Local Guideline

Cleft Management in Neonates

Sites where Local Guideline and Procedure applies	Neonatal Intensive Care Unit (NICU) JHCH
This Local Guideline and Procedure applies to:	
1. Adults	No
2. Children up to 16 years	No
3. Neonates – less than 29 days	Yes
Target audience	All clinicians caring for infants in NICU JHCH
Description	Provides guidance for the management of infants born with a cleft lip and/or palate

Go to Guideline

Keywords	NICU, SCU, JHCH, neonate, newborn, neonatal, cleft, lip, palate, feeding
Document registration number	
Replaces existing document?	Yes
Registration number and dates of superseded documents	Cleft lip and palate management JHCH_4.1

Related Legislation, Australian Standard, NSW Ministry of Health Policy Directive or Guideline, National Safety and Quality Health Service Standard (NSQHSS) and/or other, HNE Health Document, Professional Guideline, Code of Practice or Ethics:

- NSW Health Policy Directive PD2017_013 Infection Prevention & Control Policy
- NSW Health Policy Directive PD2017_032 Clinical Procedure Safety
- NSW Health Policy Directive PD2020_020: Incident Management Policy
- HNELHD Policy Compliance Procedure PD2019_020:PCP 2 Clinical Handover – Communication and Handover of Clinical Care

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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/

PURPOSE AND RISKS

This local guideline has been developed to provide guidance to clinical staff in Neonatal Intensive Care Unit at John Hunter Children's Hospital in the assessment and safe care planning for infants born with a cleft lip and/or palate.

The risks are:

- *Clinical compromise of an infant*
- *Risk of aspiration secondary to feeding risk*

These risks are minimised by:

- *Appropriate clinical assessment of infant, including investigations and monitoring where required*
- *Engagement of expert clinicians for appropriate feeding assessment and feeding management pathways suitable to individual infant*

Any unplanned event resulting in, or with the potential for injury, damage or other loss to infants/staff/family as a result of this procedure must be reported through the Incident Management System and managed in accordance with the NSW Health Policy Directive PD2020_020: Incident Management Policy. This would include unintended injury that results in disability, death or prolonged hospital stay.

*It is mandatory for staff to follow relevant: "Five moments of hand hygiene", infection control, moving safely/safe manual handling, documentation practices and to use HAIDET for patient/carer communication: **H**and hygiene **A**cknowledge, **I**ntroduce, **D**uration, **E**xplanation, **T**hank you or closing comment.*

Risk Category: *Clinical Care & Patient Safety*

CLINICAL PROCEDURE SAFETY LEVEL

Every clinician involved in the procedure is responsible for ensuring the processes for clinical procedure safety are followed. The following level applies to this procedure (click on the link for more information):

Level 1 procedure

CONTENT

- Speciality Feeding Equipment for Cleft Lip and/or Palate
- Pigeon Cleft Palate Teat
- Assembling the Pigeon Teat
- Medela Special Needs Feeder

After Hours Management of Infants with Cleft Lip and/or Palate

Discharge Planning

- Cleft Palate Team and Clinic
- Cleft Lip and Palate Follow-up

CLEFT MANAGEMENT SUMMARY

- Where there is an antenatal diagnosis of cleft lip and/or palate, antenatal counselling with a plastic surgeon experienced in cleft lip and palate surgery and a specialist in cleft lip/palate feeding is recommended
- Following birth, infants should have a medical assessment to determine the nature of the cleft and any associated anomalies or comorbidities
- Assessment of oxygen saturation using pulse oximetry should be undertaken soon after birth and repeated if clinically indicated
- Consider extended pulse oximetry if there is any concern regarding upper airway obstruction
- A feeding assessment by a professional experienced in feeding infants with cleft lip and/or palate should occur as soon as possible following birth. They should then initiate a feeding plan

GUIDELINE

While not requiring mandatory compliance, staff must have sound reasons for not implementing standards or practices set out within guidelines issued by HNE Health, or for measuring consistent variance in practice.

