

Siren Films Answer Project

Interview with Jackie Williams (mother of 5 year old Abigail – Turners syndrome)

Interviewer: Just tell me how old Abigail is and who else is in your family.

Jackie: She's five and a half and it's just Abigail and me. My husband and I separated, but in the family there's Abi, myself and her father.

Interviewer: And when did you find out that Abigail had Turners?

Jackie: Pre-natally. There was a scan, an antenatal scan done at 16 weeks and they found that the femur length was out of proportion with the rest of the body. They sent us for an in depth scan at Guy's, the results of which showed that there was a serious chromosome abnormality. They noticed certain physical things that were not looking quite right. There was a huge growth on the back of her neck. Her hands and feet looked extraordinarily large. Her limbs were shorter than they should have been and there was a heart defect. And they noticed all this from a scan at 20 weeks. From there they did a chromosome test using blood from the umbilical cord and from that they found out she had Turners Syndrome. So it was a very trying time.

Interviewer: And what was your reaction?

Jackie: When I first found out that it could be serious, we were given three choices. None of which were Turners Syndrome. We were told that the baby was either suffering from Edwards or Pato Syndrome which were basically lethal – the children just didn't live beyond birth, or the best we could hope for was Downs. We prayed for Downs Syndrome because that meant we could keep our baby and when the results came back they said well actually she's got Turners Syndrome. And we said, well what is that? We don't know what that is. And there was only someone on hand who had very limited information about Turners Syndrome. We found this out on Christmas Eve by the way and all the hospital lab technicians had gone home by then for Christmas holidays, so we were left in the dark really. We just had this very basic information about Turners. I first found out that the main problems with the girls were that they were of short stature, which could be helped with growth hormone injection, but intelligence was across the board, so mentally they were not really affected. They had their fair share of problems but with help they could live normal lives.

So at that point I was jumping up and down in the room, because we'd been given such dire information to start with. But I was worried of course. I was very concerned because she still had heart surgery to come and other problems which may follow, so it was worrying, very worrying. I think the worst I felt was not knowing what was wrong with the baby. To have this scan done and not know what it was and what was happening and having to wait five days for the results to come through. That was the longest five days of my life.

Interviewer: How did you feel when she was born?

Jackie: I was elated when she was born, because I was always worried that I would miscarry and I really wanted this baby. I loved this baby, I hadn't seen this baby but I loved her (or him). I didn't know it was a girl initially, but I was elated when she was born. She was a good weight. She was slightly jaundiced but she had a good pair of lungs on her, so she was obviously quite strong, but I could only hold her for ten minutes and then she had to go down to the special baby care unit where she awaited heart surgery which took place two days later, so she couldn't eat or drink. She couldn't drink milk or be fed at all and she had all leads on her and you couldn't really cuddle her properly and that was very hard. And I think she suffered during those two days as well. I think she was hungry and she was lonely and that was very, very traumatic. Very upsetting. A lot of tears shed then.

Interviewer: So what was it like waiting for heart surgery?

Jackie: I cried a lot. I convinced myself that she wasn't going to come out of it. Even though they had said that there was a 90 % success rate, I thought that oh she'll be the 10 % that don't make it and I was just dead, dead scared of losing her, but she went in and the operation was five hours. It was extremely hard waiting and then I phoned down to say 'any news, any news?' and they said 'yes, she's just coming out, she's coming into intensive care' and like that was it, I just rushed down there to see her. She did look a bit of a sight. Her face was covered with head gear because they needed to strap the breathing apparatus on her head to keep it in place. Her face was all puffy from where it had been strapped and she obviously had the wound where the heart surgery had taken place. Leads and tubes everywhere going in and out of every part of the body which was quite harrowing to look at. But, you know, she made it, she got there. She was in ITU for 9 days but the signs were that she was making progress every day and on the ninth day she went up to the heart ward and that's when they said "if she goes up to the children's heart ward, she's made it. " Meaning if she gets there, you know, she's on

her way. And, so I think it was four weeks later once we established oral feeding we were able to take her home. And more problems started there.

Interviewer: So what were the problems?

