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UNLOCKING ABILITY

Interview with Chris

Chris: They had already labelled her, never to do anything, never to be able to walk, talk or do anything. But I see the determination in her, I will not let the disability make her be disabled.

Celia: Chris's daughter, Rachel, was diagnosed at age three with a rare genetic disorder. After battling against doctors who didn't believe her and even accused her of mistreating her daughter, Chris developed a fierce determination to trust her own instinct when it came to knowing what was best for Rachel. I'm Celia Fielke and this is Messages of Hope.

Rachel has a determination and zest for life. Even though she has a child's mind and outlook in the body of a 26 year old. Mum, Chris, has made it her mission in life to make sure Rachel was given every opportunity to fulfill her potential, despite being born with a rare genetic disorder.

Chris: When you see Rachel out and about, she's a small, 140 centimeter little girl. She's got the mindset of a six or seven year old. However, she's also very, very, very clever in lots of ways and you've got to unearth that cleverness. People don't always see what we see. I'm very, very strong on looking beyond a disability. She has abilities and we just have to unlock that ability.

Celia: So, looking beyond the disability actually inspired you and your husband, Noel, to start a business for Rachel. How did that come about?

Chris: It sort of basically came about when Rachel got to the end of her schooling and she said to me, "Mummy, what job can I do?" There was no way she could have held down a job with her intellect however that planted a seed in the back of my mind. Then it was through me being at the Barossa farmer's market alongside Brian Pearson, who at the time was Barossa Gourmet Confections. He was like a grandpa to my girls. He was 90 years old and he was still making chocolates. And he kept saying to me, this is something Rachel could do. She could do these chocolates. I dismissed it for a few years and then one day, he said to me, "I think it's time for me to retire." And he wanted Rachel to do it. I thought, yeah, let's do this. We could do this for Rachel. We could employ her.

Celia: And so Ability Chocolates was born. How did you come up with the name?

Chris: Brian had a passion for people with disabilities and he could see lots of positive things in Rachel. When we took it over, Brian worked with Rachel for a little while, which was really nice. We wanted to select a name that resonated with that, hence ability chocolates comes from the word disability. You get rid of the 'dis' and you create ability.

Celia: That's awesome. So how Ability Chocolates made life better for Rachel?

Chris: When we first talked about it with my husband, Noel, and myself, we always said it was never going to be about money. It was going to be about giving Rachel a purpose. So, I make sure that Rachel has the ownership of it. We talk about everything. Where we're delivering chocolates, what we need to make and who they are for. She does all the delivering with her support workers. They drive her, so, when she goes to businesses, they see her, and that's what we wanted - Rachel to be seen, for them to know that she's doing this. And the businesses are fantastic.

Rachel actually has difficulty with making the chocolates. But what Rachel loves is the packaging and labelling, she will sit and label for hours. The repetition is great. It's given Rachel a purpose. It's giving her confidence. It's people seeing her in our community and acknowledging who she is, the syndrome she has, and yet they look at her and don't judge her. I love when we walk down the street, we go shopping and everyone's going "hi, Rachel, morning Rachel, g'day Rachel." That's what I want. I want people to know who she is and be accepted.

Celia: After battling against doctors who didn't believe her and even accused her of mistreating her daughter. Mum, Chris has found positive opportunities for her daughter to thrive, despite a rare genetic disorder at birth. Rachel is now 26, but it wasn't an easy road.

Chris: In the early days? Huh? It was hard. Rachel was born premature. So, doctors always said you need to give her two years to catch up. Two years came and went and she wasn't catching up.

Celia: So, what sort of things had you noticed?

Chris: She wasn't able to walk. She couldn't talk. She was able to eat food but she just wasn't gaining weight. She wasn't hitting any of the milestones. When Rachel was two we had a doctor who checking Rachel over, just took her out of my arms and said to me they wanted to keep Rachel to fatten her up. They actually did insinuate that we were unfit parents!

Celia: That's a really tough thing.

