

## **SUPPORT FOR NEW PARENTS AND BABIES IN NEW SOUTH WALES**

**Organisation:** Australian Multiple Birth Association (NSW) Inc.  
(AMBA)

**Name:** Ms Joanne O'Keefe

**Position:** State President

**Date Received:** 22 November 2017

**Paper Reason****Name: Joanne O'Keefe****Position: AMBA NSW President****Email:****Date of Submission: Wednesday 22 November 2017****Background**

The Australian Multiple Birth Association was formed in 1974. We are the only national support organisation for multiple-birth families and individuals in Australia.

The Australian Multiple Birth Association (AMBA) mission is to function as an effective network and to support multiple birth families. We fulfil our mission by providing communication, advocacy, facilitation of relationships, education and support, both nationally and internationally to individuals, families, member clubs, and organisations that have a personal or professional interest in multiple birth issues

AMBA is the leading support organisation for families with twins, triplets or more within Australia. We are recognised for our hands-on experience and knowledge, hence our motto being "Support from those who know". AMBA provides its multiple birth families with current information on parenting, multiple birth studies and support at grassroots level.

AMBA is a non-profit organisation that provides a service from family volunteers and all events and initiatives is financed by fundraising and grants which implements local support programs such as new and expectant nights, educational sessions, playgroups, new parent's morning teas and social gatherings such as school holidays events, picnics and annual Christmas parties.

Being a multiple family is very special and as twins or triplets are not planned we all have unique challenges from gestation and birth with all multiple parents being advised that they are considered a high-risk pregnancy as soon as it is announced that it is multiple.

## **Heightened Risks Associated with Multiples**

Due to the high-risk of having multiples expectant mothers are monitored for associated risks and complications of:

- High blood pressure
- Gestational diabetes
- Preterm birth
- Stillbirth
- Caesarean section
- Low birthweight

The heightened risk to babies shows there is a proportionate increased risk of complications which include and are not limited to:

- Cerebral palsy
- Respiratory distress and breathing complications due to immature lungs growth
- Difficulty maintaining body temperature and/or normal blood sugar levels,
- Feeding issues relating to feed, swallow breathe, reflex resulting in feeding difficulties
- Increased risk of jaundice.
- Growth and developmental challenges due to prematurity and size.

The gestation of multiples can impact a health and financial burden for families as the mothers in most circumstance will be required to exit the workforce earlier than a singleton pregnancy which will require more medical attention for additional tracking scans and specialist appointments to achieve and safe and durable pregnancy in the attempt of full term.

In addition to this the High Risk delivery options and multiple birth plan is planned for and managed differently by doctors, specialist, midwife and obstetrician – often resulting in the mother preference of choice being removed for the following rational:

- The expectant mother is often advised very early in her pregnancy that a caesarian section delivery may become necessary. If she has had a previous caesarian section or a complicated vaginal delivery then the chances are higher of her needing a repeat caesarean.
- Expectant mothers need to be open minded about their labour and delivery. Although they may have a birth plan and goals for a normal vaginal delivery, sometimes this is just not possible without compromising her own health or that of her babies.
- Increased presence of specialist staff required to be present in the labour and delivery suite or operating theatre to ensure adequate care and management of the expectant mother and then each individual baby. Specialist medical teams and staff are often assigned to manage, intervene and concentrate on one baby each.
- Additional focus and frequent monitoring and observations are required to ensure that expectant mother and each of the multiple birth babies are not becoming distressed during the process of the labour and delivery.

- Increased duration and frequency of complications and vaginal bleeding for an extended period compared to that of a singleton birth.
- Planning, management and establishing breastfeeding can take longer. This is especially the case if the babies cannot breastfeed and the mother needs explore options to express breast milk for her multiple birth babies.
- There is often more excess abdominal skin from stretching so much during the pregnancy and sometime medical intervention is required for hernia's and muscle separation resulting in the need for complicated surgery.
- Multiple birth mothers also experience a longer and slower process to "get back into shape".

## **Recovery and care for multiple births**

The recovery for multiple birth can also differ which may be a longer to recover generally from the labour and birth and if the babies were premature or are unwell, there can be stressful and worry for parents and can be faced with the following:

- Emotional and psychological transition of becoming a mother of multiple babies to sink in. Many parents of multiples experience adjustment issues, particularly if they do not have good family support around them
- Working out what suits you in terms of being a family. Parents often experience an influx of advice and suggestions from well-meaning friends and relatives but ultimately, you need to decide with your partner what is going to suit you and your little babies which can cause additional stress.
- If babies born are premature and require ongoing intensive/neonatal care then you will need to establish a daily routine of spending time with them. Exhaustion is a common factor and new multiple birth parents express a feeling of utter exhaustion in establishing a routine of expressing, breastfeeding whilst still recovering from the birth themselves. Parents who have older siblings at home often find this time more difficult to manage.

