Local Guideline

Cleft lip and palate management

Sites where Local Guideline applies	Neonatal Intensive care Unit , Paediatric wards and Cleft palate team , JHCH
Target audience:	All clinical staff, who provide care to infants with cleft lip and palate.
Description	Guideline for clinicians to manage the care of a newborn with a cleft lip and/or palate in the neonatal period and follow up with JHCH Cleft palate team
This Local Guideline applies to:	
1. Adults	No
2. Children up to 16 years	Yes-follow up information after neonatal period
3. Neonates – less than 29 days	Yes
Keywords	cleft, lip, palate, pigeon, orthodontist, teat
Replaces Existing Local Guideline and Procedure	Yes
Registration Number(s) and/or name and of Superseded Documents	Management of feeding and the infant with cleft lip and palate in NICU 5-5.8.12

Related Legislation, Australian Standards, NSW Health Policy Directive, NSQHS Standard/EQuIP Criterion and/or other, HNE Health Documents, Professional Guidelines, Codes of Practice or Ethics:

- NSW Health Policy Directive 2011_042 Breastfeeding in NSW: Promotion, Protection and Support http://intranet.hne.health.nsw.gov.au/__data/assets/pdf_file/0017/118061/PD2011_042_PCP_1_Breastfeeding_Promotion_Protection_and_Support.pdf
- NSW Health Policy Directive 2007_079 Clinical Procedure Safety http://www0.health.nsw.gov.au/policies/pd/2014/pdf/PD2014_036.pdf
- NSW Health Policy PD 2005_406 Consent to Medical Treatment http://www.health.nsw.gov.au/policies/PD/2005/pdf/PD2005_406.pdf
- NSW Health Policy Directive PD 2007_036 Infection Control Policy http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007_036.pdf
- Cleft lip and/or palate - feeding your baby. Health Fact Sheets http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/cleft-lip-andor-palate-feeding-your-baby.pdf

Prerequisites (if required)	N/A
Local Guideline Note	This document reflects what is currently regarded as safe and appropriate practice. The guideline section does not replace the need for the application of clinical judgment in respect to each individual patient but the procedure/s **requires mandatory compliance**. If staff believes that the procedure/s should not apply in a particular clinical situation they must seek advice from their unit manager/delegate and document the variance in the patient's health record.
Position responsible for the Local Guideline and authorised by	Dr Paul Craven, Director of Newborn Services JHCH
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Date authorised	
This Local Guideline contains advice on therapeutics	No
Date of Issue	23/06/2015
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Note: Over time links in this document may cease working. Where this occurs please source the document in the PPG Directory at: http://ppg.hne.health.nsw.gov.au/

RISK STATEMENT

This local guideline has been developed to provide guidance to clinical staff in NICU, Paediatric wards and the Cleft Palate team to assist in assessment and management of cleft lip and/or palate in the newborn and follow up period. It ensures that the risks of harm to the infants whilst caring for an infant being managed with a cleft lip and/or palate are identified and managed. Any unplanned event resulting in, or with the potential for injury, damage or other loss to infants/staff/family as a result of this management must be reported through the Incident Information management System and managed in accordance with the Ministry of Health Policy Directive: Incident management PD2007_061. This would include unintended injury that results in disability, death or prolonged hospital stay.
RISK CATEGORY*: Clinical Care & Patient Safety*

