

Siren Film and Video

Answer Project

Interview with Nicholla Docherty, mother of Sam (18months, Downs)

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

Nicholla: Sam's 18 months old. Shannon, his older sister, she's 3½, there's Martin, his Dad who is 25 and I am his Mum, Nikki, and I'm 24.

Interviewer: When did you find out that Sam was going to be Downs?

Nicholla: We found out when I was 20 weeks pregnant. We got referred to the RVI after seeing that on the scan and at the RVI they detected his heart had problems as well. He had three holes in the heart and his pulmonary artery was very narrow so at that point they said he had a 1 in 3 chance of having downs syndrome, so we just prepared for that and read up on everything.

Interviewer: And what was your reaction?

Nicholla: Martin and I, as soon as we started thinking about having children, we thought that "our child is our child no matter what and we will love it for who it is, and who they are". So that's it, as soon as we found out, it had no effect really on our family status anyway; Sam was going to be Sam no matter what.

Interviewer: So you didn't have to make a decision?

Nicholla: No, we would never, ever abort a child for any reason and we are firm believers of it will happen for a reason. Sam's meant to be here for a reason as well as Shannon was meant to come first because she's such a lovely big sister, so that's it.

Interviewer: What were other people's reactions in your family?

Nicholla: Our family has the same kind of reaction as ourselves. I was brought up in a very open family where we accepted everybody for who they were and we were very open minded on other cultures and my Dad was in the army so we moved around quite a lot so we experienced all the cultures as well. And Martin's family – he comes from a family of 8 children with his Mum and Dad – a big Catholic family. Martin has a retina bastoma in his eye which is cancer and he had to have it taken out so within their family he's had disabilities and defects as well, so their family's used to that, so it was fine. We're very lucky that every single body is so supportive of us and of Sam.

Interviewer: What about the outside community?

Nicholla: We've had a mixture of experiences. There's been people want to either cuddle him, kiss him and hold him and just want to be around him all the time, or they just don't want to be near him at all. There's never an in between, they both like and love him or they just don't understand who he is at all. It's very strange because we have people saying 'oh, isn't he gorgeous, isn't he lovely' and we say 'oh he's got Downs Syndrome' and they just walk away, so all of a sudden he's not gorgeous or lovely and you just think, well why? They just don't understand. I think people need to be educated.

Interviewer: So what happened when he was born?

Nicholla: When he was born we got to choose the date of his birth which was going to be the first of May and it was going to be a caesarean section with him having to have surgery straight away, but then Sam decided that he wanted to come when he was ready and he actually came out on 27th April with a natural birth. It only took 40 minutes, so it was very quick, and he was tiny when he came out. He was 4 lbs 15, very small, but he just came out and he didn't even cry. He just kind of opened his eyes and looked around and thought okay, and then we got a little cuddle and he was taken away to drain his stomach of all the fluids that was in and taken down to the Special Care Unit where we saw him and he was prepped for surgery but unfortunately the surgeon was over in another operation, so we waited two days until he had his surgery.

Interviewer: What was the surgery for?

Nicholla: He had a loop in his intestines that was blocked so he couldn't eat anything and he couldn't pass anything through, so they had to cut that out and then sew it back together, for his intestines. It wasn't a straightforward operation because they found all of his bile ducts and his pancreas ducts were all webbed together as well so they had to cut those as well and rejoin them and that was quite scary because we were told from then on that he may have to have surgery for life or he may not make it through with the pancreas duct which had to be cut and sewed on together. If that didn't form then he would not be here, so that was quite hard. But Sam being Sam he just kind of fought through and surprised everybody and turned around and was off the ventilator in two days.

Interviewer: So what was that surgery experience like for you?

Nicholla: Well for me, I'd just had him and I was still going through the hormones of just having a baby, not being able to cuddle him or anything. So for me it was, it's like a blank for the first week, it's all a bit of a mesh, but for Martin it was very, very hard, very hard. He remembers everything and he gets quite upset about it, but he made it through, Sam wants to be here, is going to be here and he fought his way through and that's exactly who he is – a little fighter, so we're glad.

Interviewer: So then you came home. Were there any special care demands?

Nicholla: Yes he was in the hospital for three full weeks and then came home. He had a tube down his nostril to go into his stomach because he couldn't breathe and with having his heart problems he didn't have a lot of energy. So when he had his bottle it used to take him an hour / an hour and a half to have just 4 ounces, so he was actually losing more weight than he was gaining just feeding, so eventually we had to just feed him whatever he took in 15 minutes and then put the rest down his tube. So then we had to extract his bile if that didn't pass through so we were nurses for the first couple of months when he came home. We had a lot of help – community nurses came out and we were shown how to put the tube down. We were very confident with that. We were told 'you either put the tube down or he doesn't go home' so we learnt how to do that and we could be qualified nurses now to be on the wards It was an experience and it made us bond even closer because we had to do this for him. Nobody else was going to. We had to do it. And it made me form a bond without having ... because I couldn't hold him an awful lot, so that was another bond that we had with him because we couldn't cuddle him all the time. It was nice to be able to do that for him.