Introduction

The cleft lip and cleft palate defects are embryologically distinct disorders. 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. Fusion starts anteriorly and progressively occurs towards the soft palate. The cleft lip and palate is the most common birth defect occurring in approximately 1:700 births.
Whilst cleft lip and/or palate may be an isolated finding on ultrasound, it can be associated with other congenital anomalies or rare syndromes. Following birth, infants should have a medical assessment to determine the nature of the cleft and any associated abnormalities or co-morbidities. Clinical assessment should also pay particular attention to possible airway compromise and associated breathing difficulties. Initial assessment of oxygen saturation using pulse oximetry should be undertaken. Ideally, antenatal counselling with a practitioner experienced in feeding management for infants with cleft/palate has occurred. Mode of feeding (including benefits of breast milk versus formula) and anticipated feeding issues should be discussed. Antenatal breastmilk expression can be encouraged if this is the woman's feeding preference.

Types of Cleft Lip and/or Palates Top

Unilateral Cleft of the Lip Top

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 (see Figure 1).

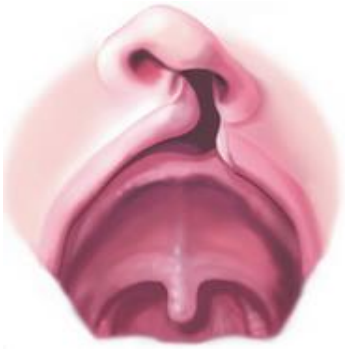

Figure 1: *Unilateral Cleft Lip (Image from Google images)*

Bilateral Cleft of the Lip Top

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 (see Figure 2).

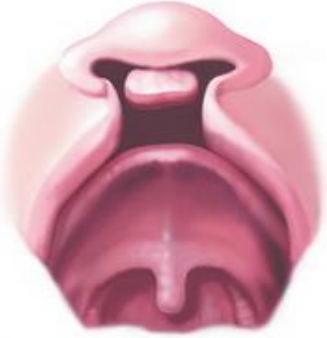

Figure 2: *Bilateral Cleft Lip (Image from Google images)*

Cleft Palate Top

Cleft is seen in the palate only. The cleft may be minimal (e.g. a submucosa cleft, where a bifid uvula may be present) or may include the entire soft palate, up to and involving the bony hard palate (see Figure 3). A cleft palate is always midline.

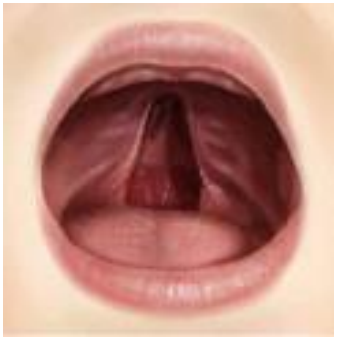

Figure 3: *Cleft Palate (Image from Google images)*

Some infants with a mid 'U' shaped cleft palate may have Pierre Robin Sequence (PRS) (see Figure 4). This is a combination of the cleft palate with retrognathia/micronathia glossoptosis and airway obstruction. A detailed assessment by the Neonatologist together with the cleft team is required to determine if this diagnosis is present. An ear, nose and throat (ENT) assessment may be required to assess the airway patency in those infants with PRS. Side lying/prone positioning with cardio-respiratory monitoring, plus or minus respiratory support may be required.

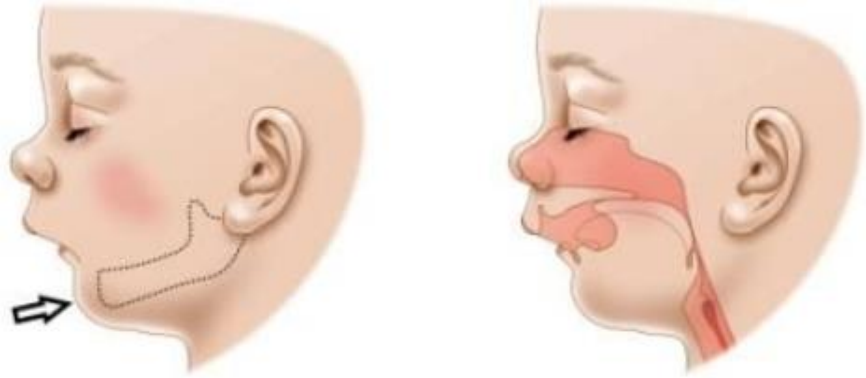

Figure 4*: An infant with Pierre Robin Sequence (Image from Google images)*

Unilateral Cleft Lip and Palate

Top

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 (see Figure 5).

