



SM8annah

In March 2020, Life's Little Treasures
Foundation lost our beloved CEO
Shusannah Morris. Shusannah put her
heart and soul into making LLTF a success
and cared deeply about the families
who needed LLTF's support during her
time. As co-founder her legacy is our
amazing organisation created to support
all of Life's Little Treasures across Australia.



The past 12 months have without doubt been incredibly challenging for everyone on so many levels. It would have been so easy to pack up, and put a sign on the door that says 'closed until post-COVID'. But premature babies, like time, wait for no one, and families across Australia have needed us more than ever.

Losing our wonderful co-founder and CEO Shusannah Morris has been incredibly sad. Saying goodbye to her has impacted everyone:

from the families we work with and our volunteers to our sponsoring partners. It's left a hole in our hearts and within our Foundation a presence that can never be filled; instead I think it has had us working towards 'our new normal'.

Despite everyone going through their own grief, I feel like everyone has asked 'what would Shus do?'. And in true Shus fashion they have rolled up their sleeves and kept things moving – to fulfill what our co-founders set out to do in the first place: to be Australia's leading support provider for families with premature and sick babies.

It's with this in mind that I'd love to thank our interim CEO Karin Vosmansky who has kept things on track, our amazing team in head office who kept working (safely and within the guidelines) to ensure programs could be tweaked for digital or COVID-safe running, and our volunteers who have remained committed and consistent with their generosity. Shusannah brought the troupes together to lead another successful Walk for Prems event in 2019 raising more than \$380,000.00 which played a crucial part in allowing the Foundation to carry on supporting families in 2020 and onwards.

Our biggest achievement for the year is to actually still be operating when many charities and businesses have had to close. This is not by

a stroke of luck – it's by the careful planning and financial management that Karin has practised from day one that means we will be OK.

Overall, we have had significant growth, in the number of programs we offer as well as the outputs and numbers of participants.

#### THIS INCLUDES:

- Several programs have been made available digitally including Precious Prems Packs and NICU Connections, with separate groups for families still in hospital and for those that have made their way home.
- Expansion into four more hospitals which is extraordinary given the pandemic – and almost doubling the number of tips sheets distributed (almost 20,000).
- We've established or continued partnerships with very well-respected medical bodies including MCRI (Murdoch Children's Research Institute), EFCNI (European Foundation for the Care of Newborn Infants), NIDCAP Australasia (Newborn Individualized Developmental Care and Assessment Program) and GLANCE (Global Alliance for Newborn Care)
- More than 6650 Special Care Nursery Booklets and NICU Guiding Hand folders distributed (up from 4000 last year).
- Almost 70 families benefiting from the financial assistance program. This provides petrol and food vouchers to struggling

Chair's Report 2020 LLTF Annual Report

Chair's Report 2020 LLTF Annual Report

families with babies in NICU or Special Care and is particularly helpful for families who may be staying away from home during this time. Sadly, we don't see demand for this declining any time soon.

- Little Bag of Calm has done incredibly well, which takes a holistic approach to self-care. Developed by our product team, it's been snapped up by more than 1770 families to help them to focus on their self-care, as well as making a lovely gift for parents of premature and sick babies.
- My Colourful Journey was developed in partnership with NIDCAP Australasia and has already helped more than 1500 families prepare younger siblings for what to expect to see in the Neonatal Unit through storytelling and colouring-in activities.
- The LLTF NICU Connections program has continued in line with COVID-19 guidelines

and has continued to be an important way to bring people together. The LLTF NICU Connections program has continued in line with COVID-19 guidelines and has continued to be an important way to bring people together. The team also introduced a whole new online NICU connections on Facebook which has been extremely successful and has ensured no family is left unsupported during the period where we cannot have face-to-face contact.

