CLEFT PALATE/LIP

WHAT IS A CLEFT?

A cleft is a separation in the skin, tissue lining of the mouth, muscle, and bone that is normally fused together; however, no structures are missing. Clefts can be either **unilateral** (one side) or **bilateral** (both sides) and may include the lip, soft palate and/or hard palate or any of the structures in isolation.

TYPES OF CLEFTS

- Cleft Lip separation in the lip and may include the bottom of the nose
- Cleft Palate separation in the hard palate and/or soft palate
- □ Submucous Cleft separation in the muscle of the soft palate with the tissue lining of the mouth intact. Often, it is not easily viewed.

WHEN DID CLEFTING HAPPEN?

During the 4th week of fetal development, the primary palate (line from nostril to upper lip and mucosa behind upper teeth) fuse together. By the 8th week, the tongue drops in the mouth and the secondary palate (hard palate and soft palate) fuse together with the nasal septum. By the 12th week, if the process is not complete, a cleft (separation) will develop.

WHAT CAUSED MY CHILD'S CLEFT?

The exact cause is not known but theories include:

- □ Low intake of Folic Acid (Vitamin B)
- □ Large intake of Vitamin A
- □ Genetic disposition
- □ Syndromes or Sequences (Pierre Robin, Treacher Collins)
- Drugs, alcohol, medication, and smoking

CLEFT PALATE MANAGEMENT

You and your child will be in contact with many different healthcare professionals who need to work together. Every case is individualized, therefore your child will need a thorough assessment to the appropriate treatment plan. It is recommended that your child be followed by a Cleft Palate Team who will provide the best coordination of care. Team members may include the following: Audiologist, Pediatric Dentist, Geneticist, Lactation Specialist, Neurosurgeon, Oral Surgeon, Orthodontist, Otolaryngologist (ENT), Parent Advocate, Pediatrician, Plastic Surgeon, Prosthondontist, Psychologist, Social Worker, Speech Language Pathologist, and Team Coordinator.

FEEDING

A newborn with cleft lip/palate will have some degree of difficulty breast feeding/bottle feeding; however, there are many ways to nourish your baby, including modifications, positioning, and techniques. Some suggestions may include:

- □ Use different nipples and/or feeding to help feed your baby.
- □ Adjust the breast milk/formula amount per feeding and/or frequency of feeding.
- □ Hold baby upright to prevent breast milk or formula from entering in the nose.
- □ Consult with the Plastic Surgeon and/or Feeding Specialist about diet modifications immediately following repair.

Discuss any questions, problems, or concerns with your **Pediatrician** or Feeding Specialist (Speech Language Pathologist and/or Certified Lactation Consultant).

NORMAL SPEECH & LANGUAGE DEVELOPMENT

- □ 3 months Cooing
- □ **3-6 months** Babbles same sounds, laughs during play, begins to imitate.
- □ 6-9 months 2-syllable babbling (mama) with same pitch.
- □ 9-12 months Varied consonant vowel combinations (ie: bakaba) with changing pitch, first word.
- □ 18-24 months 2 word combinations, <u>emerging sounds</u> p, m, h, n, w, b.
- □ 24-36 months 2-4 word combinations, <u>emerging sounds</u> k, g, d, t, ng; followed by f, y.
- □ 36-48 months 4-5 word sentences, <u>emerging sounds</u> r, l, s; followed by ch, sh, z.
- 48-60 months 4-8 word sentences, describes objects, retells stories, all sounds should be produced but not all mastered, emerging sounds j, v, followed by th.

SPEECH & LANGUAGE DIFFICULTIES

Children with Cleft Palate may be more likely to have articulation/hypernasal speech errors, which will be assessed by a **Speech-Language Pathologist.**

- □ Articulation errors: articulation errors are made when a sound is substituted ("gog" for dog), distorted ("dog" with increased nasality), or deleted ("og" for dog). These errors may either be due to normal development, structural deviations related to the cleft (obligatory), or learned behaviors (compensatory).
- □ Hypernasal Speech: sometimes children have a "nasal" sound to their speech that is called hypernasality. Nasal emission (audible air through the nose) may also be present. In the English language, there are only 3 sounds that should allow air to pass through the nose: m, n, and ng. Some children may have velo-pharyngeal insufficiency (VPI), where air enters the nose because of the cleft or muscles not closing adequately. Therefore, sounds that require a lot of air or pressure (s, z, sh, j, f, v, ch, p, b, t, d, k, and g) may go through the nose. Your child may try to compensate for the inability to build up air pressure by producing (b, t, d, p) at the back of the mouth (this is called backing). Do not encourage backing articulation. Encourage your child to play with sounds made in the front of the mouth (e.g. baba, tata) by having them imitate you.
- Language Delay: as compared to the general population, children with cleft palate have a greater risk of language delay.

SPEECH THERAPY

Speech therapy, usually for articulation and sound specific hypernasal resonance, should be intensive and frequent with additional work at home. The Speech-Language Pathologist will use intensive drill work to:

- □ Improve sound discrimination
- □ Eliminate learned articulation errors
- □ Focus on front speech sounds and movement
- □ Increase accuracy of articulation placement
- □ Increase mouth opening
- □ Eliminate sound specific hypernasality

HEARING

Children with cleft palate are more prone to developing ear infections because the muscles of the soft palate control the muscle that opens and closes the middle ear (Eustachian tube). The **Audiologist** and **Otolaryngologist** on a Cleft Palate Team collaborate to manage hearing difficulties. This type of hearing loss is often correctable.

SURGERY

The **Plastic Surgeon** is responsible for the decision of when to perform surgery to repair the lip and/or palate. A common time line may include:

□ Cleft lip – first few weeks after birth.

 \Box Cleft palate – 12-18 months or when the baby has gained a sufficient weight and the plastic surgeon says it is safe. Additional surgeries may be performed at a later date as needed to improve hypernasal speech or facial structures.

SPEECH APPLIANCES

Non-surgical procedures to reduce VPI nasality:

- □ Speech bulb (obturator)
- □ Palatal lift

ADDITIONAL FACTS

- □ Clefts occur in one out of every 700 births in the U.S.
- □ Cleft lip or cleft palate in isolation is not associated with decreases in IQ.
- □ Native Americans have the highest prevalence of cleft palate/lip followed by Asians, Latinos, European ethnicities, and African Americans.
- □ Isolated cleft lip and cleft lip and palate are more common in males, and isolated cleft palate is more common in females.
- Because of feeding concerns, children with cleft palate can easily suffer tooth decay. It is important you provide good mouth care for your baby.

Foundations & Organizations:

American Cleft Palate Craniofacial Association Cleft Palate Foundation Stony Brook Medicine Cleft Palate Team Coordinator

> Stony Brook Medicine 33 Research Way East Setauket, NY 11733 Phone: (631) 444-4191

Website: <u>www.cleft.org</u>