Interviewer: How did it affect your relationship with Martin and Shannon?

Nicholla: We were very close anyway and Shannon ... we as soon as we found out about Sam, when we were pregnant we bought her a doll. We put the scars on the doll where its heart and its bowels would be and bought her a doctor's kit and she was two at the time. So every night we used to tell her, 'we'll check the baby's heart and we'll check the baby's tummy and make sure he's okay'. So she used to get her doctor's kit out all the time, so by the time Sam was born she was ready with her doctor's kit to check him over. She came to all the scans with us, we told her everything. We told her that Sam may or may not be able to be here long and she well understood, as much as she could as being two. And when he was here and he had his tube down she used to help me feed him with his tube – she used to hold the milk while it was going down and we

involved her with everything. So she knows he's very special and she's a very special big sister for him being able to do that. She's just lovely.

Interviewer: Was it quite hard work looking after the two of them?

Nicholla: It wasn't, actually, it was quite easy. It sounds strange being easy with two, I found that I had to be organised, so that just came with being a mother of two, just being completely organised. But with Shannon, because she's so understanding and so she just accepts things the way they are we've never had any jealousy, any times where she just wanted to be cuddled, just her. She's always from day one involved Sam in everything, so she's been like his second mother, really. We still now don't have any jealousy from her; she's just the big sister everyone hopes for really.

Interviewer: What happened when he had heart surgery?

Nicholla: From leaving hospital we had a couple of scans to see if he needed surgery straight away. With him being under 7 lbs it was going to be risky to have surgery then, so we waited and it got to a stage where he was losing weight rather than gaining weight, so we would give him a pump when he was sleeping during the night to feed him constantly. So he was getting three times as much milk as any other baby his age would need, and still he was losing weight - just rolling over or sitting up was a big exercise for him, so he lost quite a bit of weight. He was five months old and he was 7 lbs and they decided that that was going to have to be it or else he was going to just deteriorate. So we got a phone call on the Friday, they had a space on Monday to do the surgery, so we were quite glad it happened that way, because we didn't have months to stew over it, we had days to get ready. I thought that was very well done of the hospital to be doing that. So we went in on the Sunday night and the Consultant came to see us and explained everything which we already knew - we'd gone on the web site and we'd checked out what would happen to him so we knew just as much as the surgeon at that point. So the next morning, Monday morning, we couldn't really sleep that night and five o'clock came and that was his last drink of water. Then seven o'clock came and we were preparing him with his little gown, putting two pairs of socks on and gloves to make sure his feet and hands were warm enough so that they could put the drips in his feet and his hands, so his veins were up. We got upstairs to the intensive care room where he would be going through into surgery and Martin took him through, because I was quite upset at that stage, and we had a little cry, and we said our goodbyes to him, and we waited. It was six hours. We were given pagers so we could go out

instead of waiting in the hospital. So we decided that we would go to town. We got there and we sat in MacDonald's. We must have been the only people there that never had a smile on their face. People must have been walking past and 'God look at those two grumpy people'. We decided we couldn't do that, we couldn't sit around and watch everybody carry on with their lives while we were waiting to see if our little son - - so we went back to the hospital and sat in the waiting room for the rest of the day. And every time someone was coming up the corridor we were sticking our heads out and see if any news, and then finally four of them ran up the corridor and said 'he's fine, he's fine, he's out, he's fine and we had a big cry then again and we were given half an hour that we could sort our selves out and go up and see him. So we ran up the stairs and washed our hands and everything and went in to see him and he looked great actually, he had colouring. He was white as white could be before hand and he was peachy, and he was trying to roll over and everything. He had just had surgery. He was drugged up with morphine, but still had decided that he wanted to roll over. So, they had to tie his hands and legs down so he couldn't move because his rib cage had been torn apart so he had to stay still. Then later on that day he plummeted. He deteriorated quite a bit and that night we were told to prepare for him not to be here the next day. Unfortunately Martin had to go to work the next day. He couldn't get the time off. Through the night I was given a room in the flat at the hospital and I got a phone call through the night to say that he'd stopped breathing. We had to go down. I ran down and they'd just got the pump on him and he started breathing again. They found out it was the morphine that had slowed all his organs down and instead they put him ibuprophine and the next day he was back to Sam again, off the ventilator and he just turned around again like he did the first time. He just decided that he wanted to be here, and he was meant to be here, so I was just so grateful that whoever's upstairs decided that he was going to stay. We were walking on clouds then really and Shannon was allowed to come in and see him and she sat beside him for 20 minutes and held his hand. She was only two and a half. She sat there and held his hand for 20 minutes. Then we were allowed to give him a bath, take his bandages off and have a look to see his scar which was very big. We got him changed and dressed into a baby grow and we were allowed to take him downstairs to recover. So it was a great big ordeal that was over in a day. It was a lot of emotions all in 48 hours, and we got downstairs. He carried on getting better and bigger and when we left he was 7 ½ lbs. Five weeks he was in the hospital and when we got home he still had his tube down just to make sure he was feeding okay, but we found when we got home he was finishing 8 oz bottles in 20 minutes which was just excellent.