- We've taken considerable time to invest in ourselves, as well as the families we endeavour to support. Our volunteers are the heartbeat of our organisation, and we are grateful and respectful of the time and knowledge they share with us.
- We have implemented a new volunteer management system and taken on a new online training program. This means we

have improved tracking, reporting and communication with the team, which will hopefully result in ongoing help from the volunteer teams.

Karen Peters successfully launched the Little Bag of Calm which has been a roaring success and has just completed its second print run. In addition we are working with NIDCAP to start the Little Read-a-thon of families reading to babies in NICU in hospitals around Australia.

Merryn Csincsi has continued to do a wonderful job leading our partnerships and sponsorships. In addition to ensuring we deliver to existing partners, and meet with potential new ones, she led the way for LLTF to receive a Seed of an Idea grant (Thanks to Seed Heritage). This will allow us to develop the next stage of our 'My Colourful Journey' series. This will be a colouring book for children developed to guide them through the emotions of having their sibling stay in hospital.

These one-off opportunities are hugely helpful to get projects off the ground, but we have been incredibly grateful for the long-term ones that continue to support us, even when they are managing their own challenges in how they run their businesses. Baby Bunting has continued to support us on so many levels, with the passion for our work so apparent in everything they do for us. In addition, we have continued our partnerships with Britax, Medela and Earlybirds with great success.

So that's a wrap for FY19/20. Not an easy year but one where I really feel we have made an impact on many families. None of the above could have been achieved without the tireless work of our 75-plus quality volunteers and our interim CEO, Karin. We are all so grateful for your time, commitment, expertise and passion.

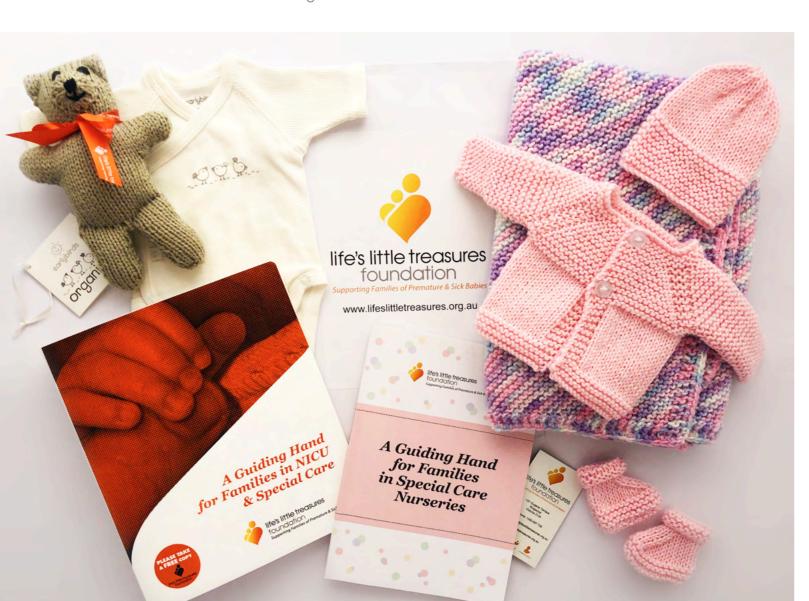
Thank you to everyone who has been involved with Life's Little Treasures Foundation, from fellow board members, management, volunteers, supporters and suppliers to our families and friends who have been generous in their time and energy to support this cause.

Chriss Mannix, Chair 🗳





looking at photos on your Facebook page wondering how I could ever end up like the other premie families that were celebrating birthdays etc years later! But here we are. Thanks guys. You helped me keep my eyes on the long term prize! 99 MUM, SASKIA



## who we are

Life's Little Treasures Foundation (LLTF) is Australia's leading charity dedicated to providing comprehensive information and support to families with a premature or sick baby.

Life's Little Treasures Foundation is working across Australia, supporting families through pregnancy, birth and into the early years of childhood.

We bring together the expertise and guidance of leading health professionals, social workers, researchers and trained volunteers to ease the parenting journey, reduce trauma and empower families.

