

Achieving a Dream

by Jo O'Regan

In Issue 17 of CLAPA News, Alison Baum wrote about her struggle to breast feed her son David who was born with a cleft palate and Pierre Robin sequence and how the struggle changed her life. In response to this article, Jo O'Regan, wrote to CLAPA with her own experiences of trying to breastfeed her daughter Isabella.

Here is Jo's story.

My daughter Isabella was born at Eastbourne District General Hospital on August 9 2005 with a complete cleft of the soft palate and partial cleft of the hard palate. I already had two lovely boys, Eliot aged 10 and Laurence aged 2½. The birth was induced due to severe SPD (Symphysis Pubis Dysfunction), but I had a wonderful and fulfilling labour – very quick and relatively easy – and was delighted with my new baby daughter who seemed absolutely perfect.

As I was lucky enough to have managed to cope through the birth without drugs, I felt both elated and alert, and ready to get to know my beautiful daughter. I had breastfed my first two children very successfully to almost a year each, and was fortunate enough on both occasions to have a plentiful supply of milk. I fully intended to breastfeed all my children as I saw it as a way to give them the best possible start in life, as well as enhancing bonding. I attempted to feed Isabella shortly after birth but she wasn't interested and I decided to leave her until we were both more rested. I tried to feed Isabella throughout the day and felt that there was something wrong, although I wasn't sure what. I spoke to various midwives who told me not to worry and tried to reassure me that the baby would be getting something and that I was probably just tired. But after feeding my two other babies I knew that it just didn't feel right and that she didn't seem to be

latching on. Isabella was very sleepy all day and was even checked by the paediatrician as I was feeling increasingly anxious. The paediatrician even put a finger inside her mouth, but not far enough in to feel her cleft palate. Her cleft palate was only discovered late on the first night after Isabella had some episodes of difficult breathing. This was probably, as we were later told, due to her tongue falling back in her mouth and partially blocking her airway. She ended up in special care that night, with all kinds of monitors and tubes attached to various places. We were told that she had a cleft palate which was in all of the soft, and half of the hard, palate. I was also told that Isabella wouldn't be able to breastfeed but would need special bottles. This was because she was not able to produce an airlock when sucking due to the hole in her mouth, and so had no strength in her suck to draw down the milk from the breast.

Both myself and my husband were stunned by the news that our beautiful girl had a cleft palate and would need an operation. Although we were told that it often runs in families, neither of us has heard of anyone who had had a cleft. We had a lot of support from the cleft nurses who advised me to express milk for Isabella to drink using the squeezezy bottle. For me though, the greatest shock was not being able to breastfeed my new baby. I felt as if the new motherhood that I had looked forward to throughout my pregnancy had been taken from me, leaving me feeling unable to fulfil my natural instincts by helping my baby in the only way I knew how.

I initially used the hospital breast pump to express and was on average expressing every 3-4 hours. I tried to do this while cuddling Isabella as the normal letdown reflex didn't happen easily, as it does when naturally breastfeeding, and so I found it hard to get the milk flow at that stage. I was determined to keep expressing until after the operation, scheduled for when Isabella was seven months, when I hoped to be able to teach Isabella to breastfeed. In hindsight, I know now that this was probably an unrealistic expectation. For the first week of Isabella's life we were in special care, as she had

some difficulty taking to the squeezezy bottles. Looking back it was during this time that I made it my mission to express as much milk as I possibly could and delighted in seeing the growing number of bottles which were collecting in the hospital fridge. I think that this was my way of coping with the situation.

When we went home I threw myself into a daily routine which consisted mainly of expressing and feeding, with little time for anything in between. By this time I had borrowed the double pumping machine from our local cleft nurse, who was really supportive, while at the same time gently warning me that hoping to express until seven months and then switching to breastfeeding might not be realistic. Despite my determination, I found the endless round of expressing completely exhausting, as I was also waking in the night to express and feed Isabella, often at different times. I was also struggling to give enough time for my two eldest children and my husband.

At times I found myself panicking at the thought that I might not have enough milk for the day and, as the weeks wore on, despite my husband virtually taking over the household tasks, I found it harder to express what I needed for the daily feeds. After five weeks my milk dried up, and I remember watching the empty bottles attached to the breast pump and willing them to be full. On advice from Sue, our cleft nurse, I went to my doctor who prescribed me tablets which could stimulate my milk flow. These took 24 hours to work, and when they did, I found that I could express about 20oz from each breast! I froze as much as I could each day, and was drinking pints of water to keep the supply going. This lasted for five days, and despite drinking and trying to rest when I could, the milk gradually ebbed away again, until it completely stopped after eight days.

In all, I had managed to express feed for six weeks. I remember phoning my cleft nurse in floods of tears as I felt such a failure as a mother. She praised me for managing to keep going for such a long time and reminded me, as I needed reminding, that I had still

given my daughter the best possible start for the first weeks of her life, in fact more than many babies have, who didn't have any feeding problems.

It probably took me another four weeks to come to terms with stopping expressing, as I had so wanted to carry on until after Isabella's operation. I felt at the time that I had let her down but I realise now that I gave my all, and couldn't in fact have done any more, especially with the demands of a young family. At the same time, I also had a huge feeling of relief that finally I had allowed myself to stop what was rapidly feeling like torture, both mentally and physically.

Initially I felt very guilty, but gradually I came to accept that I had done my best, and from there I began to enjoy my baby, instead of focusing on how many ounces I could express that day. Isabella took to formula milk as if she had never had anything else and continued to thrive and grow into a happy, healthy child. She sailed through her operation at seven months, and is now a beautiful twenty-one month old, who is trying desperately to talk, and loves nothing more than to dress up in pretty dresses and run around after her brothers causing as much mischief as she can.

As an ordinary mother looking back at my experiences, I am very glad that I tried and succeeded to express for these first few weeks when Isabella was born. It was harder than I ever imagined that it could be, and I know that I punished myself for not being physically able to carry on for longer. I also know that although feeding seemed to take over my life at the time, we came through it with our family life and my sanity intact. Despite only express feeding my baby for a relatively short time, I can say that I have built as close a relationship with my daughter as I did with my sons, with a bond just as strong, or maybe more so, because of the journey that we made together.

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