Chris: Oh I was really angry. They just assumed, they wouldn't listen to me. As a mum, you have this instinct and no one would listen to me. So they put her on a high fat, drip diet. It was so rich that she just kept vomiting! She just couldn't handle it. And after the seventh day, the doctor came back in seeing if she'd gained weight. But she had not gained, not one ounce, not one ounce!! The doctor had no explanation and I said, "Now, do you believe me that there's something not right with my little girl?" He just shrugged his shoulders. I took my little girl out of the hospital and I never saw him again.

Celia: That must've been awful. So what happened?

Chris: Just before her third birthday, when we were in hospital, and Rachel had bronchiolitis there was a doctor walking past our room and I was so scared that he was going to take her away again but he explained to me that he was a genetic doctor. He said "I'm pretty sure I know what she has." He did the test and sure enough, just before her third birthday, they had found the syndrome and it was very rare.

Celia: How did you feel when you actually got a diagnosis?

Chris: Oh so relieved. It wasn't what I wanted but I was so relieved. Finally, finally, we had an answer. The medical diagnosis we got was Wolf Hirshhorn Syndrome. From then on, it was really hard because it was so rare.

Celia: Oh, wow. What was the prognosis?

Chris: She was like a nine month old child. So, they were already saying her past will be her future. She wasn't walking. She wasn't talking. She wasn't able to dress herself. She couldn't do anything! In other words, she won't do much. They also told us that she probably won't live much past 10 years of age. So it was all down, it was all down. Everything was bad.

Celia: How do you deal with that?

Chris: This little girl was a determined little girl. Right around her third birthday, one day when I was feeling really down and really sad for myself, she stood against our lounge and she let go and took two steps! I distinctly remember thinking, if she can take two steps and show me she's determined to walk, then we need to be determined parents and give her a life.

So from that day on Noel and I said, "She's going to be treated like normal and we will do the best we can." And so that was the turning point for me and I wanted to make sure that she had the confidence to get out in the community and show who she is.

Celia: This is messages of hope, and I'm talking with Chris. Her daughter, Rachel was diagnosed with a rare genetic disorder at age three, which has left her at the intellectual age of six or seven, despite being an adult. This has come with significant challenges, but Chris and her husband Noel, continue to experience life and joy through Rachel's eyes. Chris, tell me about the wiggles.

Chris: Oh, the wiggles. Oh my goodness. We have been doing the wiggles for 24 years!

Celia: Yeah, most of us do it for what, five or six?

Chris: She just loves, loves, loves, the wiggles. She always has. She met the original wiggles in Adelaide back in 2012 and she was like this giggling little fan. She was speechless. She has a friend Ryan who has autism. He loves the wiggles too. We all dress up. Ryan and Rachel, they just get up and they sing dance and they don't care who's around that might looking be at them. Actually, we all get up and dance. It's such a simple life, non-judging life. When you do things like that. We get to do amazing things because of Rachel. We get to go on playgrounds. Hello, if she was 26 and normal, you wouldn't be doing that. We still experience all that. Yeah, she's just a happy, happy, girl and loves what she's doing.

Celia: Do you worry about her future?

Chris: Oh, you always will. We constantly keep working at abilities, obviously trying to get her more independent. Naturally one day she will possibly need to live in an independent unit with others. We don't know but we can keep striving towards those milestones. We have got a big extended family that I have no concerns whatsoever, someone will always be there for Rachel and will care for her. God's put those people in our life as well. I know that now. I know he will take care of everything. I don't know how. I can't explain that,

Celia: It's a trust thing isn't it.

Chris: It's a trust. It is a massive trust and it is massive in the sense of pray every day. Pray when you're worried, when you're happy, when you're thankful.

Celia: I can see faith is really important to you.

Chris: Yeah. The other little thing about Rachel, which I absolutely love is her faith in Jesus. We don't know what she understands about Jesus. We talk to her about heaven. She has her nightly devotion with her dad. She loves going to church and singing. This girl, she loves to sing. She loves Jesus and we want her to keep that faith. We want her to understand about heaven and what's awaiting all of us. So, its simplicity, her simple faith.

Celia: We can all learn from that can't we?

Chris: Yeah, her simple childlike faith that God wants all of us to have trust. Let the little children come to me because she will always be God's child. Even as an adult, she will always be God's child.

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