



CLEFT LIP/PALATE: PARENT GUIDE

THE CRANIOFACIAL CENTER AT CHAM

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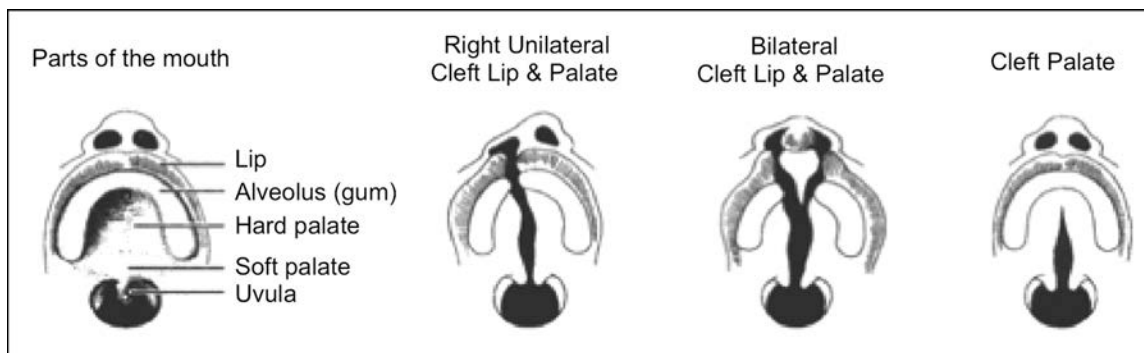
ABOUT US

Welcome to the Craniofacial Center at the Children's Hospital at Montefiore. We know this may be an overwhelming time for parents and families, but rest assured we are committed to helping you get through this as smoothly as possible.

Established in 1959 as one of the country's first and leading craniofacial centers, the Craniofacial Center at CHAM is comprised of a highly skilled multidisciplinary team of specialists, providing patients with a range of cutting-edge advancements in craniofacial care. Combined with decades of experience, the team uses the most up to date technology for advanced surgical planning and care.

Our world-renowned team places great emphasis on personalized care, high quality outcomes, and creating a family-centered environment that empowers both parents and child. As parents, you are key members of the team and will work closely with different healthcare providers to provide your child with the best possible care. Please feel free to ask us questions at any time. We want you to feel comfortable and well informed when making decisions about your child's care.

WHAT IS A CLEFT LIP/PALATE?



Tighe, D., Petrick, L., Cobourne, M. T., & Rabe, H. (2011). Cleft Lip and Palate: Effects on Neonatal Care. *NeoReviews*, 12(6) e315-e324. doi: 10.1542/neo.12-6-e315

The lips and the palate (roof of the mouth) are both formed in the first trimester of pregnancy. A cleft lip/palate occurs when the tissue that makes up the lip and/or palate does not join together properly, leaving an abnormal opening or gap. It is possible to have both a cleft lip and a cleft palate, or either separately.

Cleft lips and palates come in many different types and severities. A cleft palate can include just the back part of the roof of the mouth (*soft palate*), and/or the front part of the roof of the mouth (*hard palate*). For some babies, both the front and back parts of the palate are affected (*complete*) but for others only part of the palate is open (*partial*). Cleft lips can either be on one side of the lip (*unilateral*), or on both sides of the lip (*bilateral*). The opening can extend all the way to the nose (*complete*) or may end below the nose (*incomplete*).

The cause of a cleft lip and/or palate is not fully understood, but in some cases may have a genetic or environmental component. Cleft lips/palates are a very common birth defect, affecting 1 in every 700 babies, and can both be fixed with surgery.

THE IMPACT OF A CLEFT LIP/PALATE

FEEDING

- The hole in the lip/palate creates an opening between the roof of the mouth and the nose, making it difficult for the baby to create the suction necessary to draw milk out of the nipple.
- There are different types of special bottles and nipples available that can be used for feeding before the palate is repaired. Someone specialized in speech and feeding (*speech and language pathologist*) will help you choose which type is right for your baby.