We were getting him weighed every week and he now is 18 months old and he's 22 lbs. So, you know from being 5 months old and 7 lbs, he's come a very long way to be who he is now. So it was quite emotional.

Interviewer: So he was 5 months old then and how has he developed since?

Nicholla: When he was six months old he started just rolling all the way from one room to the other, so that was a month after surgery he never had any problems with his ribs. His sternum still stick out a little bit but doesn't give him any problems. Nine months old he started crawling and did his first macketon sign. We were teaching him macketon from six months old. He did his first sign which was 'more', for more food, he loves his food anyway. And now he's 18 months, he's crawling everywhere and he's just stood up for the first time last week. That was a big, yippee! His motor skills are brilliant. He picks up his food and everything. He says 'mummy' and 'daddy', 'nanin' for Shannon and he does six signs now with his macketon. So he's doing very well, very well indeed. Shannon teaches him all his macketon signs as well. Shannon goes to nursery and it's a mixture of special needs children and other children and they do all the macketon signs as well and she does all the macketon signs with all the nursery rhymes with all the other children. They actually recently, we bought a book for her 'My Baby Brother Has Downs Syndrome' to try and tell her exactly what Sam has and the nursery volunteered to read it out in front of all the children and then going off their own backs and bought all the books, 'My Brother Has Cerebral Palsy' etc, and her friend Joseph at school has a special baby brother as well as Shannon, so she shares a lot of things at nursery. We chose that nursery so Sam could go to the same school as her regardless – it's a special needs school and a mainstream. It's classed as mainstream school but it has all of the classroom assistants that you need and Sam will be able to go to nursery and school with Shannon and then on to middle school as well with Shannon. So we wanted them to have their school days together and we are happy that the nursery are excellent with Shannon and all the other children with special needs that I'm sure Sam will have a brilliant time there.

The teachers are just brilliant and constantly ask after him and say that Sam is Shannon's favourite subject in nursery; she talks about him all the time. They just had a family month where they were teaching everybody about family and they couldn't shut her up, saying she had a special baby brother, telling them everything. They recently had a doctors and nurses month as well and she was telling them all about

having to put the tube down the baby to be able to feed them, so that was quite funny, she takes everything in.

Interviewer: Have you had much support from health and social services?

Nicholla: Yes, a lot of support. We were very positive when we were in the hospital with him and the doctors picked up on that and immediately gave us numbers and passed us on to people they knew that if we got this help we would carry it out and we would welcome it. So I think the more positive you are about your child the more you are going to get out of. Sam got his physiotherapy and when he was 6 weeks old; his portage worker came at the same time. She just sits and plays with him for three hours and they just sit and play. How to build blocks and put hoops over, so it's just a little play time with him. Help with his physio is purely again play, getting him to move around through play. He has a speech therapist who helps with his feeding and his movement of his tongue, his speech, everything involved with the mouth area. He also has a community paediatrician we see every six months just to see if his development's fine, which it is at the minute and if it wasn't she would refer us to other people to enhance his abilities. So we are getting all the help that we need and we haven't had to fight for it, it's been handed to us on a plate really, which is lucky. There are other families who do have to fight for it, but eventually everybody gets the help that they need.

Interviewer: I know he's only very young, but do you think about the future?

Nicholla: Yes, when he was born, after, well, after all his surgery, we started thinking about the future, thinking about schooling and, well, bullying, because eventually, you know, it's a fact of life, at sometime in his life he is going to get bullied and so is Shannon. We've got to face those facts and just prepare our children for it so Shannon has a very open mind already and we told her that there are going to be some nasty people in the world, but we don't like nasty people, so we don't associate with them. So already she's pointed out there's a couple of nasty girls in nursery but that's purely because they were playing with the babies and not letting her play with them, so she's starting already to realise that we have to share and we have to accept others for who they are and they will accept us for who we are. With Sam we will try and teach him the same values that we have taught Shannon. We don't know yet how Sam is going to be at nursery, whether he will start when he is 3 or whether he will have to start when he is 4. Sam is going to be Sam no matter what and we'll just let him go at his own pace, at his own pace and just let him do things as far as he can take them and just give him that little helping hand. So, as