During this time, additional pressure is placed on families with limited medical resources with the average twin pregnancy delivered at 36 weeks and 32 weeks for triplet's babies. Based on the average statistics it is highly expectation that most multiple babies will have a NICU or special care experience.

The NICU experience is a very personally experience and mostly managed day by day depending on the degree of care and at time the families are required to leave both or one child in hospital whilst the mother still is recovery from the birth delivery attempting to breastfeed or expressing milk to stock pile feeds.

The gestation of multiples can impact a health and financial burden for families as the mothers in most circumstance will be required to exit the workforce earlier than a singleton pregnancy which will require more medical attention for additional tracking scans and specialist appointments to achieve and safe and durable pregnancy in the attempt of full term.

At all club levels, a percentage of multiples parents have experience and NICU/special care experience which results in caesarean section which prolongs recovery and psychological impacts mental health biological risks for families by medical

complications, multiple separation of children due to difference specialised medical needs, extend stays and at time not being able to bring both child home at the same time.

Below is the latest data collection for the Australian Bureau of Statistics and current AMBA NSW membership figures

<b>Multiple births(a),(b),(c), states and territories – 2015</b>						
		<b>Single</b>	<b>Twins</b>	<b>Triplets and higher order</b>	<b>Total multiple births</b>	<b>Total confinements</b>
State of territory of usual residence		no.	no.	no.	no.	no.
<b>New South Wales</b>		97 296	1 374	21	1 395	98 691
<b>Victoria</b>		71 497	1 031	24	1 055	72 552
<b>Queensland</b>		59 963	888	20	908	60 871
<b>South Australia</b>		18 972	304	7	311	19 283
<b>Western Australia</b>		34 196	464	10	474	34 670
<b>Tasmania</b>		5 532	82	-	82	5 614
<b>Northern Territory</b>		3 890	58	-	58	3 948
<b>Australian Capital Territory</b>		5 358	90	4	92	5 450
<b>Australia(d)</b>		296 741	4 291	84	4 375	301 116

- nil or rounded to zero

(a) A multiple birth is a confinement (pregnancy) which results in two or more children, at least one of which is live-born.

(b) Where necessary, small values have been suppressed or randomised to protect confidentiality. As a result, sums of components may not add exactly to totals.

(c) An issue with the identification of twins, predominantly in New South Wales, has been identified and addressed. This has resulted in a revised count for 2015.

(d) Includes Other Territories.

### **AMBA NSW Club Membership Date Collection as at 1<sup>st</sup> November 2017**

<b>Location</b>	<b>Family</b>	<b>Twin s</b>	<b>Triplet s</b>	<b>Quad s</b>	<b>Siblings</b>	<b>Children total</b>
-----------------	---------------	-------------------	----------------------	-------------------	-----------------	---------------------------

<b>Eastern Suburbs</b>	68	53	1		25	109
<b>Hornsby - Kuring-gai</b>	54	54	1		20	131
<b>Hunter Valley</b>	21	18	3		62	107
<b>Inner West</b>	129	127	2	-	67	327
<b>Lower North Shore</b>	100	85	1		34	207
<b>Multinet</b>	18	17	2		16	35
<b>Nepean</b>	58	58	1		53	161
<b>Newcastle</b>	88	84	4		37	213
<b>North West</b>	126	111	3	-	67	298
<b>Northern Beaches</b>	172	159	4	1	98	448
<b>Orange</b>	14	14			15	29
<b>South Coast / Illawarra</b>	52	46	4		68	172
<b>South Sydney</b>	255	243	12	-	188	708
<b>Wagga Wagga</b>	17	17	1		50	87
<b>Total</b>	<b>1104</b>	<b>1033</b>	<b>38</b>	<b>1</b>	<b>775</b>	<b>2923</b>

As noted it has been reported that in NSW that 1395 multiple birth have been recorded in 2015 and unfortunately this figure does not demonstrate the local impact on local clubs with which represent multiple families and siblings.

