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The Digital Access Show: Interview with Frank Paolino

Introduction

[Narelle] Hi, welcome to The Digital Access Show. Thank you for joining us. Today's guest is a guest with a difference. I met Frank through some work I'm doing with the Disability Discrimination Act Review Lobby Group.

I'd like you to welcome Frank Paolino, who is a member for the Legislative Assembly in Western Australia. Frank, thank you so much.

[Frank] Thanks very much, Narelle. And it's a pleasure to be here and to speak with you again.

Frank's Background and Nystagmus

[Narelle] Oh, thanks, Frank. The reason I really wanted to talk to you is you were talking about a type of vision impairment that's created many barriers for you, and it's one I hadn't heard of. Please tell us a bit about yourself, and the type of vision impairment that you've got.

[Frank] Thanks, Narelle. It is a pleasure to be here with you. I was born in Brisbane and raised in Brisbane, then came over to Western Australia for work in 2008, and I've pretty much lived here ever since. WA is a great place to be.

[Frank] If you haven't visited yet, you should all get over here and visit Western Australia. I'll get that little plug in, if you don't mind, Narelle.

[Narelle] That's okay.

[Type here]

[Frank] So, yeah, a little bit about me: I was born with a condition called congenital nystagmus, which we were told was caused by a forced natural birth through the use of forceps.

[Frank] From what I've been told, it was quite unnoticeable at first, and it wasn't until I started to get into my toddler years that there was some noticing of there being a problem.

[Narelle] Can we take a step back? What is congenital nystagmus? I hadn't heard of it until you mentioned it when we spoke.

[Frank] Congenital nystagmus is involuntary, rapid movements of the eyes that are uncontrollable and can often go undetected until you get a little bit older. In most cases, I'm told it can be detected in babies from around six weeks.

[Narelle] Okay.

[Frank] I went through this again when I had my own children, because I was concerned and wanted to understand it better.

[Frank] As I started to grow, my grandparents—particularly my grandfather—were concerned because the uncontrollable eye movements make focusing quite difficult.

[Frank] The first sign there was an issue was me turning my head to the left or right while turning my eyes towards the television screen. What we now know is that this was my null point—a direction or angle where you can get a good focus point.

[Frank] The null point can change over time as you develop as a person. That was the first real sign that encouraged my parents to investigate further, and this is how it became apparent that I had congenital nystagmus.

[Frank] There was not a lot that could be done then, and there still isn't a lot that can be done. There were no miraculous laser or cosmetic surgeries that could reverse the damage, although I believe there is now some technology that can provide some rectification.

[Narelle] Okay.

[Frank] I'm too old for that surgery now, I'm led to believe.

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[Narelle] Yeah, but age has its bonuses.

Schooling, Reading, and Bullying

Challenges, Determination, and Finding Strategies

[Frank] When I was 12, I was taken to a clinic in Brisbane for extensive examinations and testing. I was told my nystagmus was quite severe, that I would never be able to drive a car, and that I needed to prepare for life with barriers and limitations.

[Frank] That was pretty hard to take as a 12-year-old because I loved cars and riding my bike. It doesn't matter what age you are—it's always difficult to hear that you can't do something, and that can make you even more determined to do it.

Digital Environment, Reading Techniques, and Public Speaking

[Narelle] Frank, from the sounds of it, we're a similar age. Did the digital environment make a difference for you, going from paper to digital? Did it help?

Driving, Technology, and Daily Life

[Frank] I've always loved cars, bikes, and sport. I played soccer as a kid, which was challenging, but I still enjoy watching my children play now. The key has always been to come to terms with the condition and work out ways to make things work.

Family, Philosophy, and Inclusion

[Frank] I also want to say that I'm very fortunate. There are many people living with disabilities who face challenges far greater than mine, and I'm very conscious of that. If I find things difficult, I can only imagine how hard life can be for others.

[Narelle] Sounds like our grandparents had something in common. Mine said the same thing: you made do and worked out how to make it work.

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Contact Details and Closing Reflections

[Narelle] Frank, how can people keep in contact with you if they want to find out more about your philosophy, more about nystagmus, and the messages you've shared?

[Frank] They're very welcome to get in contact with me. I'm available on social media, but the most effective way is to write to me or call my office. More importantly, I want to hear other people's stories, and if I can simply be someone who listens, I'm very happy to do that.

[Frank] In my electorate, one of the most unique programs is Star Kick, an all-abilities football program started by a local dad whose son loved footy but had no opportunity to play. The motto was, 'If you want to play, we'll find a way.' Today it has spread throughout Western Australia and transformed the lives of many young people through inclusion.

[Narelle] Different to what we grew up with, and it's awesome to hear. Frank, again, thank you so much for being on the show. If you like what we do, please like, share, and subscribe. Please get in contact with Frank Paolino. He's someone who has faced the challenge and risen to it, and he may be able to help you. See you next week.