to have you, excited to have you. I've never spoken to a Miss Chile or a Miss Anything before. I'm interested to know a bit more about that. I need to apologise because I have a cold, so if my voice sounds a bit funny, that’s why. What is it like being Miss Chile and what has your journey to be crowned been like?

AZ Being Miss Chile is such an amazing experience because it has a lot of responsibilities. It comes with a lot of time management, to work hard on the purpose that you are fulfilling, on who you are, your communication skills, your talents. It is a competition that goes all around. You have a sports challenge, you have a talent challenge, you also have this purpose activity, because the core of Miss World is Beauty with a Purpose. It has been amazing to explore and to enhance my abilities in all those topics.

The thing that fills my heart the most is to be able to put the topic of hidden disabilities, of conditions that are not visible, and about dysautonomia, on this platform. This is a condition that I also have. It has been amazing, super challenging, but I love challenges, so I'm super happy.

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CB Can you tell me a bit more about how you’re fulfilling the Beauty with a Purpose?

AZ Yes, of course. As Miss World, my fulfilment for Beauty with a Purpose has a name. It's called Turquoise Heart. The main purpose of Turquoise Heart is to raise awareness and advocate for invisible conditions, starting with dysautonomia. As you said, it's a condition or a malfunction of the autonomic nervous system, that can affect a lot of the functions of your organs, the way you regulate temperature or digestion.

It also varies from one to another. Two people with dysautonomia don’t necessarily have the same symptoms. I'm collaborating with other dysautonomia organisations, with experts, with healthcare professionals, and with national and international health platforms to also raise this message throughout different tiers to get it outside Chile. The way I'm doing it is doing little conferences or talks in schools. I talk to children because it's very important.

80% of the disabilities in the world can develop in your body before 18 years of age. It's super crucial to the kids to know what this is, to know that there are conditions that they can see either with their eyes and others that they cannot. Also, to the parents and to the schools, the professionals, the teachers, to be aware of these conditions.

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I have also talk at universities because I'm super interested in promoting the investigation of these conditions and to also have better understanding about how it works and how we can develop better treatments. I have also recently joined a group of other leaders of organisations related to healthcare, that are talking with the government to improve the laws that we actually have on healthcare. I'm doing all of that to fulfil my Turquoise Heart purpose.

CB It's quite a lot. Those organisations that you're working with, are they international or just from Chile?

AZ I have visited FENPOF in Ecuador. It is a federation that works with rare or less frequent conditions. There are also a lot of dysautonomia groups. There's one in Mexico. There are others in Uruguay. I have also been talking with them. Actually, when I was doing my campaign for winning the Chilean pageant, I made a video. It's super nice. I have it in my Instagram.

At the end of the video there's people from all over. It's mostly South America. They say, hi, my name is, and I have dysautonomia. I love that. I feel goosebumps when I say it.

CB It's a good way to capture, in a very quick way, just the fact that it can affect people of different ages and races and sizes. It's a good way to do that and also to highlight how it is a hidden disability. Can you tell me how dysautonomia affects you personally?

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AZ Personally, it has been a life challenge. I have been diagnosed now for almost six years, when I was 22 in June. I will be 28, so almost six years. At the beginning it was really hard because I started having the symptoms when I was 18 years old. I faint a lot. It was super hard. I was going to university, trying to balance my studies with my work. I worked since I'm 16 years old, so it was working, studying and having this health condition that I knew nothing about.

At the beginning it was really hard, but I suddenly started recognising little things that helped me to prevent the symptoms to go higher, if I can say in some way. So it was amazing when I did have the diagnosis because I knew what I had, and knowing what I had helped me to also know how I can manage it. I am really lucky because even though I have this condition, I can manage it.

But there are a lot of people out there that even having it, it's hard for them to manage it because they have higher degrees of dysautonomia. You can have a severe dysautonomia. It can lead to a disability condition. So, you need someone that takes care of you and helps you to do your daily life. I'm lucky that I don't need that.

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CB What were the symptoms that you started experiencing that led you to get a diagnosis?

AZ I started with a lot of dizziness when I was working or standing up. I work as a model, so I worked standing in high heels for four hours, five hours, just standing still. I started feeling a little ticklish in my toes, and then I feel like I was hungry, but I was not hungry. Then the respiration, it started to be harder to breathe. Suddenly, I start seeing white points, or blurry, until everything's black.

It's also like a slow way to faint. Because other people that I have known and did interviews with, because I'm also promoting talking with people so that they can talk about their specific condition and symptoms, they tell me that it's instantaneous. For me, it's a slow process. For example, just for me, because not to all people need this, but I need to eat salt every day. I'm travelling with my salt sachet on my bag to all the places I go. I drink a lot of water because you need to balance the salt in your body.

I also do a lot of exercise because if I don't work out, I feel awful.

CB So the autonomic system, that's our nervous system, is that right?

AZ Yes.

CB So salt is having an effect for you to keep that balance in your body. I was going to ask what are the coping strategies, so you've got exercise, you have salt, you have water. Is there any medication that you can take for it?