I say, we're hoping he will go to the school with Shannon and then hopefully on to mainstream school. I would prefer him to go to mainstream school just purely to be accepted in society for who he is and to make friends and then prepare him for life really. I think mainstream school will prepare anybody for life whether they have special needs or not. Everything happens in your teenage years and that's a big lesson for everyone when they go to school – you find out who you are and who your friends are and that will be what we want for Shannon and Sam to learn - who they are and what kind of friends they want to have in life and who they want to be. And hopefully that will happen. We are expecting some bumps along the way as every parent experiences, whether your child has special needs or not. Shannon is going to be a teenager one day and just as rebellious as I was, so that will be fine, and Sam as well, he's going to go through his teenage years just as anybody else.

Interviewer: Do you imagine him being independent one day?

Shannon: Yes, we do. We are open minded about it actually. We have met quite a few adults with Downs Syndrome who have their own living quarters and have their own lives, have jobs, girlfriends / boyfriends, pay their own way through life, cook their own meals, travel to work by themselves. It's not impossible. But I do believe you put in what you get out and we are going to work very hard with Sam. It's pulled off already. We've taught him all his macketon signs and prepared him with the physio and his portage worker and already he's doing quite a lot, so if we carry on putting the work in with him and Shannon, hopefully they'll turn out to be independent adults. If not, we're prepared to put a granny flat on the end of the house, for him to have his own independence and that's fine with us. They can stay at home as long as they like.

Interviewer: What would you say are the most rewarding aspects of having Sam?

Nicholla: With Sam he's so loving. He loves his cuddles and his kisses and he will give them to you every day all the time. He is very patient. He's not a cry baby, never has been. Doesn't cry, unless there's something wrong, which is why we take him to the doctors if he cries and we say, 'what's wrong, he's crying!' He laughs at everything. He finds everything hilarious. Everything's so funny with Sam. And he just makes everybody laugh around him. You can't fault Downs Syndrome children at all until you've met them and they just rub off on to you. Sam charms everybody he meets and they don't forget who he is. Everybody remembers him. He just takes everything with

his stride and lets Shannon mother him. He lets her cuddle him and change his nappy and bath him and he's very patient like that. He doesn't mind Shannon throwing him about everywhere like a little doll, but she's learning that he's not a doll and he's her little brother and to treat him like that and he's such a lovely little brother to have. He teaches Shannon a lot as well as Shannon teaches him a lot and they work together. We're very happy.

Interviewer: What would you say is the hardest aspect of it?

Nicholla: His surgery. Not every Downs Syndrome baby has to have surgery and that was the most terrifying part in his life, in our lives and we've gone through it. Sam himself as a baby, is no different to Shannon as a baby. We don't find any difference at all, just the fact that everything takes a little bit longer and he will be a baby for a little bit longer. That's fine. We get to mother and father him for a little more. Shannon grew up so quickly and now we get to cherish the baby times with Sam. I wouldn't say there was anything that I would change about him. Nothing at all. Just his surgery. But then Sam wouldn't be Sam if he didn't have heart problems or bowel problems. You've just got to accept that into his life.

Interviewer: What would you say to prospective parents who've learned they're going to have a Downs Syndrome child?

Nicholla: I would say to read up on all the information, speak to parents if possible, who have Downs Syndrome children. Not everything is bad, not everything. The thing is, me and Martin have never felt negative about Sam so I wouldn't know how it feels to feel that negativity if you had a Downs Syndrome child so I would say to people who aren't sure that it is wonderful. It's so fulfilling, and yes it is hard work, its hard work with any child. Yes, I have given up work to be with Sam, with his physio and his portage worker and his speech therapist, but they are here to help him along the way and we welcome that. It is difficult in the world when you take them out for the first time to see people's reactions. As I say, some are good and some are bad, there's never an in-between. And you've got to be strong enough to ignore that. Strong enough not to retaliate, which is something I've had to overcome. You've got to accept that he or she will have these times in life that are going to be very hard and you've got to be there for them. But any child can be very hard to deal with. It's really whether you feel up to being a parent. Whether you feel up to being a parent of a Downs Syndrome child. If you are happy to be a parent you are happy to be a parent to any child, regardless of who they are. So, if you are worried about having a child with Downs Syndrome there's no need to worry at all, they're so

rewarding and so fulfilling like any other child in your life. There is no difference. It's still the same feeling, still the same love I have for him. Still the same changing of nappies, giving his bottle. Still the same telling him off when he's being naughty. Still the same smiling at his first word, his first clap, his first crawl. You still have all the same feelings as you do with being a normal parent.