Founded in 2005 by parents who had experienced this first-hand, LLTF truly understands the challenges that these families face.

LLTF's vision is to ensure that all families enduring the difficult and life changing experience of having a premature/sick baby have easy access to critical information and community support.

LLTF services are available in the hospital (neonatal and special care units) and in the community when families come home &

### We provide:

Easily accessible and relevant **information**.

**Programs** offering practical and emotional support.

Pathways for parents to address mental health issues that have emerged due to the stressful circumstances of their child's birth.

Continued **assistance** to ease the transition from hospital to home.

A resolve to increase community awareness of the unique issues faced by our families

Education opportunities to families and also healthcare providers who support the families of premature/sick babies.





### Join our community

The Life's Little Treasures Foundation, 1/21 Eugene Terrace, Ringwood, VIC 3134

Phone: 1300 MYPREMMIE / 1300 697 736
Email: contact\_us@lifeslittletreasures.org.au

facebook.com/lifeslittletreasuresfoundation

instagram.com/Iltfoz

www.lifeslittletreasures.org.au





## we are here for:

Pregnant mothers at high risk of giving birth pre term

Mothers who give birth pre term or with a sick baby

All families in NICU or SCN

Families needing emotional support

Families needing financial support

Families needing information

Families away from home

Families having to travel long distances to and from hospital

Grandparents

Families needing ongoing support (up to school age)

We are here to provide a shoulder to cry on, an ear to listen and a hand to guide you.





## meet our corporate partner

## BabyBunting 👪

At Baby Bunting our core purpose is to support new and expectant parents, and we are delighted and proud to be associated with the wonderful work Life's Little Treasures Foundation do to support families during the difficult, and often life-changing experience of having a premature or sick baby.

We are particularly proud to continue on the legacy of Shusannah Morris when she established the Life's Little Treasures Foundation in 2005. Shusannah's passion for helping families with premature and sick babies was inspirational and we at Baby Bunting were so privileged to have known and worked with her.

We look forward to continuing our special relationship with Life's Little Treasures Foundation by creating more opportunities to expand the reach and support provided by this incredible organisation. As always, we will continue to encourage everyone to show their support – because alone we can do so little, but together we can do so much."



# meet our supporting partners

### **MEDELA**

Medela has partnered with Life's Little Treasures Foundation since 2014 and is still a strong supporter. As a Major Sponsor of the 2019 Walk for Prems and sponsor of our NICU Connections online events, Medela continues to enable LLTF to support families throughout Australia. Medela also provides discount vouchers and breast pads for inclusion in our Precious Prem Packs.



### **BRITAX**

As a Major Sponsor of the Walk for Prems, Britax once again demonstrated its commitment to LLTF and our community. Britax also donated incredible prizes including Strollers and continues to donate hundreds of Unity Inserts for our Precious Prem Packs





"Thank you for listening and just getting it! These chats have been so helpful! Wish I was brave enough to start earlier."

CHRISTINA, MUM TO A 25+6 WEEKER AND PARTICIPANT IN OUR FACEBOOK LIVE GROUP CHAT













Life's Little Treasures Foundation provides products, programs and services that help families with premature or sick babies



Made several programs available digitally including our popular Precious Prems Packs.

Delivered

104

NICU Connections events

digitally and face-to-

face to ensure families

can connect, offer each

other support, share their

experiences and reduce

any feelings of isolation.







Provided financial assistance to almost

70

families. This provides petrol and food vouchers to struggling families with babies in NICU or Special Care, and is particularly helpful for families who may be staying away from home during this time. This program is the focus of our 2021 appeal.



**Expanded LLTF services** 

into four more hospitals

taking our total to

Australia wide with

over 20,000 tip sheets distributed nationally.