HEARING

- A baby born with a cleft palate may be prone to ear infections, caused by fluid build-up behind the eardrum. This extra fluid can also cause temporary hearing loss. For this reason, it will be important for your baby to be seen by an *otolaryngologist* (also known as an *ear, nose, and throat doctor, ENT*), and may also be seen by an *audiologist* who will test your baby's hearing.
- If the pediatric ENT doctor feels your baby is at risk for infections, he/she may recommend placement of ear tubes in order to drain the extra fluid. This often can be placed at the same time as the cleft palate surgery.

DENTAL

- Sometimes the gums where the teeth come in (*alveolar ridge*) is part of the cleft palate, which can cause problems with teeth coming in. Your child will need to see a *dentist*, and possibly a dental specialist (such as an *orthodontist, prosthodontist, or oral surgeon*).

SPEECH

- Sometimes children with cleft palate have difficulty sealing off the nose from the mouth when speaking, leading to nasal sounding speech and mispronouncing words and sounds.
- These issues can continue even after the cleft palate has been repaired due to scarring from surgery or abnormal muscle function.
- For this your child will be seen by a *speech-language pathologist*, and may need further surgery in the future.

MEET THE TEAM

Genetics

Robert Marion, MD

Paul Levy, MD

Fetal Medicine and Surgery

Pe'er Dar, MD

Tamar Goldwaser, MD

Neonatology

Suhas Nafday, MD

Zahava Cohen, RN

Otorhinolaryngology (ENT)

Michel Nassar, MD

Christine Yang, MD

Mona Gangar, MD

John Bent, MD

Plastic Surgery

Oren Tepper, MD

Elyse Uppal, NP

Speech-Language Pathology

Emily Stoddard, CCC-SLP

Melissa Levy, CCC-SLP

Hannah Tahhan-Jackson CCC-SLP

Dentistry/Prosthodontics/Orthodontics/Oral Surgery

Alice Lee, DDS

Rajendra Rana, DDS

Gary Rogoff, DDS

Kenneth Kurtz, DDS

Jairo Bastidas, DMD

CONTACT INFORMATION

Craniofacial Coordinator: Elyse Uppal

Phone: (718) 696-2580 OR (718) 920-4800

Email: craniofacial@montefiore.org OR euppal@montefiore.org

SURGICAL REPAIR OF A CLEFT LIP/PALATE

The treatment for a cleft lip and/or cleft palate is surgical repair by a plastic surgeon (Dr. Tepper). The repair for a cleft lip typically happens when your baby is around 3-4 months old, and the repair of the cleft palate is usually done when your baby is around one year old.

THE MONTHS BEFORE SURGERY

Nasoalveolar Molding (NAM): a pre-surgical treatment for certain types of cleft lip/palate with the goal of reducing the size of the cleft before surgical repair. A mold is taken of your baby's mouth, and from that a mouthpiece is made. This mouthpiece sits on the roof of your baby's mouth, and is secured with small rubber bands that are taped to his/her cheeks. You will have weekly appointments where the team will adjust the mouthpiece and the rubber bands, gradually decreasing the size of the cleft. Once the size of the cleft is small enough, your baby will be ready for surgical repair.

Preparing your child for surgery: CHAM's child life specialists are trained to help you and your child handle the stress of a surgery and hospitalization. They ensure proper communication and can explain complex clinical information in a way that both children and families can easily understand. Additionally, they can give you a pre-operative tour which will help you and your child become familiar with the medical equipment they will see on the day of their surgery. You will visit both the pre and post surgical areas as well as the operating room.

Presurgical testing: your child may require pre-operative labs and/or a meeting with an anesthesiologist before surgery. If necessary, this will typically be scheduled within the week of surgery and will take place at CHAM on the 3rd floor.

THE DAY BEFORE SURGERY

You will receive a call from a nurse at CHAM with instructions on what time your baby's last feed should be (it will typically be around midnight the night before surgery) and what time to arrive to CHAM the next morning. Plan to pack special comfort objects for your baby (blankets, pillows, stuffed animals, favorite toys, iPads, etc).

