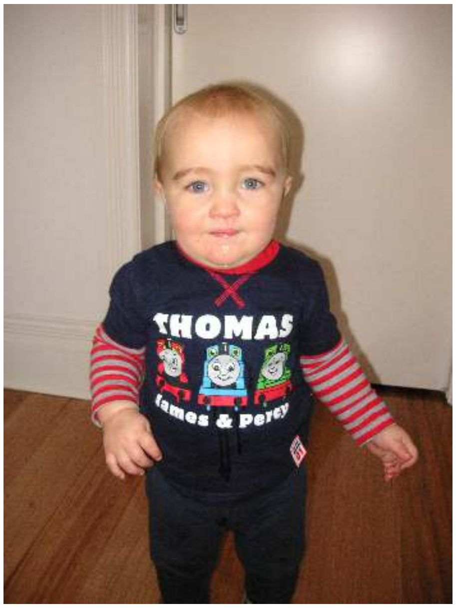
OLIVER'S STORY

Oliver is the gorgeous son of the author of this story, Alison. Oliver was born with a unilateral cleft lip and palate.



Oliver's unilateral cleft lip and palate was detected at our 20 week scan. The sonographer reassured us that 'if we were going to have a problem, then this was the one to have - as its all fixable'. We were fine about it at the time and thankful it wasn't a developmental problem. However, it was still an unknown world we were entering and the first thing I did when I got home was to 'google' cleft lips!! That's how I found CleftPALS, as well as lots and lots of other websites that kept me reading for ages. In the next little while, I did have some sad days worrying about what my baby would have to go through, the severity of it, and the reaction of others – though I hate to admit it!

When Oliver was born on 23 April, we couldn't believe how beautiful he was. He arrived all wide eyed and calm and was taking in the world around him from the first minute. We didn't even really notice his lip as it was just all part of this beautiful little boy. We couldn't wait to show him off to everyone!!

Dr David Chong came to see us that night in hospital. His care and concern for children shines through and he helped us to feel very calm about Oliver's lip and palate and confident that it could be treated all in good time. Breastfeeding didn't really work, so I expressed milk and started using the Haberman Feeder. Oliver fed well from the start. Tony and I had more trouble with his feeding equipment trying to put all the bits together so it wouldn't leak, and trying to get the squeeze motion right. Sometimes the teat was on too tight and the milk wouldn't flow. It took quite a few weeks before we felt like it was working properly all of the time. It was a bit frustrating, especially when we had a hungry baby to deal with!

I contacted CleftPALS again as soon as I knew exactly what Oliver's cleft condition was. They put me in contact with Evelyn Culnane, and Evelyn and her little boy Jarrah came over to visit when Oliver was only 2 weeks old. It was so generous of the Contact Parents to give up their time. It meant so much to Tony and I to be able to speak to Evelyn and to see her photographic record of Jarrah's progress. This again helped to ease our mind and concerns about what Oliver would need to go through and what sort of results we could expect.

We had a visit to the orthodontist in the first month. He took an imprint of Oliver's mouth and photographs of his face from different angles. He showed us how to apply Steristrips to Oliver's lip to try and encourage the lip muscles to grow together as much as possible before the operation. We also visited an audiologist who advised us that Oliver had a mild hearing loss in both ears.

Oliver had his lip repair operation at the Mercy Private Hospital on August 20th when he was 4 months old. He recovered from the general anaesthetic well and was feeding about three hours after the operation ended. When I first saw him, I felt that I almost had to bond again with his new little face. He stayed in hospital overnight, and the next morning after learning how to put his arm splints on and practising bathing him, we went home. He wasn't quite himself for a few days but he gradually returned to his usual happy self. I also had to clean his wound daily with saline and a cotton bud and apply antiseptic ointment. He didn't mind that too much but he couldn't work out why his hands wouldn't go in his mouth for the first few days! As soon as the splints were off twelve days later, his fingers went straight back into his mouth!

Five days after the operation we went to the Royal Children's Hospital where Oliver's stitches were removed under general anaesthetic. He wore plastic stents in his nose that were kept in place with tape. The stents kept falling out the first night and I wondered how I was going to do this for the recommended 4 to 6 months. I felt a bit down that my beautiful boy would still have to be taped up when I just wanted him to shine through like all of the other babies in my mothers' group. It just didn't seem fair.

Oliver's cleft palate was repaired in February 2009 when he was almost 10 months old. I think that the hardest part of the day of the surgery was the fasting! Imagine trying to keep food and drink from a very hungry, boisterous, crawling boy for 5 hours! His dad did a great job in the hospital keeping him distracted with toys.

I went into the theatre with Oliver. It was a little daunting seeing him go under general anaesthetic but I was glad to be there for him. The operation took just over two hours. In recovery, he looked like he had just done a round with Mike Tyson as he had residual blood around his nose and mouth. When he awoke from his anaesthetic that evening, the pain relief started and we attempted to give him some milk - which he took carefully but gratefully! He also had a little bit of fruit gel. He also had to have the dreaded arm splints on again – Mummy's favourite! Not!

That first night, he woke up regularly to catch up on his milk but the next day he stopped taking the fruit gel and wouldn't even eat custard (his favourite) so it was a milk-only diet. We could have gone home then but I decided to stay another night just to make sure he was monitored and for the nurses to administer extra pain relief if required. I was very glad I did stay because we had a very upset little boy for the whole of the following week at home. I think initially he was uncomfortable with pain and the new sensations in his mouth, but as he had stopped eating solid food, he became hungry all of the time. It was back to almost four-hourly feeds.

After seven days, I decided to cut back on the pain relief and I was desperate to try and get some extra nourishment into him. I started giving him runny rice cereal in a syringe and when he got the taste for that, he would sometimes even take the spoon. It was a very, very gradual process getting him back on track with his eating.

When I look at Oliver's palate, it seemed so raw and there seemed to be a huge gap on the left hand side of his palate and at the front. I was so concerned that I eventually rang the surgeon. He assured me that it would look pretty bad and unless Oliver seemed unwell, it was probably all okay. After eight days upon my request, the surgeon examined Oliver's palate and said that the palate repair did seem to have come away slightly at the front but that it was still okay. It did take a long time for the palate to heal. After a few more weeks, the hole in Oliver's palate still looked like it hadn't completely healed over and he still had some food coming out of his mouth. It turned out that he did have a small fistula (hole) in his palate, which is quite common. His teeth appeared in this area around this time too which may have affected the healing tissue.

Six months after the operation, food rarely came out of his nose. We were advised to wait and see what if the fistula would heal over naturally in time. I wanted to be sure, however, that Oliver had no problems resulting from this by the time he started school.