Jackie: The problems were feeding. I mean heart surgery seemed to pale into insignificance compared to the problems we had with feeding. She was every day taking less and less from the bottle. Moreover she would refuse the bottle completely and wouldn't drink. And one day, I think we would have been home about a week, I could hardly wake her up. She was very floppy and I immediately got her dad and we rushed her to hospital. She was described as conscious but unresponsive and I was then told that she basically wasn't taking enough nutrients. 'You know she's not drinking enough milk, you need to consider tube feeding for her' - which I was really against, but eventually trying all sorts of methods to get her to feed. So in the hospital we tried spoon feeding and she'd spit it out. We tried all sorts, feeding her with a syringe, just gentle amounts in her mouth, she would choke, and in the end I had to give up trying to orally feed her and sadly the nasal gastro tube went back down her nose and into her stomach and she was fed that way for the next year, but then we had problems with vomiting. Even though she was tube fed, she would vomit all day on a daily basis and it was really awful to look at because she was obviously struggling and even tube feeding her she would kick and scream throughout the whole process. There were many trips to the hospital about this - what's going on, why's she doing this? Is she going to make it Various tests were done. The only tests that found anything that seemed to show signs of Abi having problems internally were that her stomach wasn't emptying very quickly into the bowels. So her stomach was filling up and filling up and she just couldn't cope with the amount. So then it was very much a tube feed of little and often amounts and she could tolerate it better then. But she would still vomit and she was vomiting up to the age of about a year, quite badly. But the good thing was she was still gaining weight, which was slow but she was still gaining weight and that was the thing they'd wanted to see. They said we don't care, as long as it's not in the other direction, we want to see her gaining weight, not losing it, even if it's an ounce a week, that's something. And gradually she moved in that direction. It was slow, it was painful. She wouldn't take solids. If I showed her the bowl with the spoon and some solids on it she wouldn't eat it, she would scream as soon as she saw the bowl. Eating, drinking, was the most horrific experience for her. Eventually I went to see a speech therapist that I had and to try a completely different approach to feeding Abigail whereby I had to make the food as pleasurable and as

wonderful as possible. She said 'I don't want you to sit her in a chair and give her a bowl with a spoon to feed her. I want you and your husband to sit on the floor with a big mat and eat your dinner on the floor, don't offer anything. Just let her come over and look at it, and if she wants to play with it I want you to let her play with your food, and put her hands in it,' We were renting a flat at this time so it was very difficult, so we had to cover everything. We were also able to offer her things like chocolate mousse, fruit puree, yoghurt, all the things that we were not really allowed to give her for dinner. But anything she would eat and she liked we would offer her and if that meant eating chocolate and yoghurts then so be it. But let her do it. Don't sit her there and sort of say 'eat this, eat this'. It was let her be curious and if she doesn't want it, forget about it. Over a period of a year this worked very, very well. Yes, that was a long, painful process of getting Abi to eat and drink, but she did get there. But it was very, very traumatic and very stressful for all of us concerned really - especially myself and Abigail who were the ones really in it, but I would say that was probably one of the worst, I would put that above heart surgery as probably being one of the most stressful times of her life. Heart surgery paled into nothing compared to that. That was an ongoing nightmare. But, yes. By the age of two she had her gastrostomy tube, which was in her tummy, removed and she was eating. She was still eating pureed food but nevertheless she was eating and drinking unaided. And from there she's progressed onto pretty much normal eating and I remember the health visitor saying, oh if you give her chocolate mousse for lunch she'll never eat vegetables, but she does. She eats vegetables, she eats fruit, she eats pretty much anything you put in front of her actually, so that's worked wonderfully well.

Interviewer: So you've obviously had quite a lot of help from people along the way?

Jackie: Yes. I couldn't have got through it without the support of Arlene and talking to other parents who had been in similar situations. And I must say, I owe a great debt to Sheena Riley, the Speech Therapist who literally ordered me to feed Abigail and treat her in the way I did, because that was a big turning point and Abigail was not going to be a child that you sat in a high chair and sort of fed her spoonful after spoonful. She needed to do it in her own time and eat her own things in her own way and not be pressured. And that had the effect that we wanted it to. But we did have a lot of help from speech therapy. I can't say the dieticians were enormously helpful. I didn't find them very helpful at all. I think that basically they just didn't know what to do with Abigail. They really didn't know what to do with her at all. But despite that, you know,

with the help of family and the TSSS and other parents, Sheena Riley, we got there. Thank goodness.

Interviewer: How is she doing now?