THE DAY OF SURGERY

You will bring your baby to the 3rd floor of CHAM (3415 Bainbridge Ave) at the designated time. You and your baby will be given a bay in the pre-op area, and you will be given a hospital gown for your baby to wear. The pre-op nurses will usually be the first ones to see you and ask questions. You will then see Dr. Tepper and an anesthesiologist, making sure that your child is fit for surgery. Be sure to ask any additional questions you may have.

When everyone is ready, your baby will be brought back into the operating room by the anesthesiologist. At this time you can either wait in the waiting room on CHAM 3, head down to the café, or take a walk around the area. The operation generally takes around 3 hours, and you will be notified when it's finished. Dr. Tepper and/or someone from his team will update you on how the surgery went, and you will be allowed to go into the recovery room once your baby is settled.

WHAT TO EXPECT AFTER A CLEFT LIP REPAIR

- Your baby will have one IV, usually in the hand or foot.

- Your baby will have stitches on his/her face and in the mouth where the lip was repaired. Most of these stitches are dissolvable and will start to dissolve in 7-10 days. Any stitches that aren't dissolvable will be removed at your first post operative appointment.
- Your baby will have splints ("NoNo's") on his/her arms to prevent him/her from touching the stitches. These should be kept on until at least the first post operative appointment.
- There will be multiple wires hooked up to a monitor. The wire measuring the oxygen saturation in the blood will be kept on overnight. We also monitor the heart rate and rhythm, as well as the blood pressure.
- Your baby may be uncomfortable after the surgery, and pain control is a priority. Your nurse can help with this.
- Once your baby is fully awake and alert and has had something to drink (using the same method of feeding as before the operation), they will transfer him/her to one of the floors in CHAM. Your baby will typically only stay 1 or 2 nights, to make sure the pain is under control and he/she is eating well.

WHAT TO EXPECT AFTER A CLEFT PALATE REPAIR

- Your baby will have one or two IVs, usually in the hands or feet.
- There will be a stitch in the tongue taped to the cheek, so that while he/she is recovering from surgery and anesthesia the tongue does not fall back into the airway. The stitch does not hurt your baby and will be taken out in 1-2 days.
- Your baby will have splints ("NoNo's") on his/her arms to prevent him/her from putting hands in the mouth. These should be kept on until at least the first post operative appointment.
- There will be multiple wires hooked up to a monitor. The wire measuring the oxygen saturation in the blood will be kept on overnight. We also monitor the heart rate and rhythm, as well as the blood pressure.
- Your baby may be uncomfortable after the surgery, and pain control is a priority. Your nurse can help with this.
- Typically a couple hours after arrival in the recovery room, when your baby is fully awake and stable, they will transfer him/her to one of the floors in CHAM. Your baby will likely stay a few nights, to make sure the pain is under control and he/she is eating well.

FEEDING AFTER CLEFT PALATE REPAIR

Your baby will have a special diet for the first few weeks after surgery in order to allow the surgical site to heal, as well as for his/her comfort. Please note that someone will meet with you after surgery to discuss specific feeding recommendations for your baby, but our general guidelines are as follows:

- Week 1: full liquid diet (formula, milk, juice) through either a syringe or sippy cup with no lid. No bottles or pacifiers.
- Week 2: pureed diet (Gerber Stage 2 foods, applesauce, yogurt consistency foods), spoon feeding (no forks, still no bottles or pacifiers). Do not allow spoon to touch roof of mouth (do not put it past the teeth).
- Week 3: normal diet as he/she was eating before surgery (using the same bottle). Your baby may resume feeding therapy at this time.

Your baby may not be very interested in eating/drinking for the first week or so after surgery. Make sure he/she has a wet diaper at least every 8 hours in order to avoid dehydration. Try to offer smaller more frequent feedings. Try to feed about 30 minutes after giving pain medication.

For the first couple of weeks it is also a good idea to give your child a couple sips of water after eating in order to wash out any food residue that may remain near the stitches in the mouth.