The purpose of capturing the family statistic is to note that member families in some circumstance can up to 3 or more children under 5 at that are not eligible for in home child assistance even though they meet some of the criteria of one or more of the following:

- The child has, or lives with another child who has, an illness or a disability.
- The child's guardian (or guardian's partner) has an illness or disability that affects their ability to care for the child.
- The child lives in a rural or remote area.
- The work hours of the child's guardian (or guardian's partner) are hours when no other approved child care service is available.
- The child's guardian (or guardian's partner) is caring for three or more children who have not yet started school.

## AMBA family insight

Feedback from families to AMBA NSW is that majority of families failed to be eligible for In Home care and for families that received care felt that the need to be considered and mental unable and or that the babies were at risk due to a difficult category difficult to be accepted as this makes the perception of failure.

AMBA NSW would like for all higher multiple families with triplets or more to be provided with in home care automatically to ensure a safe and durable care for newborns and to attempt to reduce the risk of perinatal anxiety and depression.

Another major impact of multiple families is the financial strain due to a reduction of income and the additional expenses of purchasing nappies, wipes, formula if required, medication, utilities and the most important parents with multiple children and siblings the cost of childcare and education and sporting costs.

It is acknowledged that Department of Human Services you may be eligible for parental leave pay and if you have a multiple birth, including twins, you may receive the following for each child:

- Newborn Upfront Payment, as a lump sum of \$540, and
- Newborn Supplement, at a maximum rate of \$1,618.89 if you are eligible for the whole 13 weeks, even if you already have other children

Higher order multiples of triplets are entitled to receive \$155.12 a fortnight for triplets or \$206.64 a fortnight for quadruplets if you receive FTB Part A. Currently you don't need to submit a separate claim.

As funding is always appreciated and assists families with the cost of living the expenses of twins and triplets impacts social and developmentally do occur due to the extravagant costs of having two or three children and sometimes more with siblings.

The AMBA families have stated financially burdened and with additional funding it could provide:

- Better medical care as some families do not continue with medical care due to the financial costs or the embarrassment of not being able to offer care in a timely manner
- Access to additional opportunities on care plans for Speech / Occupational therapy
- Access to discounted or higher subsidy for childcare - access to bulk billing for paediatrician appointments
- Multiple families not having to rely on families to assist with babysitting or care responsibilities as due to the high cost of childcare and the emotional strain of caring for children
- Multiple families enrolling children in essential activities such as swimming lessons and fine motor activities such as soccer, little athletics, dancing or gymnastics
- Multiple enrolling children into preschools and day-care for school readiness and social interaction

It has been identified with discussion with AMBA NSW multiple families that due to the high cost of childcare most families have a more reduced amount of time in day care and preschool due to the extravagant cost of paying double and triple the daily cost and transitioning to school delayed with some families having to delay.

Delays impacting from:

- Affordability to be able to send child to day care or preschool
- Affordability for families for speech therapy due birthing complications and developmental delays
- Affordability for families for occupational therapy due birthing complications and developmental delays
- Social isolation due to financial strain which then can result in a child emotional not prepared for school

It's important to remember though, that despite all the challenges, the excitement and joy of having a multiple birth makes up for the hard work regardless of the impacts on the family system; developmental environments; and individuation processes this is a difference from a single born child.

The difference is the primary reason that AMBA continues to seek improvement and initiatives to support multiple families and currently has 4746 members families and purely provides a service by having parents on committee and local, state and national levels who are in most circumstances time poor but very dedicated and passionate about promoting awareness and support for multiple families across Australia.

### **AMBA National and State Committee**

It has taken a highly committed Chairperson and Board in the past years to present to implement changes in improved services and this has been achieved by growing relations relationships with external partners to be able to provide a discount card for members, having sponsorships but more importantly forming relationships with the Twins Research Australia, Panda and expert medical access from our patron Professor Mark Umstad Director of Maternity Services Royal Women's Hospital, Melbourne and invitation to the International Society of Twin Studies.

As these relationships developed it have highlighted internal areas of improvements of lack of data collection which currently being reviewed so members details can be captured members demographic and capturing statistic from members that have children require medical assistance due to prematurity or identify medical diagnosis from resulting in a multiple birth.

With the collection of data this will enable us in the future to be able to assist in research and reviews to better equip out support to multiple families and to whole hearty provide more technical insights of multiple families.



## Conclusion

As AMBA continues to strive to achieve the best support for local members families we are yet to be successful to provide continual support for families from birth, adolescences to adult hood as we have a history of once both parents return to the workforce or commence school and this impacts local clubs as it limits the opportunity for growth and to engage community.

