

## BabyGym baby Traynor and oesophageal-tracheal fistula

Sent in by Shaylene Lendrum

Traynor was born on the 4 November 2010 with an oesophageal-tracheal fistula. This in everyday terms means that his oesophagus had a gap in it.

His paediatrician and surgeon assured us that the operation would be nothing to worry about. It was scheduled for the next day. So, when he was not even 24 hours old they wheeled him into theatre. That's when things went horribly wrong.

Apparently, after a test dose of anaesthetic, his heart rate started slowing and they had to massage his heart. Eventually he was stabilised, and they moved him back to the PICU on a ventilator. Again, he had to be resuscitated. He then became acidotic for a few hours, which means that he had too much carbon dioxide in his body. His kidneys stopped functioning and we were told he wasn't going to make the night. But he did.

After a while he managed to come off the ventilator and have his oesophagus repaired when he was 10 days old. He then struggled with weak lungs, an unfortunate complication of the fistula. Unfortunately, because of the prolonged period of acidosis, he sustained major brain injury and is now showing signs of having spastic cerebral palsy and damage to the optic nerves. Also, because of the brain injury, he is unable to suck, so he had to undergo a further two operations to insert a gastrostomy tube into his stomach, which enables him to get food directly into his stomach. He spent a total of 73 days in the PICU.

When he first came home from hospital, he got upset when he was touched and had a very strong gag reflex due to all of the suctioning done to him in hospital. With the help of repeated BabyGym massage and other positive experiences with touch I was able to start getting him over his aversion to touch. In general, the BabyGym massage has made him more aware of his body and where it is in space.

His thumbs were stiff and he wouldn't unclench his fists very often even though he was nearly 3 months old. The neuro-physiotherapist was concerned that his thumb would always remain tucked in, as it never straightened by itself. Using the BabyGym hand massage techniques, I brought him to the point where his thumbs were no longer so tightly retracted. His hands started relaxing in general when he was about 5 months old and, when he is calm, his thumb now lies in a more normal position.

The stiffness of his muscles will always be a problem because of the spastic cerebral palsy but was made worse because of the stress of being in hospital. The stiffness in his muscles has been lessened by using the BabyGym leg massage techniques. The BabyGym calf muscle massage has been particularly useful in calming him down and the medical professionals have shown surprise at the amount of movement he has in his legs.

He also has a tendency to stiffen and arch his body, especially when he is upset, which is, in part, as a result of the cerebral palsy (according to the neuro-physiotherapist). Using the calming techniques suggested in BabyGym, I am able to calm him down quickly, which should help reduce the harmful effect on his muscles in the long term. I have found that the BabyGym ear massage, the bear hug and tapping on the breastbone are particularly effective in this regard.

Using the activities and exercises for rolling have also helped with his motor development. He has learned the correct leg position and, to some extent, how to position his arms (though he still needs help with that from time to time), in order to roll over from his stomach to his back on his own. He started rolling by himself when he was 6½ months old. Again, medical professionals have been surprised that he has been able to reach this milestone as quickly as he has.

Giving him lots of rug and tummy time has definitely helped strengthen his neck and core muscles. He was able to hold his own head up much sooner than expected at the age of 2½ months and closer to the usual age for this milestone. More tummy time is still needed though, because he does not hold his head up for long periods and tires easily. Therefore his neck and core muscles need further strengthening.

Since his first 73 days in hospital, he has spent over a month in hospital to date (on three separate occasions) because of inflamed airways due to aspirating vomit into his lungs and a collapsed lung. All of this additional time in hospital has been very stressful for him and some of the progress he has made has been nullified. I continue to work with him in the hospital, as far as his condition will allow. He still has good movement, despite being stressed and not being able to have as much tummy time and exercise.

His improved sense of where his limbs are in relation to the space around him is clearly seen in his improved ability to remove his oxygen mask on a regular basis, giving the nurses a difficult time.

Overall it is clear to see that the techniques employed have given Traynor a much greater chance of improving his motor skills, despite being heavily delayed by the cerebral palsy.