130

800 Precious Prem Packs either digitally or physically to new parents with babies in NICU and Special Care Nurseries.

Delivered over



Distributed 1770

'Little Bag of Calm' which was developed by our product team. We've taken a holistic approach to self-care and this pack treats parents of premature and sick babies.



Developed 'My Colourful Journey' in partnership with NIDCAP Australasia which has already helped more than

1500

families prepare younger siblings for what to expect in the Neonatal Unit through storytelling and colouring-in activities.



Distributed more than 6650 Special Care Nursery Booklets and NICU Guiding Hand folders

# walk for prems

On Sunday 26 October we proudly celebrated our 10th Annual Walk for Prems. Families across Australia walked together in support of the 48,000 premature or sick babies born in Australia every year.



More people than ever before are touched by premature birth rates and this was reflected by the response to Walk for Prems 2019 with our loyal supporters walking in 12 locations; Melbourne, Sydney, Brisbane, Adelaide, Hobart, Canberra and Perth – as well as regional locations such as Cairns, Townsville, Ballarat, Goulburn Valley and Gippsland.

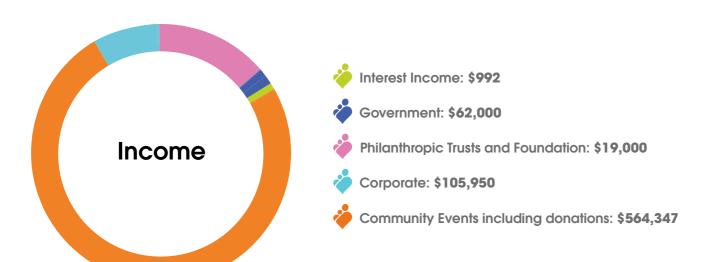
At the beginning of each Walk for Prems event, participants pause to show their respect for the families whose babies have sadly passed away. Life's Little Treasures Foundation honours their babies' memory with the ceremonial release of white doves by a family that has lost a child or a ceremonial bubble ceremony in the regional settings.

The Walk raised a record breaking \$372,380 and was supported by Baby Bunting, Medela, Huggies, Britax, Earlybirds, Web Intelligenz, Cold Fusion, Fly Pelican, Oricom and Balance Water •





# financials







ASSETS		
Current Assets	\$374,139.41	
Other Assets	\$425.00	
Property & Equipment	\$61,567.33	
Total Assets		\$436,131.74
LIABILITIES		
Current Liabilities	\$93,612.54	
Total Liabilities		\$93,612.54
Net Assets		\$342,519.20
EQUITY		
Directors Capital	\$60.00	
Retained Earnings	\$328,800.44	
Current Year Surplus/Deficit	\$11,150.49	
Historical Balancing	\$2,508.27	
Total Equity		\$342,519.20

Parent Story 2020 LLTF Annual Report

It's very hard to imagine what it is like to have a premature or sick baby unless you've gone through the experience yourself. We encourage families in our community to share their stories with us to help raise awareness and to give a point of reference and hope to new families facing this unexpected and traumatic time themselves.

# jennifer's story

I had a difficult start to my pregnancy with four weeks of constant bleeding and as a result a perpetual fear of having another miscarriage. My 12-week scan was normal and I was hoping I could finally relax and enjoy the rest of my pregnancy. Instead, we left the scan and headed straight to the emergency department.

On the way to emergency and while waiting to be seen, I was Googling like mad – what did it mean to have a short cervix? I found out that a short, weak, or incompetent cervix is one of the leading causes of late-term miscarriage. I felt sick and terrified. I simply couldn't face losing a healthy baby at 20 weeks just because my cervix was too short. I was admitted to the hospital and given my options. We went ahead with a cervical cerclage and progesterone. Ever since the cerclage (stitch) was placed in I never felt comfortable. I felt constant pressure especially if I was standing. Instead of feeling 20 weeks pregnant, I felt like I was in the late stages of pregnancy.