AMBA can successful say that we thoroughly support new families with new and expectant nights, new mums catch ups and playgroup but we struggle at local level to continue the level of services for older children, siblings and fathers as we in most circumstance contact and engagement is with babies and mothers and we continue to look at ways to retain members to look at growing additional support mechanisms for families and with better care and support from the Government better social and medical outcomes can be achieved.

If multiple families had additional assistance with financial assistance for:

- All multiple families have access to antenatal care at hospital with specialised assistance for multiple births such has accurate birth weight charts, tandem breast-feeding support and physiotherapy for mother's recovery muscle separation.
- All multiple birth families of twins and higher order multiples have access to bulk billed medical appointments or subsidy if a health plan is required
- All multiple families with 3 children or more under five are considered for in home care if the mother has medical complications or health plan but do not have to be considered high risk or children's wealth fare is in danger
- All multiple birth families are provided a rebate or subsidy for child care and preschool to ensure that child is emotional and physical prepared for school.

Thank you for this opportunity for request of submission and we strive to achieve the best for all members of the AMBA and would more than happy to assist or provide more insight if required.

Joanne O'Keefe  
NSW President  
Australian Multiple Birth Association

I hope to share my story and experiences with my twins to date gives an insight to some great support, some much needed support and some understanding of day to day life situations arise as a parent of twins.

My beautiful identical twin girls, Violet and Willow were born on the 20th of February 2015. Realistically to the "general" perception of the public at an ok/"allowable" premature gestation of 34 weeks. Yes, being born a twin myself 34 weeks is fantastic however, my girls were born at this stage to save their lives due to TTTS which we will discuss further in how it can relate to further areas of discussion.

Pre-birth and pregnancy.

Cannot fault my experience within my area of public health, the access I had to specialists within the Nepean district were great. I Had weekly scans from 24 weeks at an excellent high-risk clinic and this helped a very stressful pregnancy feel a little calmer. I am lucky I had access to this care as at 30 weeks my scans were twice a week. Without this I can say if I was in a more rural / remote area my twins would not be here.

note... I did attend local hospital antenatal classes, however much to my dismay did not offer or even try and relate birth information for parents pregnant with multiples, so I left my classes still with no idea what to expect, not even any leaflets that would mention twin resources apart from a wonderful MB clubs.

### **Birth and NICU stay**

NICU staff and resources for my district are good, personally and mentally having to have twins separated for 3 weeks is daunting and heart breaking, taking twin 2 home after 10 days and twin 1 after 3 weeks, the process to juggle visits and feeding is a nightmare, having not been in labour or my body knowing my babies were being born due to having to just get them out to save them meant tireless pumping to try to get a droplet of breast milk to then choose what twin got it.

My only complaint would be that in the antenatal ward there was 1, just 1 breast pump?

### **Home and settle period**

Many endless days of no sleep and pumping, breast feeding, formula top ups and more pumping, supply just isn't there. Even sourcing local chemists to hire a hospital grade breast pump, and most my local chemists all had their pumps already on loan - saw 1 lactation consultant in the nicu who didn't even watch one of my twin's latch on so how do we even try as twin parents to breast feed if a lot of the staff deal with singletons and don't have many suggestions for multiples?

sleep was all over the place and even out of desperation calling a nearby hospital's sleep clinic in tears they suggested rocking them in a pram - twins are so overwhelming when advice isn't twin specific you feel even more alone. If it wasn't the support of my local multiple birth association I would not have found a mothercraft nurse that turned my sleep around for my twins and my sanity.

Most of my support has come from volunteer groups and or multiple birth Facebook parent groups.

## **TTTS**

(twin to twin transfusion syndrome) to be brief my girls got this in later pregnancy hence immediate delivery at 34 weeks. This condition affects around 15% of MCDA pregnancies and affects things such as growth within womb, development and can cause more severe issues such as cerebral palsy, kidney issues heart issues etc... We only had stage 1, possibly stage 2, as they were over 30 weeks the answer was delivery, So I am very fortunate, this did result on twin 1 severely growth restricted in overall size and development than her sister.

As TTTS is not a much talked about or known condition it has been commonly overlooked in most of my specialist appointments I have attended since the birth of my girls. As there is not much solid proof on how TTTS can hinder a child's development it isn't recognised on funding such as speech or OT etc...

