

INTERVIEW WITH KYLIE (TURNERS, AGED 17)

Interviewer: Tell me how old you are and who else is in your family?

Kylie: I'm seventeen, my mum Arlene, my big sister Carlene and my dad Peter.

Interviewer: And how old were you when you found out that you had Turners?

Kylie: I was diagnosed at birth and I always sort of knew I had Turners Syndrome. My mum always spoke about it when I was around and when I was playing with my dolls she always used to say that not everybody can have children because some people have to adopt, so I always sort of knew.

Interviewer: So what do you like doing best in life - what are you good at?

Kylie: I like school and my gymnastics and looking after children.

Interviewer: I know you've had great successes in your gymnastics. Tell me how you got in to that and what's happened with it.

Kylie: I went to school and we were doing gymnastics in P.E. and my P.E. teacher then, told mum that I had a flair for it, for gymnastics, and that there was a special Olympics trials for the gymnastics team. And I had been ill through that entire summer, I'd been in hospital for three weeks and my mum said, "do you think she'll be strong enough", and my P.E. teacher said, "yes of course she will". So we went along in the October and I did the trials and to everybody's surprise I got in and I trained for a year and then I competed in the Portsmouth Special Olympics and won a silver medal, so that's how I got started.

Interviewer: And how has it gone since then?

Kylie: Through special Olympics, I went in 1999 to the World Games in North Carolina and I won five gold medals and I have been to a few different British competitions as well and won various medals there. Two years ago I was in Belfast for the first ever open International for people with disabilities and I won a silver medal there for individual and a gold for the team event. That was two years ago and last year I won silver individual again and then in November I became the British senior champion.

Interviewer: That's great. Tell me again, what else you're good at.

Kylie: I like working with children as well, and I help my mum with looking after some of the kids at different open days and that.

Interviewer: What are you not very good at?

Kylie: I'm not very good at being patient. I like everything to happen quickly. I'm not really sure.

Interviewer: Do you have any health problems? You said you were in hospital, why was that?

Kylie: I had an infection in my toe which had tracked up my leg as cellulites.

Interviewer: So that was nothing to do with Turners?

Kylie: Well it was sort of because Turners girls have a tendency to in-growing toe nails and it was an in-growing toe nail that became infected and tracked up my leg to cellulites. It's sort of to do with the Turners.

Interviewer: How do you find going to school?

Kylie: Well Scotland have primary and secondary school, so I'm in secondary school now and I'm really enjoying it. It's good.

Interviewer: Have you ever had any problems with being bullied?

Kylie: I was really badly bullied and I had to move schools because of it. I used to go to a school just across the road, and I moved to a special needs school nine years ago.

Interviewer: How old were you then?

Kylie: I think I was seven years old.

Interviewer: So when did you start taking growth hormones and how did you find that?

Kylie: When I was five and a half. It was strange at first. But it just becomes like you're brushing your teeth now, before you go to bed you take your injection, brush your teeth and you go to bed. It becomes part of your routine. It wasn't easy to start but you know mum like if I took my injections every day for a week I'd get a little treat on a Friday or if I hadn't taken my injections then I wouldn't get

my treat and we did little star charts and other wee things just to help. It was hard but I know it's worth it now I've got to the height that I am.

Interviewer: Yes, you're quite tall aren't you?

Kylie: Yes, 5'1 ½".

Interviewer: So then you became a teenager. How did you cope with it when your friends were starting to develop?

Kylie: It was really difficult. And you know, I suppose knowing from when I was little ... sort of prepared me, prepared me for knowing that I wasn't going to be the same, you know just thinking 'I'm not the same', I always knew that I wouldn't be but I mean it was still difficult and you just have to get through it as best you can. There's not really that much you can do to make it better. You've just got to wait.

Interviewer: Did you have any bullying problems then?

Kylie: No. Because I was at the special school by then and the classes are all smaller and you know everybody knows everybody and because there was less than 100 pupils in my school and there were ten maximum in a class and there was only five in my whole year. So it was hard, but the girls were nice to me and they never really drew much attention to that.

Interviewer: How do you feel socially now - do you feel self-conscious at all?

Kylie: No not at all. I've got really good friends and they're all understanding, they're nice.

Interviewer: So when did you start taking the HRT?

Kylie: Oestrogen when I was 14 - which was late because I'm part of the double Blind trial that's happening at Glasgow and happening in the UK, but it's run from Glasgow and that part of the treatment is to see if delaying the puberty gives you more height. So that was an added complication for me. Because it meant that I was waiting even longer for my development but I mean it's so worth it now for my height.

Interviewer: How do you feel about the infertility?

Kylie: I mean, it's pretty much the same as everything else. I've always known about it, and you know there's other ways. I know other people with Turners that have adopted and had children from donor eggs. And it's so nice to see like Sue and Steve with their two adopted children, Melissa and Geoffrey and then you've got little Lisa with little Luke and you know there are so many people out there that you know have adopted successfully and it just reassures you that one day it could happen for you and then there's other, you know like there's a lady in Ireland that's got a wee girl from a donor egg and you know that there are possibilities and that one day it can happen for you.

Interviewer: Do you think there are good things about being a Turners child?

Kylie: I'm not sure. There are certainly advantages because it can seem hard sometimes in that once you get to a certain age and you look back on everything that's happened you think 'I hated it' and everything, but it's all been okay and it's going to be okay. You know I don't know if there are any advantages as such but it's certainly not as bad as it first seems.

Interviewer: What would you say the worst thing is about it?

Kylie: I mean there are a few things that are hard to deal with. First you've got the injections and then you've got the development and then you've got the infertility and I mean the three of them are the main problems you have to deal with if you're Turners, but they're all, you can deal with them all and none of them are that bad.

Interviewer: What would you say to someone who was pregnant but they knew they were going to have a Turners child and were trying to decide whether to go ahead or not? That's a difficult question for you isn't it?

Kylie: I think it's a difficult question for anybody. I think you should have to try and not influence them too much. They have to gather enough information to make a decision. All I would say to them is that, if they decide to go ahead, they will have a child that they will love and that will love them back and they'll all be okay. It will work out in the end. It will be hard, but it will work out.