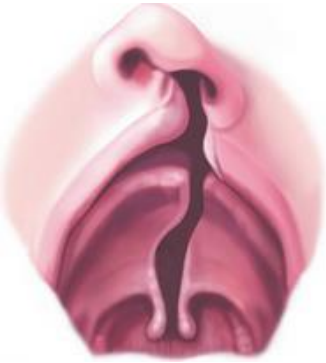

Figure 5: *Unilateral Cleft Lip and Palate (Image from Google images)*

Bilateral Cleft Lip and Palate

Top

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 (see Figure 6).

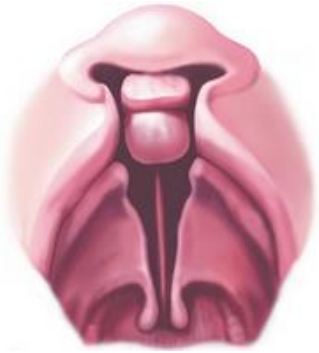

Figure 6: *Bilateral Cleft Lip and Palate (Image from Google images)*

Neonatal Teeth Top

May be present at or around the cleft site. They are considered part of the deciduous dentition. Management is only required if they are mobile and are interfering with feeding or are an inhalation risk. For assessment contact paediatric dentist or oral maxillofacial team.

Antenatal Support Top

Infants where a diagnosis of a cleft lip and/or palate has been made from a prenatal ultrasound are referred through the Maternal Foetal Medicine (MFM) team at John Hunter Hospital (JHH). Prospective parents are also seen prior to birth by the Cleft Team Paediatrician, for information about cleft management and outcomes. The neonatal team will additionally meet with the parents and discuss what to expect following the birth and provide additional information.

Admission to the Neonatal Unit Top

All infants who present with a cleft palate and/or lip following birth are admitted to the special care unit for assessment for feeding and ongoing management. Clinical review by a Neonatology team occurs within the first few hours of admission. A Lactation Consultant (LC) and Speech Pathologist will review the infant to provide guidance regarding feeding.

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. Ideally antenatal counselling and support measures including information provision has occurred through MFM. Children's hospital fact sheets are available or the following support services are helpful for families, Cleft Connect or CleftPals NSW.

Feeding Management Planning Top

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 infants' anatomy allows for successful feeding from the breast. An informed decision is made by the mother on the method of feeding most appropriate for her infant.

The decision concerning feeding recognises that breastfeeding an infant with a cleft lip and/or palate may be affected by:

- 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
- 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
- Their willingness to express breast milk in cases where breastfeeding is not possible
- Family situation and support mechanisms

All mothers of newborn infants with cleft lips and/or palates should be referred to an LC. 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.

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. 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 an LC and/or Speech Pathologist for advice and assistance.

Breastfeeding an Infant with Cleft Palate (hard and/or soft palate)

If compression between the tongue and the palate is not able to be maintained, and 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. Refer to Speech Pathologist for assessment.
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

All breastfeeding women must be shown how to manually express their breast milk. If, after discussion with the Medical team, Speech Pathologist, LC and mother; if 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.

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 Cleft Palate 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 valve 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 silicone. Thicker silicone is used in the top of the teat (same side as the air valve) so the teat sits firmly against the palate. Thinner silicone 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 silicone 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.

For Infants requiring a specialised cleft feeding bottle, a Pigeon bottle set will be provided by NICU. The pigeon bottle set includes a bottle, two teats (a premature teat, and a term infant teat). When working with term infants, always use the term size teat and remove the premature size teat to avoid confusion. Additional bottle and teat sets are available for purchase from the onsite pharmacy located in the Royal Newcastle Centre or can be purchased on-line from Cleft Connect or Cleft Pals NSW.

Before use it is important that all components of the bottle and teat are sterilised.
Pigeon teats are to be washed in hot soapy water, then rinsed and dried with a lint free cloth. Following this remove the teat and place into a clean, dry container ready for the next use.