AZ There is medication. I personally don't like taking medications. In case it gets stronger, I will probably need to take it. This medication is a specific one and it's really expensive. It's $130 for one box.

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It's also hard for the people who need to take the medication to afford it. I'm also working to raise money to help people that need to take the medication, to have it at a lower price or have it for free. I hope I don't get to that point but it's a possibility. I also need to be aware that it's part of the condition and maybe that would be the way it is. I talk openly about it and I encourage people to also recognise themselves with the positive things and the things that maybe are challenges and learn from them.

CB It's interesting you say about challenges. I wanted to ask you, so you're a model, it's your profession, and you study as well. Is that correct?

AZ Yes, I'm an Industrial Chemical Engineer.

CB You've got a lot going on. What are the challenges that dysautonomia...? Did I say that correctly?

AZ Yes, dysautonomia.

CB I'm getting better as we're getting into it. Where do you think you got the strength from to overcome the challenges of your health condition and to persevere with your studying? Your studies sound like they take a lot of brainpower, so a lot of energy, and then modelling is such a physical job, isn't it? Where do you think you've got the strength from and to not be held back by the symptoms?

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AZ At the beginning I got the strength from my family and friends. Especially from my mother, because I have seen her working really hard in life. Both of my parents are art dealers. They sell art. Now my mother also cooks. She does these little dishes you can buy for your house. She was having maybe five jobs at a time for my brothers and I to have education, to have health, to have everything. We never felt that anything was missing. I saw her working really hard to take care of us and for everything to be good for us.

I felt like it was my way to say thank you, to embrace this and tell myself you can do this. If your mother can have five jobs and she can do it, you can deal with this. You can do it. It's also my way of being. I'm a little bit strict with myself. It's also something I've been learning to manage, because I also need to take some time sometimes and say, today, I can't. I want to, but today, I can't. It's good also.

Nowadays, the strength for continuing and to go on this challenge is also the people out there. When I start talking openly about this on social media, when I start talking about this outside and winning Miss World with this purpose, a lot people reached out to me and said to me, Amber, thank you. Thank you for doing this. Thank you for having the condition, knowing the challenges that it implies and talking about this out there, because I can't.

They tell me I have a high degree of dysautonomia and it's hard for me to take a shower, for example, they say to me. But you can do it, so thank you very much for doing it. That gives me the strength. It's amazing. I feel super happy about that.

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CB So your mum is an absolute inspiration and a very positive role model.

AZ Absolutely.

CB And then, like you say, you’ve got the added sense of purpose because of the platform that you're able to give the condition, because of what you're doing and the stage that you're operating on. I can see that. It's strength to strength to strength. You said that some people you spoke to aren’t able to have a shower, so the degrees that it can go from are that they are really big barriers that are presented with how the sliding scale of the symptoms can be.

AZ Can you help me, two minutes. I need to plug my computer. I'm really sorry.

CB That’s all right. I’m blowing my nose every two seconds.

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CB I just wanted to know a little bit more about dysautonomia. I don't think I'm saying it correctly.

AZ Yes, dysautonomia.

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CB I just wanted to ask a little bit more about dysautonomia. You mentioned that you have people coming to you, thanking you for what you're doing. They're not able to have a shower, the extremes of how it can impact somebody, what symptoms have you heard of in other patients with it?

AZ There are seven symptoms that are recognised by the American Health Centre. These seven symptoms are nausea or problems in the digestion. There is also dizziness, like when you change positions from sitting to standing up, or when you are in a car or in transport. There is also a confusion. I don’t know if it’s confusion but problems with memory. Like you go to a place and you want to pick up something, and when you get there, you forget what you were going to do, or you want to say something and you forget what you were going to say.

There are also the problems for standing straight without moving for a long time. It's hard. There are also the fifth symptom, problems with respiration, like you feel you don’t have air or your chest is helping you not to breathe, if I can say it like that. There is also tachycardia or high palpitations. The seventh is to feel tired. This is like the people with the shower thing that I put as an example. Hot water commonly affects the symptoms, because your body usually has troubles to regulate temperature with you have dysautonomia.

So, when you have hot water, it makes it harder to regulate temperature. It's also a standing post. There are some people that put a chair in the shower and it's easier if they're sitting down because they don’t need to be standing. Also, with the hot water, for example, I don’t take hot showers. I use the water a little cold, so that’s easier for me to manage it.

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There are strategies but there are also people who need someone to help them in these daily routines.

CB We have also recorded a podcast with a couple of ladies about postural tachycardia syndrome, PoTS, and that’s autonomic health condition. I was having a little read up that dysautonomia, is it an umbrella term for PoTS or they sit side-by-side?

AZ With time passing and there are more investigations about it, the umbrella structure is losing a bit of strength. Dysautonomia is the common name for all the malfunctions of the autonomic nervous system. You have now at least 16 different possibilities that could lead to having a malfunction of the autonomic nervous system. One of them is, I don’t know how to say it in English so I’ll say it in Spanish, but it's ciência ortostática. Inside that group is PoTS, you have PoTS and you have other ones. It's one of the dysautonomia groups.