Specialists, just some we have seen

- ophthalmologists
- hand specialists (both twins have trigger thumbs and need surgery)
- ENT's
- hearing tests
- hip ultrasounds
- heart checks
- paediatricians
- speech therapy

while a lot can be public cover some cannot and as twins for us, most issues have been in both twins so having to pay double fees upfront for specialists is very expensive and cannot be avoided

Speech therapy is currently private for us as at 2.5 years old my twin's severe speech delay was of that of a 9-month-old. We could not wait 10 months or more to get maybe 12 public speech sessions. I pay \$90 per twin so \$180 combined a week, I cannot get funding as the girls only currently have a speech problem and need a secondary issue. You can only get 5 EPC 's a year for speech which is nowhere near

enough in assisting twins trying to catch up on delays from birth problems. Also to note I have exhausted my private health for speech a mere \$400 is all we can get

- day to challenges /financials
- double formula usage
- double nappy usage
- swimming lessons double cannot afford but necessary skill
- double day-care fees
- preschools not entitled to CCB or CCR

I work part time while my husband works full time so we can pay our mortgage and bills and groceries, it is only the fact that my husband is a shift worker and my mother is retired that we all share the load of watching my twins.

Socially it is suggested by most GPs, and child development professionals, that day-care/ preschool is a good idea to help with speech or other delays. Paying double for day-care is very costly so I have not currently got them in care as I could not afford it. If I had no family to help and my twins were in care I would make no money as a minimum day-care cost a week would be \$500, not including the extra cost when your rebate runs out.

I was so excited when i found my local council preschool was \$52 a day as being 3 early next year I was so excited that I could find something else to assist my twins in developing, only to find out no rebate is given in preschools. How do I as a twin parent even get ahead?

### **In summary**

- Multiple birth classes more advertised by all public hospitals
- More breast pumps in maternity wards
- Resources of lactation consultants with premature or multiple specialities
- More funding in TTTS and how it could be linked into funding for children with delays needing therapy
- Suggested 10 EPC's for parents of multiples for speech. If i only had 1 child in speech I could manage the \$90 a week, but 180 a week is not possible. At least 10 sessions off speech would be beneficial for my children while awaiting trying to get into public facilities.
- some form of CCR for preschools

I really hoped this small insight into some of my challenges has shed some light on a somewhat complicated but very happy loving twin life

Kind regards

The Gibbons Family

## Our Journey with Twins.

On Tuesday 3<sup>rd</sup> July 2012 we welcomed our fraternal twins Hannah and Hudson into this world at 32 weeks and 5 days gestation. Hudson was 2174gram and Hannah a mere 1086grams. Both Babies were delivered via c-section under the management of our private obstetrician at Nepean Hospital.

Our Journey into parent hood wasn't smooth. During my pregnancy at a routine scan at 22 weeks it was identified that my cervix was open and I was at immediate risk of delivery and ultimately our dreams of parenthood shattered. Within 1 hour I was admitted into a ward of our Local Public hospital on strict bed rest. At 22 weeks we were too high risk for cervical stitch so I was managed on progesterone and rotating antibiotics. I had weekly growth scans on each of the babies as well as cervical length. For this I was managed by my obstetrician and the high risk unit of our public hospital. Within that 10 week stay of hospital bed rest I have 4 significant scares that almost resulted in emergency section delivery.

During a scan at around the 26 week mark we were advised that our daughter was showing signs of IGUR (Inter-urine growth restriction). I had daily ultrasounds and scans and was ultimately advised to be ready for surgery at any point.

On delivery of our twins – each was taken to the NICU. Hannah our smallest twin was provided with supplementary oxygen whilst Hudson our larger twin required more intensive ventilation for the first 24 hours of his life. Our Journey through the nicu was relatively smooth.

The services we engaged were social worker as well as NNICUPS which is the NICU Parent support group of our NIC U. We had also engaged with our local multiple birth association for support via email and phone. Each of these support services were invaluable during our NICU journey and beyond. (Because of our experience both my husband and I currently volunteer for both of these support services and provide the same support we received for other parents with a premature and multiple birth journey)

As part of having a baby effectively the size / growth of a 26/27 weeker (due to IGUR) we weren't afforded the same access to ongoing support services. Our babies born at 32 weeks didn't qualify for a local physio (bush babies) program and they didn't have access to the growth and development clinic. (Babies must be under 1000gram or born less than 30 weeks). As part of our journey we rallied with the Nursing Unit Manager and raised our concerns. All information from neo-natologists suggested that IGUR babies have greater risk of Cystic Fibrosis and Cerebral Palsy as well as speech and developmental delay. Ultimately our concerns were met with understanding and we were afforded the opportunity to attend Bushbabies – a monthly outpatient service to monitor the growth and development of premature babies.

