

HELEN & SOPHIE'S STORY

Hi, my name is Helen Gillan and I'm the new Membership Co-ordinator for CleftPALS NSW and my little girl is Sophie Lou (15 Months Old).

I first came across CleftPALS NSW in October 2011. I was given their details after my 20wk Morphology Ultrasound scan showed my baby had a Right side unilateral complete cleft lip +/- cleft palate.

It wasn't an easy pregnancy, none of mine have been!

It got worse though, when the radiologist took me aside at the end of the 20wk scan and suggested that I should consider a termination, but at the very least, an amniocentesis.

We went away with a referral for an amnio back at the x-ray department the following week and genetic counselling at the Royal Women's Hospital, Randwick.

As you can imagine we didn't get much sleep that night, nor the night after...

I decided against an amnio, so the Doctor at the Royal Women's, who was the Chief Obstetrician in NSW, scanned me every month until 36 weeks.

I felt in very good hands and he told me all he could spot was the cleft lip +/- palate involvement.

It was at this stage that I contacted Fil at CleftPALS, as I wanted to order the bottles/teats etc to be prepared for the hospital. Fil was very helpful over the phone and advised me to get a couple of each type to see what we preferred using.

(Membership to CleftPALS was the last thing on my mind at this point, but I wished I had joined straight away as I would've saved myself heaps, with the discounts on the bottles!)

I was having my baby at St George Public Hospital, so I made an appointment to see the lactation Consultant on the maternity ward.

I was very reassured there after I'd met with her, seen the ward and been told that I could attempt to breast feed.

I stocked up on bottles, hired a Hospital grade Breast Pump and was ready to go!

Sophie Louise was born on 20th February 2012 via C-Section.

It went perfectly and I remember the first thing my husband and I asked when the doctor's were examining her, was "Is her Palate intact?"

After hearing "yes", I could've jumped off the operating table, had they not been stitching me up! ☺



We knew we had the easier end of the Cleft spectrum, so to speak, but we were still anxious as to how feeding would be.

Sophie was a "little trooper", as the recovery nurse put it. She latched onto my left breast and had a breast feed only an hour after being born. There was no milk there, but she got some colostrum.

That all seemed too easy I thought...

What came after that were days of squeezing nipples, so hard I thought they would fall off, to try and get my milk to come in and pumping and syringing colostrum etc...

The milk did come in and still I thought I could breast feed....

However, after 3 weeks and a few weigh-ins with the Early Childhood nurses, I was told she hadn't even got back to her birth weight ☹️

I was devastated. I was so hoping to be able to continue to breast feed, but it wasn't to be. I had to go purely onto the bottles (with the occasional BF when Sophie needed settling) and continued to pump. I also supplemented her with Formula to "bulk her up" for her lip repair at 3 months.

I also hoped to continue to pump till after her surgery, with the idea that I could go back to breast feeding – yeah right!

The Breast pump was sent back and I stocked up on more bottles and formula, this time I switched from the Pigeon bottles and teats to the MAM bottles with CHuCHu teats.

I found them easier to squeeze and the teats seem to last longer in the Milton.

(I know you're not supposed to leave them overnight in the Milton, but I could never remember to take them out until I needed one).

We "bulked her up" for the surgery and she's now a healthy thriving toddler ☺️



It was at this point that I joined CleftPALS and I've felt supported ever since.

Admittedly I'm a "Facebook junkie" so I do go on there more than I go on the website, but it has been a great point of call for me. To realise there are so many families out there affected by this and to see how everyone's doing is a real comfort and inspiration.

When I read my first newsletter, it was the one with Emily's Story in. It jumped out to me, not just because she lived near to me, but because she was a "grown up" who'd had a cleft and I remember thinking, "OMG, She's Gorgeous and she had a Cleft!" ☺️

It really stopped me from worrying so much about the surgeries and how Sophie would look when she was older – thank you Emily x

I have got so much out of CleftPALS and met such lovely people, that I volunteered to be the Membership Co-ordinator when the vacancy arose.

I am lucky that I work from home, and have a very understanding Boss (my hubby, Craig), so I can fit this role into all the other roles I have as a Mum.



Sophie's surgery was a year ago now and she's due a check up soon, but so far we're really happy with the result.