CB How did you discover the Hidden Disability Sunflower and what do you think about it?

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AZ It was in two ways at the same time, so I think it was supposed to be part of my life. One of them was, because I work with another dysautonomia organisation here in Chile, and the kinesiologist of the group is also the vice president of the organisation. She talked to me about this, that she had heard of it and saw it on TikTok. On the other side, my mother’s massagist told my mother that he wanted to introduce me to a friend of his. He introduced me to Flavia, who is the one in charge of Sunflower Hidden Disability in South America.

CB A small world.

AZ It was maybe two weeks difference, something like that. I knew a little bit about it, then I met Flavia. We had a coffee and talked about it. I really love the work that the Sunflower Hidden Disability has been working worldwide. It's super valuable and important to keep doing things like this. Also, to encourage companies to be part of the solutions that we have helping people to make the invisible visible. It's amazing and it's also an inspiration for me to keep doing what I'm doing.

CB What’s the reaction to it been like so far? Have you taken it to any of your modelling or pageant competitions?

AZ I have it with me here. I always have it with me.

CB Amber is holding up her Sunflower lanyard and her Sunflower card proudly.

AZ Since I had it for the first time, I take with me everywhere. When I travelled to Ecuador, I wore it so that people in the aircraft could know I have dysautonomia. I almost never have trouble flying, but it could happen, so it's easier if you can say it to people.

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Because one time in my life, I was travelling. When I got inside the plane, it was super warm for me. It was hard to regulate the temperature and I needed ice, like an ice pack or something. When I was trying to explain to the flight attendant, do you have ice, and she was like, why do you want ice? I was like, I have this condition and it's hard for me to regulate temperature, so it's super-hot inside here, and I need to help my body to go down in temperature to feel better.

They were like, but then you can't fly. You need to go out of the plane. I was like, no, I can do this. I just need ice. It was a bit of a long conversation, but in the end, they helped me and they gave me ice. Now with this it's much better, because the last time I travelled, I flew to Ecuador to talk about dysautonomia. When I got inside the plane with this, it was with LATAM, I don't know if all the aircrafts have it among them.

CB LATAM has joined the Hidden Disabilities Sunflower Network, yes.

AZ When I was going inside, they went to my seat and said, hi, Amber, if you need something, just let us know.

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CB That's amazing. What a big change, just from that very simple, discrete Sunflower symbol. Can you tell us about your preparation for Miss World and what you're having to do?

AZ I told you that there are a lot of challenges. We need to do a lot of little competitions in the big competition. In my preparation I have been refining my talents. I will sing in the competition, so I'm practicing every day and doing exercises for my vocals to be the best quality they could be. A special day. I'm also enhancing my communication skills in Spanish and in English. I also love languages, so I started learning a little bit of French last year, and if I'd love to have the chance to practice it a little bit.

Engaging with wonderful people worldwide, with different organisations all around the world. It has been really special for me to empathise with people from all around the world, that they are working in other purposes. For example, with the girls from other countries, what they are doing, and it's super nice to see all this. I feel like this is a life changer. I cannot say it any other way. It's like I'm preparing myself to be the best version of me I have ever been.

CB That's a great purpose. When is the actual competition? Is it in America? Is that where you have to travel to?

AZ It's going to be in the United Arab Emirates. It's at the end of the year. There are some rumours because I have seen them on social media, but they haven't told me the exact day, but because of what I've seen, it's supposed to be November, December this year.

CB You would have thought they would have let people know. How many contestants will be there? Do you know how many countries are taking part?

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AZ There may be more countries, but up to now, there are 89 contestants from all around the world.

CB Gosh, that's a lot, isn't it?

AZ Yes. It's a tough competition. It sounds super clichéd what I'm going to say, but I really feel like a winner as of now, because just having the space and the platform to talk about Turquoise Heart, to talk about dysautonomia, to talk about the hidden disabilities, it is the most important thing for me. Of course, winning, it's like I can't be happier about that. If I do win the final competition, it would be amazing because I could keep doing it and also help even more people.

Because the winner gets the chance to travel all around the world helping people and volunteering in different causes, so it's really special and amazing.

CB It really is. It sounds rather epic. Thank you for using your platform to not only bang the drum for dysautonomia but also for Hidden Disability Sunflower. Disability isn't confined, as you said, to a particular country or region, it's global. We are very excited to be working with you to help raise the profile of The Sunflower even further and to let people understand that just because you can't see it doesn't mean it's not there.

Of course, we wish you all the luck in the world for the final competition. I look forward to getting another update from you towards the end of the year.

AZ Thank you very much, Chantal, for the interview and for giving me this space to talk about this. It's really important to me. I'm really happy to be part of Sunflower. I hope I can have a great impact in the role I do have now.

CB If you are interested in any of the advice discussed in this podcast, please, follow up with your GP or healthcare practitioner. Thank you for joining The Sunflower Conversations podcast. Remember to hit subscribe.

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