On discharge at two weeks – Hudson weighed 2.8kg. Hannah was discharged 6 weeks later at 1.6kg. As part of her discharge we were provided with a paediatrician, speech pathologist and dietician. We weighed in every 2 days for the first week.

At 6 days discharged (approx 7 weeks) we were readmitted to children's ward for 4 days monitoring due to dusky episodes (forgetting to breathe – slow breathing). Concerns were raised regarding her lung development. Our community health nurse was present during this episode which raised concern.

As part of the paediatrician management we were referred to a hip specialist and it was identified that Hannah had hip dysplasia. (An often common issue with twins) Hannah was doubled napped for 6 weeks to rectify this issue. To this day Hannah still has a right side that turns in when walking.

Hannah and Hudson both suffered extreme reflux and were managed with reflux medication and specialised formula. They were given along with supplementary nutrients and iron.

Hannah also saw a skin specialist for management of her Hemangiomas. Her largest haemangioma that was along her eyebrow line above her right eye. Hannah was given propranolol to manage this condition. Hannah had to have a heart stress test as an outpatient of the Children's Hospital at Westmead prior to commencing treatment to minimise possible side effects.

Hannah had 4 more admissions during the first 6 months at home – Mostly due to small cold or heightened temperature. Each time Hannah would require oxygen support and steroids.

At 9 months old Hannah had her most serious admission. After 4 days of management and treatment on the children's ward of our local hospital Hannah's condition was not improving. Her body was tired and her breathing and respiratory rates were not responding. Hannah was placed onto C-Pap and was emergency transferred to Randwick Children's hospital via NETS Transfer.

Upon arrival at Randwick Hannah was placed into isolation. Hannah had RSV and was positive. Ultimately our little girl was so sick and we didn't know what the outcome would be. As parents we waited, watched each rise and fall of her breath and prayed our little girl would be ok. After 4 days Hannah still wasn't showing any sign of improvement. We met with the doctors and specialist at each 12 hour shift change over. Her body was fighting the virus but it wasn't enough. If her statistics did not improve within the next 4 hours she would be placed into a induced coma. At this point we watched and waited. With a change in medication Hannah started to show signs of improvement.

Hannah slowly relied less on supported oxygen and as the antibiotics and medication started to work slowly each of the tubes were removed. On discharge to the children's ward Hannah still had a nasal feeding tube to supplement feeding. At this stage we had seen a speech pathologist to help encourage feeding as she had a refusal of bottles. After 11 days we were discharged home.

As apart of the discharge strategy we had follow up referrals at with the respiratory team. Hannah had fortnightly visits for the first 6 months. Hannah as a result had developed a persistent wheeze in her chest. She had a consistent cough and always seemed lethargic. She wasn't the happy go lucky baby anymore.

Hannah had a referral to the Mt Druitt Hospital children's outpatients to check for allergy testing. As she was a twin we were able to have Hudson tested too. I believe this is invaluable to us as parents as we were able to rule out allergies early for their respiratory issues.

The repository clinic was amazing in identifying the cause of the cough and wheeze. Hannah saw many specialist, she was tested for Cystic Fibrosis via patch test, Had a barium swallow to rule out hemangiomas in the throat blocking airways. Hannah also saw a sleep specialist who organised a sleep study. The sleep study identified the main cause of our breathing and respiratory distress. Following this overnight sleep study in hospital Hannah was diagnosed with obstructive sleep apnoea.

Upon referral to an ear nose and throat specialist we were booked into Prince of Wales private hospital. Hannah tonsils and adenoids were removed and she spent 2 days in hospital following due to a low respiratory rate.

The removal of tonsils and adenoids defiantly had a dramatic improvement for Hannah. She was sleeping better, settling easier and her reflux was manageable. Hannah no longer coughed continuously and her wheeze had lessened.

By Age 2 and still under the care of the amazing team at Randwick respiratory team Hannah was officially diagnosed as severe asthmatic and given Flexiotide as a preventer and Ventolin to manage

her asthma like conditions. Hannah also was prescribed Singular to help manage and treat her asthma. We were managed monthly and then 3 monthly until aged 4. Within that time we would be managed by our wonderful local GP and as needed during flu and winter season our local children's ward of the hospital.

At age 5 we officially graduated from needing ongoing respiratory care appointments. We now only have a check up once every 12 months. Hannah is very self aware of her asthma and can manage her Ventolin via a spacer effectively. Hannah's educators at preschool are aware of her triggers for an asthma attacks and these are minimised when possible.