As much as I tried to resist and people told me not to, I couldn't help but consult 'Mr Google'. Sometimes what I read made me feel so anxious and sick I just didn't know how I would get through the day and other times I read things that inspired me and gave me hope.

For the next three weeks, I anxiously visited the Pre-term Labour Clinic at the hospital so they could measure the cervix and monitor the stitch. Each time the stitch was holding, the cervix was closed and the length shortened only slightly. Each time I came home feeling optimistic that I had moved one week closer to viability. When I reached 24 weeks I felt some relief but this didn't last long.

At 24 weeks and 4 days, I had some tightening pain much like Braxton Hicks which I had with my first pregnancy. After six hours it was clear they were not Braxton Hicks and they were now very painful and regular. At 2am we made the first of many late-night trips to the emergency department. I was admitted to the birth suite and was given medication which luckily stopped the tightening and pain. I stayed a few days in the hospital before returning home again. One week later the exactly the same thing happened again. I was told by the doctors that in addition to the incompetent cervix I also have an 'irritable uterus' and I can expect these episodes to continue and potentially get worse. And that they did.

Another week later on the 27th December at 26 weeks the pains started again. I went to bed that night feeling mild pain but as the night progressed it got worse, more painful than the previous two episodes. I got up to get some pain relief and go to the bathroom and it was then I noticed a large bleed. I woke my husband, we grabbed our bags, the two-year-old and once again made our way to the emergency department. The doctors were fabulous in reassuring me and were able to deliver some good news that my cervix was still closed. But a bleed is never good news so I needed to stay in

One of the things that I read that gave me the most hope was these parent stories on the Life's Little Treasures website. I feel like I read every single one!



hospital for much longer this time. I got settled into what would be my home for the next 27 days and waited anxiously for the visit from the Paediatric doctor. I don't remember a lot of what she told us that day but I do remember I was crying the whole time. I know she went through survival statistics and health outcomes and prepared us for the worst. She left us with a pamphlet on what to expect when your baby is born at 26 weeks which I think I read 20 times over.

The next day was my 39th birthday. I had not seen my son much over the past few days so it was really special to have him there. He didn't know or care what was going on; he got to see mummy, eat cake, blow out candles, play with the blue surgical gloves, and help open presents. After my son had been taken home my husband and I were

I never thought
I would feel any
happiness while
going into labour
at 31 weeks... but I
knew it was going
to happen and when
thinking about
how I would get to
meet my baby boy
soon and I felt the
smallest ounce of joy
overriding the fear.

Parent Story 2020 LLTF Annual Report

taken on a tour of the NICU to prepare us for what we were likely to face. A birthday tour I will never forget. I still vividly remember being taken down in my wheelchair and through those NICU doors for the first time. Again, I don't remember much of the information I was given. What I remember was seeing, for the first time in real life, a tiny baby covered in wires, laying in his isolette with mum sitting in the big red recliner next to him. I remember that mum giving me a little smile. I think it was a smile of reassurance. Something like "this is hard but you will get through it".

Although the tour was completely overwhelming and emotional it was so important for me to be able to see and visualise what my baby's first weeks of life would look like. Unlike some other mums who have Premie babies unexpectedly, I could prepare myself. It was heartbreaking to know that it was likely I would not be able to hold my baby straight away, to breastfeed my baby straight away, or take him home after a few nights but at least I had time to prepare. I eventually got to a point where those things seemed unimportant. All that was important was that my baby would be alive and that he would be receiving the best care possible.

The following night I woke about 4am to more tightening and pain. I got up to go to the bathroom and as I stood up I felt an awful gush. My first thought was that my waters had broken and I felt a huge rush of adrenaline surge through my body. "This can't be it," I thought, I am really not ready yet. I pushed the emergency button and rushed to the bathroom to discover it was not my waters but a huge gush of blood. I wasn't sure this was any better. Contractions started coming fast and strong. Between the contractions, my body was shaking so violently from the fear I felt like I was going to vomit. I was rushed to the birth suite and given more drugs. To my absolute disbelief when the doctors checked my cervix it was still closed. Over the next few hours the drugs kicked in and miraculously the contractions stopped. The bleeding continued and I knew then that I would be in the hospital for some time.