OTHER POST OPERATIVE CARE

- Pain: your baby may be uncomfortable after surgery. Typically Tylenol will be enough to control this pain. You can give it as directed on the package.
- Activity: keep the arm splints (“NoNo’s”) on your baby until at least the first post operative appointment. Take them off (one splint at a time) several times a day to bend your baby’s elbows and exercise his/her arms. Pay close attention during this time to make sure your baby does not touch the stitches. It is important for the first month to ensure that all play is carefully supervised, and that no hard toys go in the mouth. Only soft/cloth toys should be used during this time.
- If you have any questions regarding your child’s care, please email craniofacial@montefiore.org or call our office at 718-696-2580.
- Immediately call 718-920-4800 if your child:
 - Has a temperature greater than 101 degrees
 - Is persistently vomiting
 - Is excessively bleeding (enough to saturate a wash cloth)
 - Has a sudden increase in drainage, pain, or swelling at the incision site

FOLLOW UP APPOINTMENTS

The follow up appointments will vary from case to case, but typically your first post operative appointment with Dr. Tepper/his team will be around 1 week after discharge from the hospital. At this first post operative appointment we will remove any non-dissolvable stitches, and we will determine how often your baby needs to be seen by us. We will start out with frequent appointments and gradually space them apart.

WHAT HAPPENS NEXT?

Your baby will be followed by many specialists throughout his/her life. This will vary based on the type and severity of cleft lip/palate. He/she may require additional procedures and/or surgeries in order to eat, speak, and develop properly.

TODDLER AND PRESCHOOL YEARS

Ears/Hearing

- Your child will need close monitoring by an otolaryngologist (ENT) to evaluate the ears for fluid build up (which can then cause ear infections).
- Hearing testing will be done periodically by an audiologist.

Teeth

- Your child should continue to be monitored by a pediatric dentist, as children with clefts can be prone to dental issues. The top teeth may come in crooked, malformed, or may be missing altogether.

Speech and Language

- Your child should continue to be monitored by a speech and language pathologist, and may need regular speech therapy.

SCHOOL AGE YEARS

Teeth

- Your child should continue to be monitored by a pediatric dentist regularly.
- Alveolar Bone Graft: if the cleft palate includes the alveolar ridge (the gums where the teeth come in), the permanent teeth may not be able to grow in in the proper spot. Your child may need surgery to take a small amount of bone from the hip and place it where the cleft in the gum is, to give the permanent teeth a stable place to grow in.
- Your child may also need to see an orthodontist at this time. Sometimes children with cleft palates will have a cross-bite or an under-bite.

Speech and Language

- Your child may need to continue to be monitored by a speech and language pathologist.
- Velopharyngeal Insufficiency (VPI): during normal speech, the soft palate reaches to touch the back of the throat, effectively sealing off the nose from the mouth. Sometimes children with a history of cleft palate have issues making this seal, and the