OUTCOMES

1	Efficient and expert neonatal care for an infant born with a cleft lip and/or palate.
2	To provide expert support and information when diagnosis made, before and/or after birth to parents and families for a baby with a cleft lip and/ or palate regarding their short term and long term management and outcomes.
3	The following to be implemented when an infant with a cleft lip and /or palate is admitted to NICU: Identify or confirm the presence of a cleft lip and/or palate, including uvula. Inform medical staff / NP who will take a detailed family and clinical history and perform and document a full neonatal examination. • Appropriate monitoring, investigation and observation will be instituted for associated defects e.g. cardiac. Be aware that a cleft lip or palate can be an isolated finding or part of a spectrum in genetic conditions. • MO /NP to notify Dr Roddick (paediatrician) or a team member to involve the cleft team on the next working day following infant's admission to NICU. • MO/ NP to refer infant to Speech Pathology team for assistance with establishing feeding • Encourage family to be involved in the management and provision of care • Safe and effective feeding of an infant with a cleft lip and/ or palate • All mothers will be supported in their choice of feeding, • Mothers who choose to breastfeed should be provided with practical support to assist in the establishment and maintenance of breastfeeding ,including information regarding the difficulties in latching due to the anatomy of a cleft lip and/ or palate • Following consultation with medical team, Speech Pathologist, Lactation Consultant and mother, an appropriate feeding strategy for infants who have a cleft to be put into place when the type of cleft and impact on feeding is determined • Correct equipment identified and competently used by staff and family • Infant's feeding is managed with evidence based practice. • Discharge planning implemented, including an appointment for follow-up in Cleft Palate

	Clinic.

ABBREVIATIONS & GLOSSARY

Abbreviation/Word	Definition
Array CGH	Array CGH (comparative genomic hybridisation) is a laboratory technique used to look for alterations in chromosomes which are too small to see down a microscope
CNC	Clinical Nurse Consultant
ENT	Ears, Nose & Throat specialty
GP	General Practitioner
LC	Lactation Consultant
MO/NP	Medical Officer/ Nurse Practitioner
NICU	Neonatal Intensive care Unit
22q11 deletion	The features of this syndrome vary widely, even among members of the same family, and affect many parts of the body. Characteristic signs and symptoms may include birth defects such as congenital heart disease, defects in the palate, most commonly related to neuromuscular problems with closure (velopharyngeal insufficiency), learning disabilities mild differences in facial features, and recurrent infections
VCFS	Velo Cardio Facial Syndrome

Cleft lip and palate management in NICU - One Page Summary and Checklist

(Ctrl+Click on Coloured words to jump to that section)

Rationale* /*Background

Types of Cleft Lip and or palate

- Complete unilateral cleft of the lip without palate involvement ☐
- Complete bilateral cleft of the lip without palate involvement ☐
- Cleft of the soft palate (with or without hard palate involvement) ☐
- Complete unilateral cleft lip & palate ☐
- Complete Bilateral cleft lip & palate ☐

Ante natal Support ☐

Admission to NICU

- Management of feeding
- Taping of clefts
- Breastfeeding
- Expressing
- Specialty feeding equipment for cleft lip and/or palate

After hours management of infants with a cleft lip and/ or palate

Discharge planning

- Check weight gain ☐
- Notify Dr Roddick of impending discharge ☐
- Arrange f/u appointment for cleft clinic-obtain referral ☐

Discussions with LC's prior to discharge-document expressing and BF concerns	
F/U appointments with speech pathology and dietetics if feeding problems	
Provide cleft pals information booklet: Contact 02 9294 8944	
Provide contact details for equipment :02 4358 8394	

Cleft Palate team

Follow up Guide

Rationale

Top

- To provide support to the family when ante-natal diagnosis occurs
- To provide clinical care for the newborn with a cleft lip and/or palate
- To provide support and education to the parents and family in the newborn period as well as follow up management
- To provide education to staff in NICU to care for infants born with a cleft lip and/or palate and their families.

Background

Top

The cleft lip and cleft palate defects are embryologically distinct disorders. The lip and palate of the human embryo develops from five to twelve weeks of gestation. The lip and nostril development takes place from five to seven weeks of gestation. The hard palate develops in the sixth week of gestation whilst soft palate development occurs during the ten to twelve week period[2]. When the maxillary process fails to merge with the medial nasal elevation on one or both sides the cleft lip occurs. When the lateral palatine processes fail to meet and fuse with each other a cleft palate occurs[13]. Fusion starts anteriorly and progressively occurs towards the soft palate.

The cleft lip and palate is the most common birth defect occurring in approximately 1:600 births. In New South Wales from 1999 to 2005 the number of isolated cleft palates ranged from 60 – 88 per year and for total cleft lip (including cleft lip and palate) ranged from 71- 88 per year[4].

