Article for SOFT newsletter about my daughter, Sadie Elizabeth Collins

09/06/10

We honestly felt that the world had ended and that there would never be any more joy in our lives when we were told our precious baby girl would die. Sadie had arrived on 30/12/09 by caesarean and weighed 4lb 8oz and from the moment she let out her first little cry I felt that I had always known her and the love I felt was something I could never have imagined. Upon hearing the most terrible and shocking words the next day I just clung on to my husband, Drew and the world just crumbled. It’s indescribable. We have never been the same people since then. Paediatricians believed that Sadie had full Edwards’ Syndrome (and a large hole in her heart) and this was quickly confirmed with a diagnosis and we were told she would not survive her first 2 weeks.

As I write this Sadie is nearly 6 months old and has just started to enjoy her first tastes of solid food. Today she enjoyed some blended parsnip. This was a sight that Drew and I never expected to see and the joy of watching our darling girl experience new sensations is immense. It’s taken me several months to understand fully that Sadie is not just a baby with a shorter life expectancy, but a wonderful living soul who is enjoying her life to the full and she will do so for as long as she is able. I have also come to realise that Sadie’s life will always be different to that of an average child. She has her own needs and will develop in her own way and at her own pace.

Don’t get me wrong; I have always enjoyed Sadie from the moment she arrived (both in my tummy and into the world). It’s just that in order to help us face reality and come to terms with Sadie’s condition, it was made very clear that there was no hope and any that we tried to cling to was quickly discussed with us by the medical staff in the Neonatal Unit to ensure that we did not live in denial. There were a few occasions in Sadie’s first couple of weeks where we nearly lost her. We watched those machines in the NNU and cuddled and fed our daughter (by nasal gastric tube back then) and tried to be the strong parents she needed us to be - no longer praying for her survival, but for her comfort and peace and a little more time with us. Sadie was baptized on her third day and we tried as best we could to prepare ourselves for her death. It all seemed so wrong when we’d arrived in hospital full of joy and anticipation of new life and all around us new life continued to enter the world.

The staff in the NNU were absolutely fantastic. I can’t begin to express how much we owe to them for pulling us through and giving us strength. We also discovered what amazing friends and family we have. The text messages, visits, hugs, food parcels and kind words pulled us through and lifted our spirits to get through each day. We’ve had to accept that not everyone has the strength and compassion in them to offer support and comfort but those who are able to, just offer kindness in the simplest of ways make a huge difference.

Making the decision to bring Sadie home was a long and terrifying decision to make. I was then and remain now, so afraid of discovering her dead or of not being able to comfort her and make her all better. In the early days the utter helplessness engulfed me and I just watched Sadie each day, ‘making the most of her’. I felt so isolated. Like a temporary mum, just waiting for the worst to happen.

Nearly 6 months on and here comes another cliché – it’s been a roller coaster. Having Sadie has been the happiest and saddest time of my life. I have never cried so hard or smiled with such pleasure. I never knew such depth of emotion existed. When she looks up at us with her huge blue eyes and watches intently she could make the coldest heart melt. We are so very lucky to have her and we treasure our time with her.

Sadie has surpassed all expectations and has doubled her birth weight. She smiles and laughs, feeds through a bottle and is now weaning. She is also extremely vocal and happily coos, gurgles and makes her favourite ‘la’ sound. She loves trees, baths, cuddles, bouncing, coloured lights, leg massages, taking showers in our arms, sucking her beloved dummy, grabbing her elephant, going for walks in her pram, watching my friends’ children...... the list goes on and on. In short: she is living her life and loving it.

It’s not easy. Aside from handling our own emotions, the practicality of living with Sadie’s condition is not always straight forward and there has been little advice available other than trial and error and gut instinct. Sadie struggles with sunlight and has had some earlier breathing difficulties (she turned blue and choked during most feeds). She also struggles to fight off mild illnesses and for many months I lived in fear of her contracting any germs as it’s not clear how her immune system will develop. She has however shaken off jaundice and a nasty cold all by herself. Sadie has low tone and so we perform a series of physio-led exercises on her. It’s hard to find positions for her to be comfortable in that won’t impede her development as she just loves lying on her side, so we have to balance between keeping her happy and thinking of her long term comfort. Going out can be tough because Sadie can become easily distressed. I also find myself worrying about the questions people ask or comments they make. I find I hold my breath in anticipation that someone might make assumptions about her which I’ll have to correct. I’ve learnt how to concisely explain Sadie’s condition without making people feel too awkward now I hope, but initially the fear of being around people was paralysing for me and I still struggle with that, but I will push myself more.

About 2 weeks ago I started to realise that my daughter could actually remain with us for a while longer. I am under no illusions but I have dared to imagine life with her over the coming years. A second wave of fear gripped me as I realised she would be severely disabled and I struggled to understand how that would be and to worry that I just couldn’t be strong enough to manage that. As with each wave of fear, once I faced it and talked it through things have become easier and I can see the possibilities. I’m still scared of what the future holds as we know there are tough times ahead no matter what happens. I know though that Sadie, my husband, and I will enjoy the good times and with the support we have from family, friends and amazing charities like SOFT and Francis House Children’s’ Hospice we’ll be just fine and face the challenges each day brings.

I could fill a whole book already about our experience so far, but I hope what I have said here gives a good insight into Sadie’s life to date and how we’re finding our way. I’d love to talk to other parents of T18 children to share experiences, comfort and advice.