Hudson's journey is more on developmental. At around age 2 we noticed Hudson was toe walking and fidgety. Our community health nurse put a referral to our local hospital outpatients for physio. (Which happens to be run by the same team as the growth and development clinic)? This referral took almost 3 years to get an appointment – (including many follow up calls to our community health nurse).

Following this appointment we have been advised that Hudson has hyperflexitivity in his joints. He lacks fine motor skills and displays some sensory concerns. We have been working on home tasks / preschool task to help build these skills. Hudson is also ambidextrous so doesn't have a right or left hand preference.

We have had one appointment with a Developmental Paediatrician at Burwood and have a follow up appointment in December. He has identified Hudson's as evidence of motor planning delay as well as sensory issues regarding texture/food. We are currently waiting to access the services of an occupational therapist. At this stage I am again on a waitlist for services to assist my child. Our Local OT simply does not have capacity at this late stage of the year for services for him prior to starting school.

Whilst these concerns are minor and do not fall into a diagnosis of sorts – we will have to access additional services and specialist to help manage the concerns. At this stage they will be a speech pathologist as well as the occupational therapist. We have the support of the 2 preschools our twins attend to help smooth their transition to kindergarten in 2018.

My thoughts on sharing our journey is to highlight the many support, specialist and medical professionals we have seen within the first 5 years of life for our twins. We do have access to private services as well via our health fund. But as a 1.5 (I only work part time) income family we find these services financially restrictive. Our hope in sharing our journey is that you can identify the services that may be needed for families and work towards making funding or availability for families to access.

Thank you for your time and consideration.

Lynda Cowen.



## Alison Buckley – **Mother of 4 ½ year old triplets and older sibling aged 6**

The initial support for new parents and multiple newborn children is often underestimated and even more so in the world of higher order multiple births. As a family who found out we were expecting naturally conceived triplets our world was thrown into a spin, as we were soon to become a family of 4 children under the age of 2 years of age. People often ask what it was like and honestly it's an intense pressure cooker of emotions, exhaustion and on some occasions just aiming to make it through the day. However, it's abundantly clear having support for multiple birth families is what can make the difference between a family who are unable to cope, or alternatively a family who can smile on occasions as they juggle their team of small and often premature babies.

There certainly is some support available for multiple birth families but we found major inconsistencies between Australian states and major inconsistencies for who is able to access this support.

- **In Home Care (IHC)**– a wonderful program that can help multiple birth families in their home which was a god send for us trying to manage feeds around the clock for our premature triplets and actively meet the daily needs of our 2year old. However, this was at our direct expense to access this service although very important for daily survival for our already stretched family situation. There was an opportunity to access a number of free weeks of IHC, however, we had to give a written statement that our children were 'at risk' to be granted this free care. It's my firm belief that IHC should be a free service for triplet families in NSW like it is in other Australian states. IHC was also inconsistent for families who applied and meet the criteria (for example in NSW some triplet families were successful in applying for IHC and others with the exact same circumstances and similar geographic locations were not accepted). This service should be accessible for all who meet the criteria.
- **Multiple Birth Allowance** – This is provided to families for Triplets (not twins) and is a very minimal amount and means tested, of which we did not qualify. Most families who experience financial stress and strain is attributed to the pressure of having to purchase 3 or 4 of everything as the traditional 'hand me downs' with most families is not possible when all the children require the items at the same time e.g. cots, giant prams, clothes, shoes, toys etc. The allowance should be increased, not means tested and available to all multiple families.
- **Children's Health Nurses** are critical in the first years of life for many parents gaining support, knowledge and reassurance they are on the right track. For some multiple families getting out of the house is a struggle and accessing these services a challenge. For our family our triplet pram did not even fit into the office of the clinic nurse. Having the nurses available to do home visits for all multiple birth families would make a positive impact.
- Childcare is expensive and often a necessity for families. The '**HOM Preschool**' allowance does currently exist and subsidises the 3<sup>rd</sup> child attending Preschool. This has also been inconsistent in my experience with some preschools passing the full government funding onto the families as a discount and others not passing the full amount. The type of childcare available to families is often hard to find as triplet families take up 3 or more spots. In my opinion, having the Preschool Funding available to long day care centres for preschool aged children would also be a positive move and provides assistance to families.

Our journey is one that is unique, yet we would not change anything for the experiences it has brought. We are stronger people, parents and our children are the most important aspect of our life and we are striving to make a legacy through their growth and happiness. We hope that through further support and funding from multiple levels of government and policy, multiple families in the future can be given more support equating in real value and consistency for each situation.