The cleft is a congenital malformation that occurs during the phase of secondary palate development[11]. The congenital malformation is caused from a combination of genetic and environmental factors. Whilst one third of effected babies have a family history, two thirds occur with no known cause[6]. The majority of cases of unilateral cleft lip and palate are an isolated nonsyndromic birth defect not associated with any other major abnormalities. The most commonly associated syndromes seen include 22q11.2 deletion [or Velo Cardio Facial Syndrome (VCFS)], Stickler's, and Van der Woud[7]. Pierre Robin sequence also involves the presence of a cleft palate. Incidence is higher in males than females and there is increased prevalence in Asian populations in comparison to Caucasians. Research indicates the incidence is higher with the use of maternal medications in the first trimester in particular opiates, benzodiazepines, phenytoin, penicillin, cortisone, salicylates, acne medications and high doses of vitamin A[13]. Significant alcohol intake is also a risk factor[18].

Types of cleft lip and /or palates

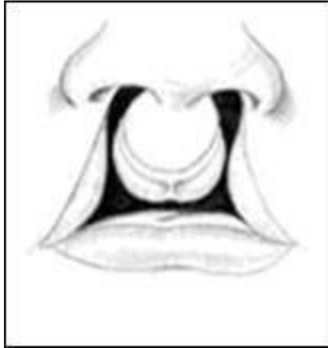
Top

Complete unilateral cleft of the lip

www.facesofchildren.org/conditions/cleft_lip.html

Cleft of the lip extends through the nasal passage. The alveolus (or gum) may be unaffected. In some cases, there may be a notch in the gum, or a cleft through the gum. It does not include the palate[5].

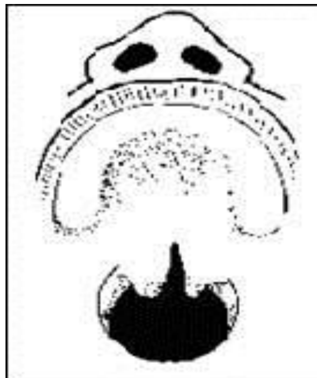
Complete bilateral cleft of the lip



www.facesofchildren.org/conditions/cleft_lip.html

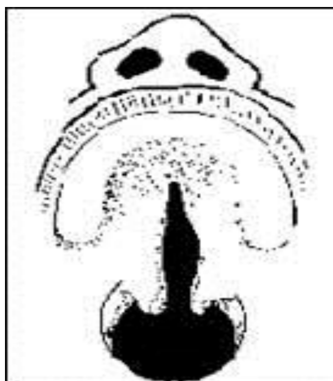
Cleft of the lip extends through the nasal passage. The alveolus (or gum) may be unaffected. In some cases, there may be a notch in the gum, or a cleft through the gum, on one or both sides. It does not include the palate[5].

Cleft of the soft palate



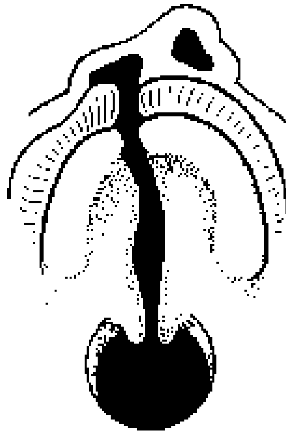
www.chw.edu.au/parents/factsheets/imgs/cleft4.gif

Cleft is seen in the soft palate only. The cleft may be minimal (e.g. a bifid uvula which is the furthest back part of the palate) or may include the entire soft palate, up to and involving the bony hard palate[5].



www.chw.edu.au/parents/factsheets/imgs/cleft4.gif

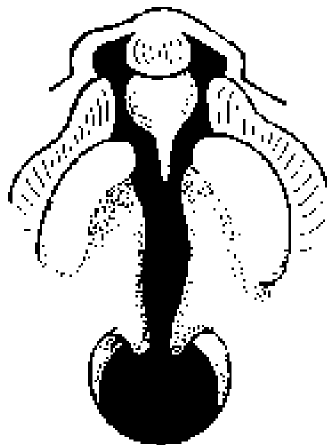
Complete Unilateral cleft lip and palate



http://www.chw.edu.au/parents/factsheets/cleftlpj.htm

Cleft is seen in both the hard and soft palates and extends through the gum to the lip on one side, opening up the nasal cavity on that side to the oral cavity[5].

