

# Achieving a Dream

## One mother's struggle to feed and how it changed her life

by Alison Baum

**My first son, David, was born with a cleft palate and Pierre Robin sequence<sup>1</sup>. He couldn't breastfeed at all. However, by expressing, I was able to feed him exclusively on my milk until he was eight months old. (He ate solids earlier, but the only milk he drank or ate with his baby rice was mine.)**

<sup>1</sup>Pierre Robin sequence is characterised by a small lower jaw at birth.

The first few months of David's life were extremely tough - we visited five different hospitals in his first five weeks. David had a very wide cleft palate, a tiny lower jaw and serious breathing problems, which meant he choked all the time. At first David was fed by a naso-gastric tube but at ten days old the tube came out and we graduated onto a special squeezezy bottle. The biggest breakthrough came when we were taught "side-lying", a technique where I fed David his bottle-feed lying on a pillow, on his side, which meant that any excess milk would dribble out of his mouth and be less likely to overwhelm him. But even still his feeds were incredibly precarious. They were like an amazing silent dialogue, with me responding to his every move, ever watchful not to squeeze too much lest he get overwhelmed and choke.

For the first ten weeks I also tried to see if David could feed from the breast but he became distressed and it was just cruel as he couldn't get any milk out - quite simply he had no suck. Even though David couldn't breastfeed I was determined that he should at least benefit from drinking my expressed milk, I started expressing on day one and didn't stop until

David was eight months old. Above and beyond the normal benefits of breastmilk there were four main reasons that gave me the momentum to express.

*a. I wanted David to have all the immunity I could give him. Before David's operation, everything he drank (and ate) came out his nose, and breast milk is known to be far less irritating than formula on the nasal passages.*

*b. Milk did sometimes go down the wrong way into David's lungs, and once again breast milk is far better tolerated than formula*

*c. David, like many cleft palate babies, had severe glue ear and breastfeeding has been shown to help glue ear.*

*d. I hoped that if I managed to express until David had had his operation to repair his cleft palate, he would be able to breastfeed after.*

Basically, I felt helpless with so much of what was going on with David medically, but expressing was something I could do - a difference I could make. If you express all your milk for your baby without them being able to breastfeed it is called exclusive expressing. It is tricky because the breast doesn't get the normal stimulation of the baby sucking. To keep the milk flowing you have to express as often as the baby would feed from the breast. At the beginning that was at least 8 times a day and once in the night. Lots of research has shown that expressing with a double-electric pump can help (Jones et. Al 2001). It has been shown to increase yield, fat content and it allows you to express more quickly. The only trouble with double-pumping is that it is not terribly practical - put simply, you've just not got enough hands. I was sat there like a lemon holding both collecting funnels on my breasts; I couldn't even turn the machine on myself, let alone drink a glass of water! I am sure I would have given up expressing much earlier if I hadn't tracked down the Easy Expression Halterneck Bra from the United States. The Halterneck kept me sane and happy, as I was able to have a life, while I expressed. The Halterneck holds the funnels of the collecting sets comfortably in place, which freed me up to eat and drink, play with David

and talk to my friends and family on the phone, all while I expressed. It was fantastic to be productive in more ways than one! It got to a point that I was so ahead of David's demands that there was no room in the freezer for any Haagen-Dazs! I am proud to say I was even able to donate milk to my local milk bank at Queen Charlotte's, a hospital in West London.

David recovered well from his cleft palate repair operation and went from strength to strength. He never got the hang of breastfeeding, but this didn't matter as he was doing so well and for the first time he was happy.

When I became pregnant again my hopes of breastfeeding were re-ignited, but once again things didn't go to plan. Joshua was born a month early and there were problems with his feeding from day one. Unfortunately, any issues about Joshua's feeding soon became irrelevant, as when he was 8 days old they found he had viral meningitis. He was desperately ill, and I started expressing for him in earnest. I would sit by his incubator, my hand resting on his head while I double-pumped for him. The care Joshua received was excellent and he was a real fighter, and pulled through. When we were back up on the ward my concerns about Joshua's feeding became more prominent. However, I was told that Joshua was breastfeeding fine and I should really cut back on the expressing and on discharge I was told to stop expressing and fully breastfeed. I so wanted to believe that Joshua could do it, that I stopped expressing. Five days after we were discharged my husband and I took Joshua off to Great Ormond Street and the consultant there took one look in Joshua's mouth and announced that Joshua had a classic and significant sub-mucous cleft – the skin layer was there, but none of the musculature was behind it, and there was a "notch" in his hard palate – it turns out that to diagnose a cleft it is not good enough just to "look" you also have to "feel".