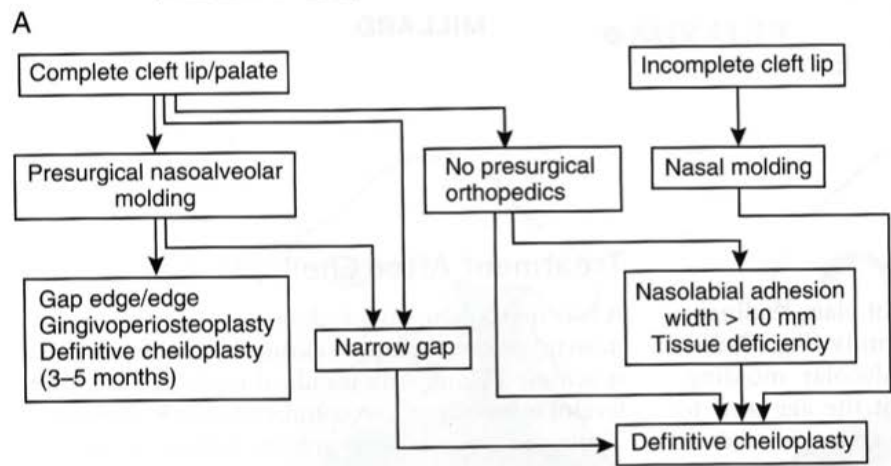
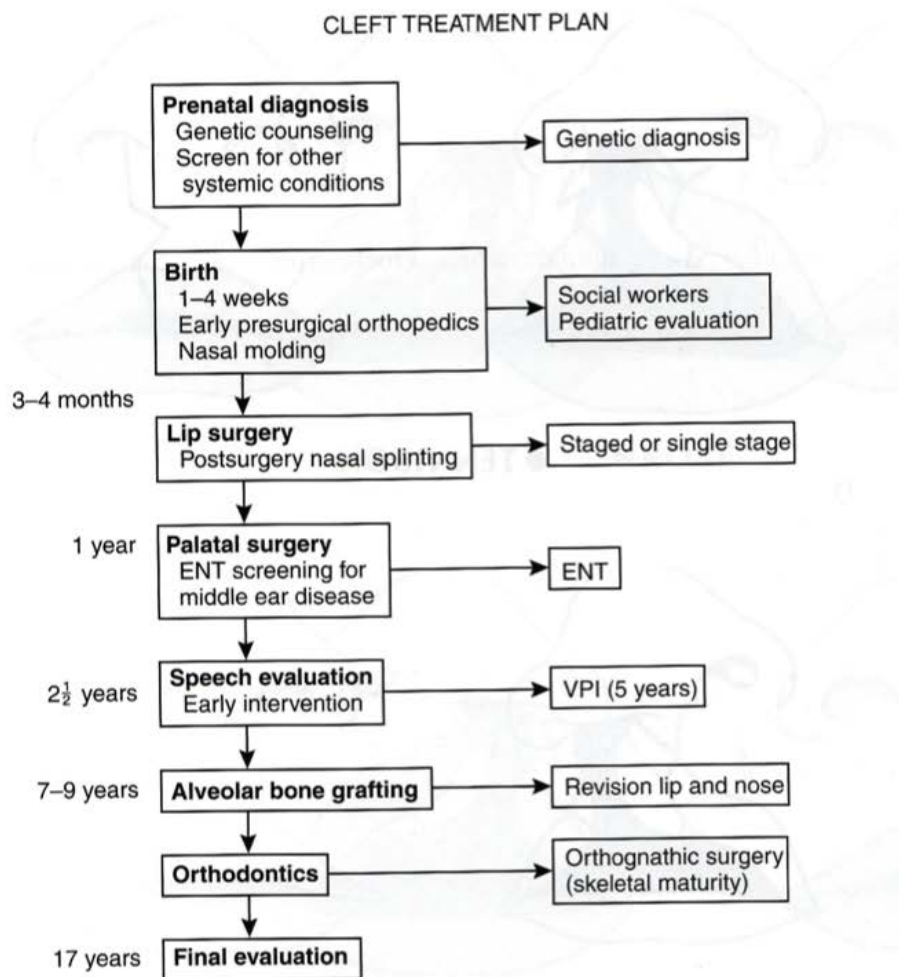
result is nasal sounding speech that may be difficult to understand. If speech therapy is not effectively correcting this, your child may need additional surgery on the palate.

TEENAGE YEARS

Surgery/Procedures

- Lip: surgery can be done to improve the appearance of the scar of the lip.
- Rhinoplasty (nose surgery): surgery can be done to improve breathing and the shape of the nose.
- Orthognathic Surgery (jaw surgery): some children with history of cleft palate have a jaw that hasn't formed properly, causing an abnormal bite. Surgery can improve the bite, which can help with chewing, speaking, and appearance

TIMELINE



RESOURCES

American Cleft Palate – Craniofacial Association (ACPA)

www.acpa-cpf.org
1800-242-5338
info@acpa-cpf.org

CleftProud

www.cleftproud.com
(919) 335-4087
support@cleftproud.com

Cleftopedia

www.cleftopedia.com

Foundation for Faces of Children

www.facesofchildren.org
(617) 355-8299
info@facesofchildren.org

MyFace

www.myface.org
(917) 720-4701
info@myface.org

AmeriFace

www.ameriface.org
1888-486-1209
info@ameriface.org

Center for Parent Information and Resources

www.parentcenterhub.org
(973) 642-8100