Complete Bilateral cleft lip and palate



http://www.chw.edu.au/parents/factsheets/cleftlpj.htm

Cleft is seen in both the hard and soft palates and extends through the gum to the lip on both sides, opening up the nasal cavity on both sides to the oral cavity[5].

The **primary** palate cleft involves the nostril, lip, alveolus and hard palate anterior to the incisive foramen. It can be unilateral or bilateral.

The **secondary** palate cleft is always midline. It involves the soft palate and hard palate up to the incisive foramen.

Ante -natal support

Top

Infants where a diagnosis of a cleft lip and/or palate has been made from a prenatal ultrasound and referred through the Maternal Foetal Medicine Unit at JHH are seen by the NICU Discharge Liaison CNC prior to delivery. Prospective parents are also seen prior to delivery by Dr Larry Roddick (Paediatrician) for information about cleft management and outcomes.

Admission to NICU

Top

All infants who present with a cleft palate and/ or lip following birth are admitted to the special care nursery for assessment for feeding and ongoing management. If the infant has respiratory/cardio instability, admission to NICU may be necessary. Review by a Neonatologist, Lactation Consultant and Speech Pathologist occurs within the first few hours of admission.

Investigations: an array CGH will determine if 22q11 deletion is present

Management of feeding

Top

Hunter New England Health endorses the NSW Health Policy Statement: PD2011_042: Breastfeeding in NSW: Promotion, Protection and Support. It recognises that breast milk is the most beneficial feed for all newborn infants.

All mothers will be supported in their choice of feeding. Mothers who choose to breastfeed should be assisted in the establishment and maintenance of breastfeeding if their baby's anatomy allows for successful feeding from the breast. An informed decision is made by the mother on the method of f*eeding most appropriate for her* infant. The decision concerning feeding recognises that breastfeeding a baby with a cleft lip and/or palate may be affected by:

1. The type of cleft and other co-existing medical conditions, e.g. cardiac anomalies, respiratory difficulties that may preclude the infant from being able to breastfeed successfully.
1. the infant's urge and ability to suck, as premature infants have an immature suck and concomitant medical conditions may preclude suck feeding in the first days of life
2. their willingness to express breast milk in cases where breastfeeding is not possible
3. family situation and support mechanisms

All mothers of newborn infants with cleft lips and/or palates should be referred to a lactation consultant.

It is imperative for all infants with a cleft lip and/or palate to have adequate weight gain as they will require surgical intervention within the first twelve months[8].

Taping of clefts

Top

A protruding pre maxilla associated with a complete bilateral cleft lip (central part of lip) may be taped to help bring the gums into alignment. In presentations of a unilateral complete cleft lip and palate where the alveolar gap exceeds 10mm, the orthodontist (currently Dr Aziz Sahu Khan) may be contacted to examine the infant to consider use of a pre-surgical orthodontic plate. The best time to initiate the plate is in the first one to two weeks of life. Use of lip taping or an orthodontic plate will be determined by the cleft palate team following consultation with the paediatrician, speech pathologist, orthodontist and surgeon in the cleft palate team. Taping of a cleft lip or use of orthodontic appliances /plates may be recommended at the discretion of the cleft team in conjunction with the speech pathologist.

Breastfeeding

Top

Not all types of cleft defects are compatible with feeding at the breast, but it is imperative to support a mother's decision to breast feed if the infant is able[14]. Breast milk provides an immunological contribution from the mother to the child in the form of secretory immunoglobulin A. Use of breast milk for feeding infants with cleft lip or palate is encouraged and supported.

