

steps

Baby Hip Health Week 24 February to 1 March 2008



Skye's Story

Skye was diagnosed with Developmental Dysplasia of the Hip (DDH) when she was 3 yrs 2 months. We had been noticing for a while she walked with a limp but had no idea it was serious. I decided to take her to the GP as a precaution. When she was diagnosed her left hip was completely dislocated. I was in shock I had no idea that it was even possible to walk with a dislocated hip and I had no idea that if a child's hips were passed as OK at birth and at eight weeks that this could develop later on. I have no idea at what point the dislocation occurred but I think it must have been when she was quite a small baby because as far as I remember from a few months she had always had an extra skin fold on her upper leg.

I felt very let down by the local health services. I appreciated that the newborn hip tests could be passed ok and that the condition can develop later, however, I felt that if I had been informed of this condition and the symptoms to look out for I would have diagnosed this myself before Skye was walking. She had an obvious leg length difference and extra skin fold. This was not looked for or noticed at her 9 month check or 2 year check by our health visitors, in fact at her 2 year check her walking was not assessed or any physical tests performed. In addition with the information I now know, I realise that at birth Skye had 4 out of 5 risk factors for developing DDH but no one even spoke to us about this or made a note of it in my maternity notes or her health book. In retrospect this makes me very angry.



Following diagnosis we were referred to a consultant at the Children's Hospital. At first we were told we would have to wait 12 weeks for an appointment. We spoke to our GP again who agreed this was far too long to wait for such a serious matter and she referred us for an x-ray at the hospital. The results from the x-ray meant we got to see the consultant a week later!

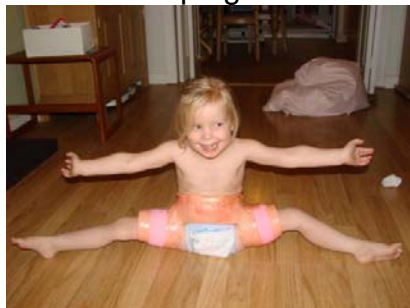
At the outpatient appointment we were told that Skye would need to spend a week in traction followed by a closed reduction. Following this she would need to have a hip spica cast for 3-4 months. A couple of weeks later we were in hospital. Skye was put up in traction. The first night was awful. Skye cried for

most of the night. The next day however she figured out how to turn herself on traction and things got much better. However sometimes she twisted and turned so much it took a while to untangle her. The worst part of the traction was having the sticky strips changed this had to be done twice and caused Skye a lot of distress and crying. After the week was up Skye was allowed a bath; her last one for the next few months! She was then free for the afternoon, although she was not allowed to walk.



Late afternoon Skye went to theatre for her closed reduction. She came back fast asleep and wearing her new spica cast. We had not seen one before and it was quite a shock. When Skye woke she was fine for about 15 minutes and then she realised she could not move and we showed her the cast. We had tried to prepare her as much as possible but I think it's impossible to prepare a 3 year old for that. We had a bad night; she screamed so much we were moved to private room. It was hard for us all, we were discharged the following day with hardly any on how to care for her or what to expect.

For the next three days Skye was not the little girl we knew. We didn't see her smile and she actually lost her voice from crying so much. It was heartbreaking to see her like this and hard work as she would not let us put her down; she needed cuddling constantly. Slowly things improved and we found a seat that Skye could use comfortably up at the table to play and eat. Night times were hard, Skye had always been a good sleeper, but now she woke up to 7 times a night, crying and needing turning over. With a baby sister to look after as well my husband and I were exhausted. She was always used to sleeping on her side and found it hard to adjust. Eventually she learnt



how to turn herself, how to pull her self along on the floor and even how to get up stairs unaided, and by the time the spica came off she could do gymnastics and entertain us all. Skye started the nursery class at her local school in September. The local education authority got her a special chair with wheels which meant she could sit at the little tables with her classmates and go out with them at

play time.

After 3 months the cast was removed. She wore a Pavlik harness for a week and then we were told it was OK for her to wear it at night times only. Skye had a check six weeks later. It was impossible to use ultrasound to check her hip joint because she was too big. The consultant had to rely on x-rays which he explained were sometimes difficult to interpret accurately. Everything seemed to be progressing well. Six weeks later we were back again for a further x-ray. It was a big shock to find that Skye's hip had deteriorated and become unstable once more. She was booked into hospital the following week for an arthrogram to assess the extent of the instability. We were told

that she would need a Salter osteotomy to re-angle her hip socket and she would need to wear the spica cast again for another 6 weeks. We were devastated. We thought she had been doing so well and she was already back on her feet running and jumping. She had even started going to gymnastic classes.



Skye's next operation is scheduled for 4 weeks from now. The consultant has advised us that there is a possibility that after this period in the spica she may need her femur re-angling at a later date. This would mean another operation and spica cast. This time hopefully we are all a bit more prepared and it will not be so hard to adjust to the cast again. We have managed to obtain a brand new wheelchair from the OT department that has been designed for children in spicas so hopefully this will make life easier for us and for Skye to attend school. Skye has been a little heroine through all of this. She has been much braver than us and hardly ever complained about not being able to run around with her friends. We are so proud of her we just really wish we had had this diagnosed earlier before Skye could run around and before she had started school.

Skye's father and auntie were successfully treated for DDH as babies.

The most common factors associated with DDH are:

- A family history
- A breech position
- First born baby girl

Signs to look for include:

- One leg appears shorter than the other
- An extra deep crease is present on the inside of the thigh
- One hip joint moves differently from the other.
- When you change your baby's nappy one leg does not seem to move outwards as fully as the other.
- Your baby crawls with one leg dragging.

After walking age you may notice:

- Your child stands and walks with one foot on tiptoes with the heel up off the floor.
- Your child walks with a limp (or waddling gait if both hips are affected).

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