

## steps

Baby Hip Health Week 24 February to 1 March 2008



### Amelia's Story – sometimes early treatment isn't enough...

In the late stages of my pregnancy with Amelia it was highlighted that she was in the Breech position, I was due to have an ECV (a procedure to try to turn the baby) on the 4<sup>th</sup> April 2006; however Amelia decided to make an early appearance and was born by emergency C-Section on 2<sup>nd</sup> April 2006.



DDH was diagnosed in both hips on her routine check and confirmed by an Ultrasound scan when she was 2 days old and she was fitted with a Pavlik Harness at 3 days old prior to leaving the hospital. We were totally shocked that our tiny little (6lb 2oz) newborn baby was going to have to wear this scary contraption for 23 hours a day!

She wore the Pavlik Harness for 6 months and went to weekly physiotherapy appointments to ensure that the harness was fitted correctly. During this time she was seen on a regular basis by the Consultant to check on her hip development, she was also diagnosed with significant torticollis (twisted neck - which is common with DDH). I trawled the internet during this time sometimes sending myself into panic with some of the things that I was reading and seeing (pictures of babies and children in hip spicas particularly scared me)! Luckily during this time I also stumbled across Steps and just reading that other parents were going through similar experiences was a relief.

During the 6 months I was praying that the harness would be successful, however in September 2006 we were given the devastating news by the Consultant that the Pavlik harness had not been successful with Amelia's left hip (she was pulled out by her left leg during the C-Section) and that she would now need to operate! She was still so small; this was the worst possible outcome. We discussed in depth the procedure (closed reduction) and the expected outcome. We were told that he would try to manipulate the hip back in to the socket under a general anaesthetic and if he could he would then put her into a Hip spica or traction depending on the stability of the hip. Both of

these options were hideous to think about. I was also due back to work after maternity leave I couldn't imagine how were going to cope!

On 6<sup>th</sup> November 2006 Amelia was admitted to our local hospital to be operated on. We had to arrive by 7am to the hospital and Amelia was not allowed to eat or drink for hours prior to this. We were really worried that she would be screaming for her breakfast prior to her operation (as she her last feed was at 6.30pm the night before), but she was very calm and did not complain at all.

As she was so young she was first to go to the operating theatre that morning. We were told that only one of us could be with her when she was given anaesthetic, so we decided that I would go in with her and my partner would wait outside, however after the long walk down to the theatre filled with dread, I could not bring myself to go into the theatre with her, I was in floods of tears, so she went in with Daddy, who also came out in tears!

Unsure what to do with ourselves during the operation we went off to the canteen and tried to drink tea, but were unable to concentrate on anything. After what seemed like a lifetime (but was only around 1 hour)! We were told that we could go to recovery to collect her. We rushed in and peeked below the covers to see what was there, only to find legs (there was no traction or hip spica). This brought mixed feelings as on one hand it was a relief that she did not have a spica or traction, however we knew that the operation had not been a success and therefore she would need to encounter further operations!



We were then referred to the children's hospital. In December 2006 we had our first appointment there. I don't know what I was expecting at our Out-patients appointment there, but it is a little like organised chaos! The surgeon advised that Amelia would have to endure further surgery but he would wait until she was around 16 months (this would be the optimum time for successful surgery). We were booked to go back to his clinic just after her first birthday to be given a date for her op. The waiting was quite awful, knowing that she had to endure this surgery and the 6-8 weeks in a hip spica during the summer!

On 13<sup>th</sup> August 2007 Amelia was admitted to undergo a left hip open reduction and proximal osteotomy (basically they put the leg back into the socket by cutting a wedge from the bone and screwed it together with plates and pins). We gave her lots of cuddles on the train journey on the way up there to enjoy the last time that we would be able to cuddle her properly before she went into her hip spica.

It was a very long day, she endured lots of blood tests, x-rays and general pulling about, however we eventually got to go out of the hospital for a meal

and Amelia had her bottle and went to sleep in her buggy then back to hospital for an early night. I got to stay at the hospital with her.

The morning of the operation eventually arrives Amelia awakes around 6.45am and plays happily. We are seen by the anaesthetist who advises that due to the fact the operation involves nerves and bone cutting she will be given quite a deep anaesthetic. We listen intently but feel absolutely powerless; our poor little girl will have to go through this on her own! Again the hellish journey to theatre and holding her whilst she has the anaesthetic, more tears from all of us!

We wandered around the streets nearby, aimlessly not knowing what to do with ourselves trying to waste the time. We then rushed back to the hospital, even although we know that she will be in the operating theatre most of the morning! We sat nervously in her room watching daytime TV watching the nurses to see if they have any news. Until we eventually get told that she is in recovery and get taken down to see her.

Amelia was obviously still heavily sedated but seemed to know we were there, we pulled back her covers to reveal a bright pink spica (you get to choose colour beforehand). Although it was a shock it was also a relief to see that it had been completed! On the way back to the ward the surgeon assured us that the operation was a success. She was sleeping for most of the afternoon and we tried to give her cuddles, it was a little tricky getting used to the plaster!

That evening she did manage to sit up and eat some toast, it is quite amazing how resilient she was, but she suffered a little sickness from the morphine she had been given.



We were actually discharged the next day after an MRI Scan (which was quite scary for her) and taken home in an ambulance (obviously due to the fact that she did not fit on a car seat). At home we found that we could manage to make her comfortable using bean bags and a big bucket chair propped up on lots of cushions. The first couple of nights we had, she woke a lot during the night, but after those she settled straight back into her 12 hour sleep pattern and even managed to sleep on her side, with one leg against the side of the cot. The nurses at the hospital had shown us the art of nappy changing and we soon got this figured out (it really isn't as bad as I imagined)!

Amelia was in plaster for 6 weeks and although I had been dreading it, it did go quite smoothly and she did not seem to be distressed during this time. When we went back to the hospital to remove the plaster she screamed whilst



they were taking it off (they do it with a noisy plaster saw) but we were discharged the same day and took her home for her first bath for 6 weeks! I thought that she would really love this, but she was in a lot of pain without the cast for support.

We have been back to the hospital for 3 monthly checks since the removal of the plaster in September and unfortunately it seems as if she will require further surgery as her hip is not forming properly (x-rays have revealed acetabular dysplasia). We are obviously devastated with this news, but Amelia is a very happy little girl and we

are taking her on her first holiday before going back to the hospital in September to face the next round!

## Did you know?

- DDH is not just one condition, but describes a range of severity from mild instability to total dislocation
- Swaddling practices which restrict leg movement and position, such as traditional methods in Japan and North American Indian populations have been associated with high incidence of DDH.
- Modern methods of caring for infants in developed countries, such as long periods spent in baby seats and the use of very slim disposable nappies and clothing which restricts hip position could also affect hip development.
- DDH underlies up to 9% of all primary hip replacement and up to 29% of those people who have a hip replacement aged 60 years and under.
- Celebrities with childhood hip problems
  - Toyah Willcox
  - Sara Cox
- Celebrities who have had hip replacement surgery;
  - Bob Wilson, Arsenal goalkeeper and coach
  - Martha Stewart
  - Barry Manilow
  - Jack Nicklaus
  - Eddie Van Halen
  - Liza Minelli

Anyone wishing to get further advice or to help distribute leaflets should contact the **steps** helpline on 0871 717 0044 or go to [www.steps-charity.org.uk](http://www.steps-charity.org.uk)