Hospital life was sad and lonely. I had way too much time to think and lots of sleepless nights but I felt safe. The worst part was, without a doubt, not seeing my son every day. Facetime each night is what kept going. I was lucky to have a room with a view and I spent most of my days looking out the window over Flemington Rd and across the Docklands while I listened to Podcasts. I also read a lot, kept a journal, and did lots of mindfulness

colouring, things I never have time to do in real life and anything that would stop my mind from the 'doom and gloom' thoughts. I had lots of visits from my wonderful friends. Those that couldn't visit sent me messages and some checked in daily to make sure I was ok. They organised food drops and meals for my husband Fabio who was on his own still trying to work full time, look after the household duties, care for our son Henrique and visit me every second day. I still don't know how he held it all together so well, he really was my rock. While in hospital I was medicated daily to manage the contractions and eventually the bleeding subsided. After 27 days and reaching the magical 30 weeks I was able to go home.

It was Australia day and I had been home for four days when I started to feel the dreaded pains. Although it felt much like it did on so many other days, I felt today was different. At 3am things ramped up and yet again we were faced with another visit to emergency. We had no time to find someone to look after Henrique so yet again he was pulled out of bed and dragged to the hospital. Once again, off to birth suite for drugs and hooked up to the ECG for what felt like the hundredth time. I was so surprised to find that the cervix was still closed, I was so sure this was it.

My husband took my son home and I was taken to the ward. As I laid down in my bed I felt a sharp excruciating pain. I pressed the emergency button and within moments was surrounded by midwives. I got up to go to the bathroom and again a huge gush of blood. This time, before the doctors had even examined me they told me straight away that the stitch had to come out. There was too much bleeding and it was likely that the cervix was trying to open. I was crushed. I was right on 31 weeks and although I had come so far it was still way too soon for me.

Shortly after and before my husband had time to get back to the hospital the painful stitch removal was underway. As they started the process the first doctor noticed that the cervix was open and I was now 3cm dilated. She could not get all of the stitch out and even with the assistance of the gas, I felt agonising pain. It took another two attempts and more specialists to remove the stitch. My husband arrived just as they were finally able to extract the last part. I felt enormous physical relief. The pain and pressure I had been feeling daily since 20 weeks were now gone only to be replaced by more painful contractions that were getting closer and closer together. No drugs were stopping it this

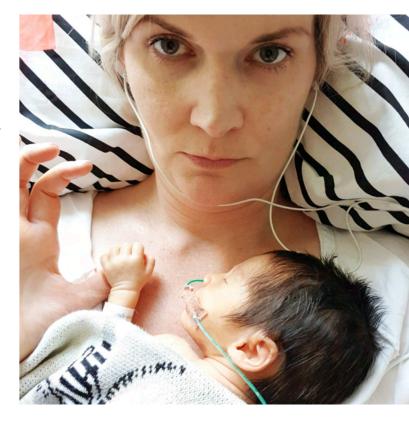
time. The doctor told me I would have my baby before sunset that night and he was right.

I never thought I would feel any happiness while going into labour at 31 weeks. Every other time I thought he was coming I was petrified, this time I was still very scared but I knew it was going to happen and when thinking about how I would get to meet my baby boy soon and I felt the smallest ounce of joy overriding the fear. It all happened so quickly after that. My waters broke and three contractions later I was pushing. Within 30 seconds about ten people came rushing into the room preparing for the delivery. I don't know if it was a doctor or a midwife but I just remember someone saying "focus, come on push - he is not being monitored anymore". I detected the faintest bit of panic in her voice. The fear started to escalate but I did it, I focused, and with one final push and he was out. I heard a good scream, saw a full head of thick dark hair and he was gone. Santino had finally arrived at 8 pm on 27th January 2020 weighing 1.7kg.