Breastfeeding an infant with cleft lip:

Infants with an isolated cleft lip are generally able to breastfeed. Some assistance may be required, with positioning, and occasionally some support is required on the lip, at the side of the cleft, to optimise lip seal. Refer to a lactation consultant or speech pathologist for advice and assistance.

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Breast feeding an infant with cleft palate (hard and/or soft palate):

If compression between the tongue and the palate is not able to be maintained, or a vacuum cannot be achieved (intra-oral pressure /suction), feeding at the breast is unlikely to be successful. A cleft palate (hard or soft) creates an air leak which prevents the creation of significant negative pressure necessary for milk transfer during breast feeding[11].

In these cases, mothers are encouraged to express, and offer their infants expressed breast milk. Information about expressing and specialty teats and bottles for infants with cleft palate follows.

Expressing

Top

All breastfeeding women must be shown how to manually express their breast milk. If, after discussion with the medical staff, speech pathologist, lactation consultant (NICU page 6334) and mother it is advised that the infant is unable to feed at the breast, then the use of expressed breast milk should be encouraged, particularly in the newborn period.

Refer to
http://intranet.hne.health.nsw.gov.au/__data/assets/pdf_file/0017/118061/PD2011_042_PCP_1_Breastfeeding_Promotion_Protection_and_Support.pdf

Specialty feeding equipment for cleft lip and palate

Top

There are several different feeding systems that are appropriate for use with infants with cleft lip and palate. The speech pathologist will be able to advise the family about the most appropriate equipment to use depending on the type of cleft the infant has, as well as provide information about how to assemble and look after the equipment.

Pigeon Cleft Palate Teat

The Pigeon teat and squeeze bottle can be used for infants with cleft lip and palate, or cleft of the hard and/or soft palate. This feeding system is designed to negate the need for suction / intra-oral pressure to achieve milk transfer. Instead, a valving system allows the infant to milk the teat using compression only, without 'suction'. This teat can be successfully used with most types of cleft palate.

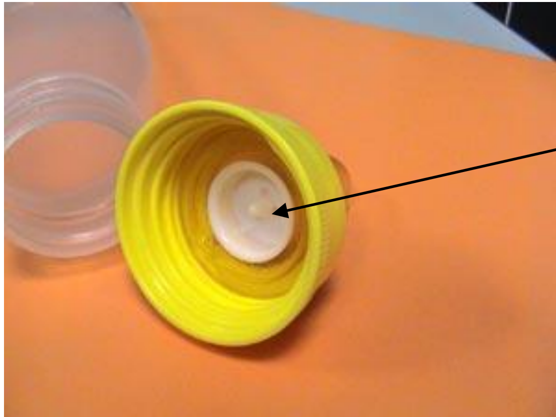
The teat is made of soft rubber rather than silicone. Thick rubber is used in the top of the teat (same side as the air valve) so the teat sits firmly against the palate. The palate is the roof of the mouth and is also the floor of the nose. Soft rubber is much less traumatic to the nose where there is a palate cleft present. Thinner rubber is used at the bottom of the teat so the infant can suck with a light push of the tongue or jaw. Variation in the rubber thickness ensures the milk flows easily by only a slight

push of the teat with their tongue/ jaw on the thin side. The teat has a Y cut to let milk out when the infant is sucking and closes off the flow between sucks[15].

The pigeon bottle set that includes a bottle, two teats and valve is available for purchase from the pharmacy located on the 2nd floor of the Royal Newcastle Centre.

Before use it is important that all components of the bottle are sterilised according to specific sterilising requirements of the Pigeon teat[3].