We were of course devastated by the diagnosis, but I knew I would be able to long-term express, so that Joshua, like David could at least benefit from my milk.

As soon as I got home I started to express, but to my utter dismay nothing came out – my milk had gone. The days of no expressing and the previous week of limited expressing had taken their toll. However, with help and support I was fortunate to be able to re-lactate which was a huge relief – especially as Joshua turned out to be extremely dairy intolerant. I used the Halterneck, of course, and became masterly at double-pumping at the same time as feeding Joshua his bottle of expressed milk and I often chatted on the phone at the same time as well! I could also sit David on my lap and read to him while I double-pumped.

Joshua had his operation at five months old. Immediately after the operation Joshua found breastfeeding less painful than feeding from a bottle but I found it painful because of the stitches in his mouth. Fortunately, my husband had the cunning idea of using nipple-shields which I used for a couple of days until Joshua's stitches dissolved.

Post-op was also tough because Joshua's new improved suck was better than his swallow, so, whether he was feeding on a bottle or at my breast he was often overwhelmed by the milk and choked. But Joshua soon mastered the "suck, swallow, breathe" pattern and I gradually increased his time at the breast while decreasing the expressing and top-ops of expressed milk. Finally, seven months after Joshua was born, I achieved my dream of being a fully breastfeeding mother.

## **A career change...**

Soon after achieving this dream I started my training to be a NCT breastfeeding councillor and embarked on an intensive 9 week Sure Start course to become a peer support breastfeeding mum. It was then I realised that mums with normal healthy babies can often struggle with breastfeeding. Primarily it boils down to lack of information, mis-information, conflicting information and a lack of support.

I then made a huge decision, to take voluntary redundancy from the BBC, where I'd been a

Producer/Director for almost 10 years, and to launch a new website ExpressYourself Mums.co.uk to help bridge the gap between wanting to breastfeed and actually being able to do it.

Express Yourself Mums has been live since January 2005 and is a central resource for breastfeeding mums, and the healthcare professionals who support them. We hope to impact positively on breastfeeding rates in the UK.

In our Information Zone, there are in-depth articles by international experts. In our Product Zone, I sell tried and tested specialist breastfeeding and expressing products to families, hospitals and other healthcare professionals

As well as offering an easily accessible resource for healthcare professionals, Express Yourself Mums is a place where mums can share experiences – inspiring success stories and problems overcome – an on-line community with a positive twist.

Express Yourself Mums is also the first specialist retailer which triggers a donation to charity with every single purchase, and for most products sold the customer can choose which charity to support from a list of twelve breastfeeding and baby charities. A donation of up to £2.50 goes to one or more of these charities (which include CLAPA) with every purchase made. See below for list of charities supported through sales of halterneck bras.

I'm now spending my time talking at conferences, talking to health-care professionals and spreading the word that help is at hand. Never in a million years could I have guessed that this is what I'd been doing....life throws stuff us at us, and I guess I've decided to pick it up, deal with it and run with it.

I had used the Halterneck for almost six months when I realised that no-one else in the UK had the Halterneck or indeed knew about it. I was determined to make it available to British women - it had made such a huge difference to my life, I wanted other mums to benefit too. So, I hooked up with the manufacturer in the US, and set up my own wee company, Express Yourself Mums. I

am now the exclusive distributor of the Halterneck in the UK. I have created a website with lots of information on how to express which many breastfeeding counsellors recommend as an extremely useful resource. [www.expressyourselfmums.co.uk](http://www.expressyourselfmums.co.uk). I give £2.50 to charity for every Halterneck I sell; 50p to each of the following five charities: The National Childbirth Trust, Great Ormond Street Hospital, Bliss - the Neonatal Charity, the Twin and Multiple Birth Association and the Cleft Lip and Palate Association.

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