Kind Regards  
Alison Buckley

Being told that you are having three babies at once certainly comes as shock, particularly when they were conceived spontaneously. Your entire life as you dreamed it would be becomes a distant memory whilst you are trying to process the news.

Once we were over the shock of it all we started researching, how to keep three babies healthy in utero, how to keep me healthy, what type of car would we need, can we get help from somewhere as one person alone cannot possibly look after three newborns. It was during this time we were told about the In Home Care (IHC) program, having three children under school age qualified us to apply we were told, so we ticked that box and put that item to one side until the babies were born. Now we were blessed, as with seven weeks bed rest I managed to get my babies to 34+3 weeks before I delivered by elective C-Section. This meant that they were well enough to go straight to Special Care Nursery (SCN) for 'feeding practice (sucking) and growing and would most likely be home with us before their official due date. As you can imagine the SCN journey was long for 2.5 weeks I would wake each morning, go to the hospital and spend the day sitting by my babies, I would (with the assistance of the nurses) feed them, care for them and learnt to wrap them just right. I was exhausted as there were no beds for the parents to rest in and I was still recovering from my surgery.

Finally the day arrived and the babies were able to come home with us, my husband had some time off work and we found it best to stick with the routine that we were on in the hospital. It was during this time we completed the paperwork and applied for the IHC program through receiving Special Child Care Benefit (SCCB) through Centrelink, originally when we had researched we were not aware that we would need to supply documented evidence that stated that our babies were at risk of harm or neglect. To be honest this requirement shocked us a little, we would never do anything to hurt the babies, but this is what the program required, just having three newborns was not enough, our GP wrote a supporting letter and our application was lodged.

As you can imagine life became a blur, we had my husband's family members taking time off work and study to come and help me during the day once he went back to work and I longed for the day we would receive the call that our application for IHC had been approved. You see my relationship with some of those family members was strained, in fact beyond strained and in between my exhaustion of having no more than 2 hour blocks of sleep a night, caring for three newborns during the day and being stuck inside the same four walls everyday with people I would not have chosen to spend time with my mental health started to suffer.

Well that call did come through, but it was not the call I was expecting. I was told by the intake officer of the IHC provider we had applied through that our application had been rejected, it was deemed that our children were not at risk of harm or neglect and we did not meet the criteria, that there were families out there with mental health issues and drug related problems who needed the service more. I cried down that phone to the person relaying this message to me, what was I supposed to do? Who was going to help me? I couldn't do this on my own and I couldn't be with these people who were helping me anymore? I begged, I pleaded, I asked over and over why, I was told that the program is not a preventative service that we were not in need as others were. Well that is where I beg to differ, you see even then in that haze of sleep deprivation, feeding and nappies I knew that, that is exactly what this program was. What would it take I asked, for me and my babies to end up in emergency before someone would take me seriously?

That day I ended up at my GP, beside myself with worry on what the future would hold for us now. My GP referred me to mental health services as I was no longer coping with the thought that my life would be this and this only, through the help of Mental Health Services, my GP and the Support Worker from a Community Organisation I was finally granted 13 weeks of IHC.

I wish I could say that this was the light at the end of a long dark tunnel for me, alas it was not. You see every 13 weeks you need to reapply for IHC through the SCCB, you need to have a JP sign your declaration and you need to provide further evidence of risk of harm to your children and this requirement is a requirement that you must meet every 13 weeks. There is never a guarantee that you will be approved for the 'next round' so the future remained unknown, this is when I developed anxiety. Imagine having to go through this process every 13 weeks, not knowing if your educator will be returning to you or if you will have to start doing it on your own, or worse still be thrown back into the hell of spending days on end with people you cannot even speak to, that was my reality, the anxiety got worse and the panic attacks more frequent.

My family managed to be approved for 5 rounds of IHC before I returned to work and the babies went to long day care. My babies are nearly 5 and I am a very successful Manager within a global Company, 6 years ago I would never have imagined that my life would take the course it had or that I would have to do what I had to do to get help for my family. I have since met many families with multiples that have taken the plunge and gone through the IHC care system, some due to their babies needing medical care long after they are born and some not. Many have given up as the entire process is all just a little too hard; many have fought the fight and continue to receive the care.

My message to whoever may be reading this, change the system, change the system for these families that need it. As Mothers whether we want to admit it or not, this **IS** a preventative service and it is saving lives, not through the risk that a baby will be hurt by its parents, but through the fact that no one individual can look after two or more newborns by themselves 24 hours a day 7 days a week.

Bruzzano Family