Assembling the teat:



Place the teat into the cap
*The **valve:** prevents milk flowing back up into the bottle from the teat. Place the valve into the base of teat to assemble and ensure the flat part of the valve is inside the teat. Remember to position the **notch** facing upwards towards the infant's nose.*

Screw the cap onto the bottle. Squeeze the teat together and turn the bottle upside down. Release the teat and allow milk to flow into the teat. When you turn the bottle back up the right way, the milk should remain in the teat. This can be repeated to completely fill the teat with milk prior to a feed.

http://www.chw.edu.au/parents/factsheets/using_the_pigeon_cleft_palate_teat.htm

The squeeze bottle: it is recommended that the Pigeon squeeze bottle is used with the Pigeon teat. Not all babies require the bottle to be squeezed during the feed. The Pigeon Cleft Palate teat also fits a MAM squeeze bottle. (see http://www.cleftpalsnsw.org.au/equipment.html)

Cleaning: Pigeon teats are to be sterilised in Milton for fifteen minutes post feeds (manufacturer recommendation). Following this remove the teat and place into a clean, dry container ready for the next use. Cleft teats will need to be replaced more regularly as they deteriorate more quickly than other teats due to the special thin rubber used. The bottle and valve may be left in the Milton between feeds[3].

The Medela Special Needs Feeder or Mini Special Needs feeder may also be used for infants with cleft lip and palate. Like the Pigeon Cleft Palate Teat, the Medela system is valved to allow feeding in the absence of intra-oral pressure / suction. The speech pathologist can advise whether this system is appropriate for use with the infant.

For information regarding assembly and care of this product, see product information. The speech pathologist can provide this if the equipment is used in the nursery.

'After hours' management of infants with cleft lip and/or palate Top

In the event that an infant is admitted to NICU on the weekend, or after hours, and there is no lactation consultant or speech pathologist available, the following process can be followed:

Before 32-34 weeks gestation:

- NICU care as per medical team, including tube feeds as appropriate

After 34 weeks gestation:

Infant has cleft lip only (no hard or soft palate cleft)

- Mother consulted about preferred feeding method, and breastfeeding encouraged
- Infant can be offered a breast feed once mother medically able
- If mother / infant having difficulty with breastfeeding, continue with tube feeds and kangaroo care and refer to LC and speech pathologist on next business day

Infant has cleft lip AND palate

- Mother consulted about preferred feeding method, and use of breast-milk encouraged
- Mother counselled about why breastfeeding will be difficult for her infant given the infant's anatomy, particularly if hard palate involved as well
- Mother supported with expressing breast milk
- If infant is awake and alert and has no other medical issues that may impact on feeding, infant could be offered a bottle feed using pigeon cleft palate teat and bottle
- Pigeon cleft palate teat and bottle can be found in the milk preparation room in Level 2 NICU in the "cleft palate box"
- Instructions for using the Pigeon cleft palate teat and bottle are in the cleft palate box. Copy instructions and place into infant's notes and at the bedside
- Feed infant in an upright position to reduce nasal regurgitation of milk

- Use external pacing of the feed if required (flow too fast)
- Do not squeeze the bottle unless the infant is actively sucking
- Refer to speech pathologist and LC on the next business day

Infant has cleft of soft palate only

- Mother consulted about preferred feeding method, and use of breast-milk encouraged
- Mother counselled about why breastfeeding will be difficult for her infant given the infant's anatomy
- Mother supported with expressing breast milk
- **If the infant's soft palate cleft is very small / narrow / involving uvula only, mother may want to try breastfeeding in the first instance. If this occurs, please monitor infant's blood sugars and give tube feeds as required (the infant may need breast AND tube feeds to sustain blood sugars and achieve growth)**
- If infant is awake and alert and has no other medical issues that may impact on feeding, infant could be offered a bottle feed using pigeon cleft palate teat and bottle
- Pigeon cleft palate teat and bottle can be found in the milk preparation room in Level 2 NICU in the "cleft palate box"
- Instructions for using the Pigeon cleft palate teat and bottle are in the cleft palate box. Copy instructions and place into infant's notes and at the bedside
- Feed infant in an upright position to reduce nasal regurgitation of milk
- Use external pacing of the feed if required (flow too fast)
- Do not squeeze the bottle unless the infant is actively sucking
- Refer to speech pathologist and LC on the next business day

Discharge planning

Top

Normal weight gain is imperative in infants with a cleft lip or palate. It is optimal that the infant is achieving appropriate weight gain by suck feeding (breast or bottle feeding with cleft palate teat and bottle).

