



steps

We don't take walking for granted

Lily-Mae

Diagnosed aged 18 months
Treatment to date: Failed
Closed Reduction, Open
Reduction Sept 06. Repeat
Open Reduction & Pelvic
Osteotomy July 08.
Avascular Necrosis of the
Left Hip.

Lily-Mae's Story

Lily-Mae was born on 31st January 2005. I had a normal pregnancy/delivery & as Lily was my second child I chose to have a 7 hour discharge. She was given the all clear by the Paediatrician but I have since learnt that a hip check is unreliable in a baby under 24hrs old & Lily should have been recalled for a second examination.

Lily had her 6 week check on the 16th March 2005 & her PCHR shows that her hips were satisfactory. This would have been an ideal time for the GP to explain about CDH/DDH & give out a baby hip health leaflet.

Lily was a good baby and fed well but she was in her pushchair she always slipped downwards and I had to prop her up on a cushion to try and keep her sitting upright. In the end I bought a new pushchair thinking that was the problem but it didn't make any difference.

At Lily's 9 month check carried out by our Health Visitor I expressed concerns that Lily was unable to sit up unaided & showed no signs of starting to crawl. This was documented in her PCHR & it was recommended that she be checked by a GP. I took Lily to the GP & explained my concerns & that of the Health Visitor. The GP observed Lily sitting on the floor & told me that she was a late developer & not to worry. At no time did she examine her hips, check that her legs were equal in length or for uneven creases on her buttocks, she purely looked at her without any sort of physical examination.

Lily did eventually sit up & then crawl. She had a funny style of crawling commando style dragging her left leg. At the time we thought it was quite "cute" & it was often commented on by family & friends. Now we know it is a classic sign of DDH.

At 18 months Lily started to walk with a limp and didn't put her foot down flat. At first we thought she must have a sore foot but it didn't improve so I took her to see the GP. The GP said there was nothing to worry about & she was just a bit wobbly & hadn't quite got her balance. Again, no physical examinations were carried out or follow up appointment arranged. My mother having only just had bilateral hip replacements was convinced there was a problem & demanded I go back for a second opinion. All weekend we kept looking at her walking & eventually established that her knees did not line up, our immediate thoughts being that she had one leg shorter than the other.

First thing Monday morning, we took Lily to see another GP determined not to be fobbed off with "late developer" & "wobbly". The GP looked at her walking, inspected the creases on her buttocks & leg length. Immediately, he said she had CDH but an x-ray would be needed to confirm. I will never forget the mixed feelings of relief someone had finally listened to me & the complete devastation that my little girl needed major surgery. The x-ray confirmed Lily's left hip was totally dislocated & sitting above her pelvis. Later that week we saw the orthopaedic consultant in Jersey who referred us to Prof. Clarke at Southampton General Hospital.

Three weeks later on 29th August 2006 Lily was admitted to G3 for 7 days of traction followed by an open reduction & hip spica cast. It was the longest 2 weeks of my life being away from home, my son, family, friends & my beautiful little girl having to go through this. After surgery Lily was in a hip spica for 6 weeks, broomstick casts for 6 weeks & lastly night splints for 6 weeks.

In the October we had another blow when Lily was diagnosed with having severe global delayed development, an autistic spectrum disorder &

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moderate hearing loss.



She is now 3 ½ years old & this was her 7th surgical procedure in the past 22 months. After Lily's metalwork and cast were removed on the 26th August she developed a Staphylococcus wound infection. We are now 6 weeks post metalwork removal and Lily still needs dressings over the wound as her skin won't heal, this area must remain dry so she is still unable to have a bath or go swimming. Although her infection is now clear Lily's body is rejecting the internal stitches so further treatment will be needed. Lily has also developed Avascular Necrosis caused by damage to the blood supply to her hip which almost certainly means she will need a hip replacement at a very early age.

We continued to have 6 weekly clinic appointments and in April 2007 Prof. Clarke informed us that there were signs of subluxation & she would have to be monitored very closely. In the June Lily was sitting on the floor & was completely unable to get up & weight bare. I rushed her to A & E explaining her history of DDH but the SHO said he couldn't find anything wrong & maybe she had twisted something but did not do an x-ray. The same thing happened in the October & again I went to A & E. A more senior doctor examined her again without x-ray & said her hip was fine. Fortunately, I was due to go to Southampton the following week & told Prof. Clarke. He arranged for an urgent arthrogram to be done which had to be put off until February 2008 as Lily was ill throughout the winter & was unable to have a General.

The arthrogram was done on the 5th February 2008 & Prof. Clarke confirmed Lily's femoral head was rolling around like a "marble in an ashtray" & she would need further surgery. On the 18th July 2008 Lily had another open reduction together with a complex pelvic osteotomy.



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