When I finally left the birthing suite two of the doctors who had seen me on my numerous visits over the past 10 weeks stopped to congratulate me. One of them said that each time she saw me come back she was so happy because it meant the baby still had not been born and that they never expected me to get so far. I remember walking back to my room thinking about how strange it was to be thankful for giving birth at 31 weeks. For that moment I was happy and content that my baby was alive and earthside.

Five hours after he was born and at 1 am in the morning I made it to the NICU. I'll never forget the first time I saw Santino. Covered head to toe with wires, CPAP machine, and a feeding tube. It didn't feel real and he didn't feel like he was mine. The next morning after a few hours of sleep I got my first cuddle. I was so amazed that despite the number of wires and cables you can still hold and cuddle your baby. Those first kangaroo cuddles were emotional but so beautiful.

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Santino spent 46 days in hospital. I visited every day and sometimes it almost felt like going to work. I would get up get early to get my son ready for childcare then prepare my bag, milk and lunch for the day and head off to the hospital. I would rush home at the end of the day to cook dinner and see my two-year-old son before he went to bed. My husband would go to work and then most nights go to the hospital for his visits after work. The days in NICU were long, emotional and sometimes very lonely.

The majority of both our families live overseas and interstate and Fabio had to work so I was on my own almost every day. I was, however, lucky to make connections with a few of the other long-term mums, in particular, one mum whose baby was born at a similar gestation to me. We had many long chats about things I don't think anyone else but a NICU mum would understand. On the really hard days, I would often try to remind myself that I was one of the lucky ones as there are many parents who never get to take their babies home. Every day my boy was growing bigger and stronger and I cherished the hours and hours of Kangaroo cuddles we had.

One of the most unexpectedly difficult aspects of having a Premie baby was breastfeeding. I breastfeed my first son until 15 months and it was

such a beautiful and positive experience. I never imagined how difficult it would be with a Premie baby. Exclusive pumping in those early days just didn't work well for me. I had extremely painful chronic Mastitis that left me hospitalised and a number of other issues that made pumping so painful that I was on a constant rotation of three different pain killers to get me through each day and each pumping session.

On many occasions I just finished pumping and immediately felt physically sick about having to go through the pain again in another 2.5 hours. Even when I was not pumping I was in constant pain and could not hold my two year old and had

to sleep upright for six weeks! The NICU staff were amazing not only with bubs but with me too.

On one of my worst days, one of the NICU nurses personally took me to the emergency department and waited with me until I was seen because she knew I couldn't do it on my own. I vividly remember one of the doctors saying to me "you know you can stop", but I couldn't, I desperately wanted to do what was best for my baby and have the same positive experience I had with my first son. After six weeks of pumping every three hours (even overnight), I fed my son for the first time. I can't even describe how wonderful this was, certainly one of the fondest memories of my journey.





Finally, it was time to go home. Santino weighed 2.8kg and to me, he seemed huge! I was planning a big celebration with all my friends who had been the most fabulous and wonderful support team I could have asked for. They knew we had so little family and they supported us in every way they could. But sadly, after four months of uncertainty, sleepless nights and anxiety our celebration was never meant to be. Within days we were forced into the first of Melbourne's lockdowns due to the Covid -19 pandemic and we were faced with another eight long months of uncertainty, sleepless nights, stress and anxiety. The first ten months of

Santino's life have been lived in a hospital or in lockdown. We have just emerged from the second and very difficult lockdown and I am getting to experience some normality for the first time in over a year. It feels good.

Now Santino is a one year old. He is super cute, cheeky, and strangely, just how I pictured him to be all those nights we spent laying alone but together in my hospital bed. Translated his name means 'Little Saint' and to us, that is what he will always be; Santino, our little Saint &