Assembling the Pigeon Teat

- Place the teat into the cap
- Place the valve into the base of teat to assemble and ensure the flat part of the valve is inside the teat (see Figure 6) Remember to position the notch facing upwards towards the infant's nose (see Figure 7)
- Screw the cap onto the squeeze bottle. Note; it is recommended that the pigeon squeeze bottle is used with the pigeon teat. Not all infants require the bottle to be squeezed during the feed. The Pigeon Cleft Palate teat also fits a MAM squeeze bottle as well as disposable hospital supply bottles
- Squeeze the teat together and turn the bottle upside down
- Release the teat and allow milk to flow into the teat (see Figure 8) when the bottle is positioned upright, the milk should remain in the teat. This can be repeated to completely fill the teat with milk prior to a feed

Figure 6: *Valve positioning*

Figure 7: *'Y' notch in upright position*

Figure 8: *Squeeze filled teat*

(All images from NICU JHCH)

Medela Special Needs Feeder

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 Feeder contains a valve system to allow feeding in the absence of intra-oral pressure/suction (see Figure 9). The Speech Pathologist can advise whether this system is appropriate for use with the infant. The Speech Pathologist will provide demonstration and education when the equipment is required for use.

Figure 9: *Medela Special Needs Feeder (Image from Google images)*

After Hours Management of Infants with Cleft Lip and/or Palate Top

In the event that an infant is admitted to the neonatal unit on the weekend, or after hours, and there is no LC or Speech Pathologist available, the following process can be followed:

Before 34 weeks gestation

- Care as per managing medical team, including tube feeds as appropriate

After 34 weeks gestation

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

- Consulted with mother about preferred feeding method, breastfeeding is encouraged
- Infant can be offered a breast feed once mother able
- If mother/infant experiencing 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

- Consult with mother about preferred feeding method, expressing and breast milk use is encouraged
- Counsel mother on breastfeeding challenges in relation to the infant's anatomy
- Support mother with expressing equipment provision and expressing practices education
- 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 equipment storeroom room in the Gastroenterology section, 'cleft palate box'
- Instructions for using the pigeon teat and bottle are in the cleft palate box. Copy instructions and place at the infant's bedside
- Feed infant in an upright cradled position to reduce nasal regurgitation of milk
- Use external pacing of the feed if required (where flow is too fast for infant to co-ordinate)
- Do not squeeze the bottle
- Refer to Speech Pathologist and LC on the next business day

Infant has cleft of the palate only

- Consult with mother about preferred feeding method, expressing and breast milk use is encouraged
- Counsel mother on breastfeeding challenges in relation to the infant's anatomy
- Support mother with expressing equipment provision and expressing practices education
- If the infant's palate cleft is very small, 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 'cleft palate box' in the equipment storeroom
- Instructions for using the pigeon teat and bottle are in the cleft palate box. Copy instructions and place at the infant's bedside
- Feed infant in an upright cradled position to reduce nasal regurgitation of milk
- Use external pacing of the feed if required (flow too fast)
- Do not squeeze the bottle
- Refer to Speech Pathologist and LC on the next business day

Investigations

Top

- Microarray; if not done antenatally. It is recommended that a genetic review is completed as an inpatient if multiple dysmorphic features to guide further genetic tests
- Echocardiogram; as an outpatient, unless murmur present/ abnormal cardiac exam or if a genetic syndrome is identified with high association with cardiac defect (e.g. 22q11.2 deletion syndrome)
- Oximetry download; to be conducted on:

  - All infants with a cleft palate only
  - Infants with a cleft lip and/or palate where concerns on saturation monitoring
- Head and renal ultrasound; not required routinely. Recommended only if:
  - Other dysmorphic features
  - Abnormal antenatal scans

Lip Tape

The need for lip taping will be assessed by a clinician from the cleft team in consultation with the plastic surgeon. A waterproof surgical tape (i.e. Blenderm™) is provided in cleft palate box, where required.