Prior to discharge the following steps to occur:

- Dr Roddick (paediatrician) should be notified of impending discharge
- Arrange a follow up appointment for the cleft palate clinic extension 13750 (A referral is required to attend this clinic which is obtained by the mother from her GP). Ensure the mother has a GP prior to discharge.
- If difficulties present with feeding arrange follow up appointment with speech pathology and dietetics. Ensure that the speech pathology team is made aware of impending discharge on extension 13727.
- Discussions with lactation consultant prior to discharge to ensure any expressing/ breastfeeding issues are resolved and equipment organised.
- Give CleftPals association information booklets to parents for further education and support. Contact details (02) 92948944 or **www.cleftpalsnsw.org.au**
- CleftPals contact for equipment (02) 43 588394 or 0403 808 318
- If 22q11 deletion is present arrange for cardio echogram prior to discharge

The formation of a cleft team provides two key elements to successful outcomes of a cleft lip and/or palate:

1. Coordinated care provided by all necessary disciplines

2. Continuity of care with adequate follow up care of the patient throughout periods of active growth and on-going stages of reconstruction.

The best outcomes are achieved with involvement of a multidisciplinary team centered on the patient their family and community[7].

The cleft palate clinic is held in the Kaleidoscope outpatients department located on level 2 at the John Hunter Hospital (02) 4921 3750.

Cleft palate team- John Hunter Children's Hospital

Top

- Dr Laurence Roddick (Paediatrician)
- Dr Catherine Boorer (Paediatric Plastic Surgeon)
- Dr Helen Cornwell (Paediatric Dentist)
- Dr Aziz Sahu-Khan (Orthodontist)
- Ms Jana Carr and Ms Angeline Randall (Paediatric Speech Pathologist)
- Associate Professor Paul Walker (Paediatric Otolaryngologist)
- Associate Professor Bruce Whitehead (Paediatric Sleep Physician)
- Dr Ian Wilson (Oral Maxillofacial Surgeon)
- Dr Matthew Edwards (Geneticist)

Cleft Lip and Palate follow up guide

Top

If there is a cleft of the **LIP** then:

- At 3-4 months the lip repair is performed at the Sydney Children's Hospital (by Dr Catherine Boorer)

If there is a cleft of the **PALATE** then the following will be required:

At 7 months a hearing test (at Australia Hearing Service – 4941 3600) and a sleep study at John Hunter Children's Hospital

- At 8 months to see Associate Professor Paul Walker (ENT- 49 562460) to check for fluid in the middle ears
- Sleep study at 8 months to look for maturity of breathing, particularly in sleep.

The time of closure of the palate Cleft (by Dr Catherine Boorer) will depend on the sleep study:

A). If NORMAL SLEEP STUDY – surgery at 9- 10 months
B). If ABNORMAL SLEEP STUDY- delay surgery for 6 months until a normal sleep study

A two stage procedure is performed if there is a wide cleft involving one or both lips and the palate. The lip and soft palate is repaired at 6 months and the hard palate is repaired at 18 months.

If grommets are required, as there is fluid in the middle ear they are inserted at 9 – 10 months either at:

- At the time of the palate closure at Sydney Children's Hospital (If sleep study satisfactory)
- Or a separate operation at the John Hunter Children's Hospital (just the grommets)

Later the child may require any or all of the following

1. Speech assessment at John Hunter Children's Hospital

2. Speech therapy
3. Orthodontics (the child also requires regular checkups at local dentist)
4. Bone Graft
5. Surgery revision
6. repeat sleep study

Parent Support and Information

Top

It is important to provide written information to the parents for support as this can be a very stressful period with a lot of information to understand:

Recommended Websites:

- **www.cleftpalsnsw.org.au**
- http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Cleft_palate_and_cleft_lip
- **http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/cleft-lip-andor-palate-feeding-your-baby.pdf**

CleftPALS is a great information and support network for parent's brochures located in cleft box

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APPROVED BY:	Clinical Quality & Patient care Committee JHCH	23/06/2015

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