Jackie: She's five and a half now. Started school. Pretty much likes school. She has no siblings which she always tells me off about. She wants a sister to play with. But she likes school because she loves being with the other children. We do have a few psychological issues with Abi in that she can be very clingy. And when it's just myself and her in the house she has to be in the same room as me. If I disappear she gets very upset and distressed. We are not quite sure why. We thought at this age she would have grown out of it, but we're not quite sure why that's happening. But having said all this doom and gloom and things about bringing up a Turners Syndrome child there are enormous benefits, because I have to say she is extremely funny and she is great company. She's a really good child, actually. I've never really had tantrums from her. She's basically a good kid. I think for all that she's been through she's done enormously well and she grows in confidence. The more she does and the more she achieves, her confidence grows and she does more things, so it has to be said that I would like to see her not to have gone through all the pain that she went through but having said that I probably wouldn't change a hair on her head. I like her just as she is really.

Interviewer: So does she have growth hormones?

Jackie: She does. She's just started growth hormone treatment. She doesn't like needles. She got very distressed with her first injection, after which we decided that we would inject her while she was asleep which is working well. She does move and twitch, but the needles are very, very thin and very small and she doesn't wake up. You just put the growth hormone in and she doesn't really know anything. We're on a year's trial; there's a new growth hormone and we're seeing how it works and she's on a higher dose than would normally be given and they're going to monitor her at the end of the year to see if there's any difference in giving children a higher dose or the same.

Interviewer: So does she get well treated by other children.

Jackie: At the moment she does, and I think it's because of her size. The older children tend to mother her a bit and look after and baby her, but yes I had an interview with her school teacher who says that she's very popular in the class. She's a very friendly, very loving, affectionate child and very, very popular,

especially with the girls. But even the boys protect her. But I think that's a size thing. Because she's so small, and they describe her as 'cute'. But, yes, generally she loves being with other kids and she is doing well at school.

Interviewer: Is there anything she's particularly good at?

Jackie: She's very good at reading. She reads very, very well for her age. Her handwriting is not so good. They feel that it could be better. But I tend not to worry about things like that because my brother's handwriting was awful and he writes very neatly now. She has a liking generally, for learning everything. At the moment I can't, there are things she's interested in, I can't say that I look at her and think 'oh yes you're very good at that'. She does seem to be very good at things like gymnastics, and she loves dancing and things like that. I can't say 'oh yes, you'll be a star at that', but she really will have a go at anything really. She doesn't like sport, what I call boy's sports, like kicking a football, she prefers girly sports like gymnastics, hula hoops and things like that.

Interviewer: So what would you say her quality of life is like now?

Jackie: I would say her quality of life is very good. She is really loved by all her family. She seems to have settled in at school. I think a big part has to play on the parents and those around her, instilling confidence and - 'yes you can do it, you will do it', and have faith in them. Get them involved in as much activity as possible. But although she has to have the growth hormone injection and she has to wear glasses, she has a squint, she has gromits, she's got all these peripheral problems, but it hasn't affected her day to day life. She still does all the things that children do enjoy and loves every minute of it. So I would say despite all this, her quality of life is good. And she enjoys life.

Interviewer: How would you say it's affected your life?

Jackie: It's hard to say really. My husband and I split up. It's hard to say if we would have done had we not gone through the stress of Abigail, what she went through, but I'm sure we would have separated anyways. I would say that it has had a mental and physical effect on me, watching her for those first few years go through what she went through, the feeding and the heart surgery and the worry and it did take a lot out of me and I'd been quite ill in the last year. But looking at her now I would do it again. I would go though all that again to get where she is now and I am getting better. I see her now and she is stronger and she's enjoying life and so I'm now rebuilding my own resources up again - ready for the teenage years I suppose.

Interviewer: So what do you think about the future - do you think about the infertility aspect?

Jackie: I do, but I suppose because she's so young at the moment it's not immediately in the forefront of my head. But I do think about it from time to time and when I do I get upset at the thought of telling her because she is such a girl and she really loves playing with dolls. If you say to her 'what do you want to be when you grow up?', she says 'a mum', which kind of goes 'ah', but even so I keep very positive and I think, medical science out there is doing so many great things with infertility that maybe by the time she's older, it won't be such a hurdle and if she wants children then maybe she'll be able to have them, and there are other ways of having children and loving children, such as adopting. Maybe she won't even want children. It's like one of those things that I'll cross when I come to it. But I don't ever say to her, even now, I never say, 'oh maybe you know it might be difficult for you to become a mum'. I just don't say it because I think if they want something badly enough, all of us, we can pretty much get it in one way, shape or form.