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 are required:

- Cleft team Paediatrician/Speech Pathologist to be notified of impending discharge
- Arrange a follow-up appointment for the cleft palate clinic with the cleft team Paediatrician *Note; a referral is required to attend this clinic which is provided by the Neonatologist
- If difficulties are present with feeding, arrange follow-up appointment with Speech Pathology and Dietetics (where applicable)
- Discussions with LC prior to discharge to ensure any expressing/ breastfeeding issues are resolved and required equipment is organised (where applicable)
- If 22q11.2 deletion is present, arrange for echocardiogram prior to discharge
- Audiology; ensure the infant has had a SWISH test as an inpatient and an appointment has been made for diagnostic audiology within 6 weeks if there is cleft palate involvement (not required for cleft lip only, SWISH alone is sufficient)
- Provide CleftPals Association information booklets to parents for further education and support
- Provide contacts for equipment/family support: Cleft Connect or CleftPals NSW
- Provide cares allowance paperwork to eligible families, can be accessed from a social worker

Cleft Palate Team and Clinic

Top

The aims of cleft palate/lip treatment are:

- Cleft lip → good aesthetic and functional result
- Cleft palate → good palate function to produce good speech, normalized hearing and optimal dento-facial development including jaw growth

The best outcomes are achieved with involvement of a multidisciplinary team centered on the patient their family and community. The formation of a cleft team provides two key elements to successful outcomes of a cleft lip and/or palate:

- Coordinated care provided by all necessary disciplines
- Continuity of care with adequate follow up care of the patient throughout periods of active growth and on-going stages of reconstruction

The cleft palate clinic is held in the John Hunter Children's Hospital (JHCH) outpatient department. The cleft palate team at JHCH is a multidisciplinary consisting of the following clinicians:

- Cleft Palate Team Leader and Paediatrician
- Paediatric Speech Pathologist
- Paediatric Plastic Surgeon

- Paediatric Dentist
- Orthodontist
- Paediatric Otolaryngologist
- Paediatric Sleep Physician
- Oral Maxillofacial Surgeon

Cleft Lip and Palate Follow-up

Top

The following is a guide for long term follow-up and management planning for the infant.

For cleft of the lip:

- Between 3 to 6 months of age the lip repair is performed at the Sydney Children's Hospital (SCH) by the Paediatric Plastic Surgeon

For cleft of the palate:

- Repair generally occurs between 9-12 months of age.
- Can be delayed to between 12-18months if the infant has significant co morbidities including sleep disordered breathing.

Later the infant may require any or all of the following:

- Speech Assessment at JHCH
- Speech Therapy
- Orthodontics (the infant will also require regular check-ups with dentist)
- Bone Graft
- Surgery Revision
- Sleep Study

IMPLEMENTATION PLAN

The clinical guideline will be:

- Circulated to Head of Department and Managers in NICU
- Circulated to the clinicians via the Children Young People and Families Network and the Women's Health and Maternity Network (where applicable)
- Made available on the intranet (PPG) and HNEKids website
- Presented at facility/unit meetings and tabled for staff to action

MONITORING AND AUDITING PLAN

- The person or leadership team approving the clinical guideline is responsible for ensuring timely and effective review of the guideline.
- Evaluation will require a review of the most current evidence as well as consideration of the experience of Neonatal staff at JHCH in the implementation of the clinical guideline.
- Data derived from monitoring and evaluation should inform the review of the clinical guideline either as required or scheduled.
- Implementation, education support and monitoring compliance be completed by local Clinical Educators and Unit Managers.
- Amendments to the guideline will be ratified by the Clinical Director and Manager of Newborn Services prior to final sign off by the JHCH.

CONSULTATION WITH KEY STAKEHOLDERS

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APPENDICES

1. Glossary & Abbreviations
2. Cleft Management Flowchart

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FEEDBACK

Any feedback on this document should be sent to the Contact Officer listed on the front page.

APPENDIX 1

GLOSSARY & ABBREVIATIONS

Acronym or Term	Definition
ENT	Ear, Nose and Throat (Speciality)
GP	General Practitioner
HNELHD	Hunter New England Local Health District
JHCH	John Hunter Children's Hospital
JHH	John Hunter Hospital
LC	Lactation Consultant
MFM	Maternal Fetal Medicine
NICU	Neonatal Intensive Care Unit
SCH	Sydney Children's Hospital
SCU	Special Care Unit
22q11.2 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

APPENDIX 2

CLEFT MANAGEMENT FLOWCHART