

Better, Faster Recovery from Cleft Palate Surgery

with the Enhanced Recovery after Surgery (ERAS) Program



UR
MEDICINE

STRONG
MEMORIAL HOSPITAL

Your Child's Surgical Care Team

You will see many different people during your hospital stay. We work together to plan the best steps toward returning your child to wellness as soon as possible.



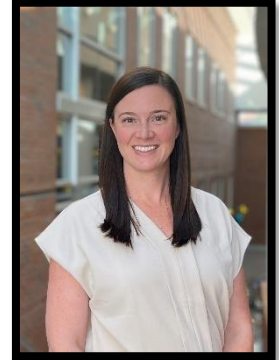
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Other team members include:



Residents, Registered Nurses (RNs), Patient Care Technicians (PCTs), Respiratory Therapists, Physical Therapists, and Environmental Services (the people who help us keep our spaces clean)

Contact us

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Our Team

At Golisano Children's Hospital, we are proud to offer the region's only center dedicated to the needs and treatment of children born with cleft lip, cleft palate, and other craniofacial anomalies. Our center consists of an interdisciplinary team of professionals, dedicated to offering a full range of services to the patient and family dealing with these types of birth defects. It is our mission to provide optimal care through a team-oriented approach and to stimulate and support research that will improve the quality of life for our patients. We strive to change faces, and,

ultimately, to change lives. At Golisano Children's Hospital, we are fortunate to have an experienced, interdisciplinary team that is recognized by the ACPA as well as other medical organizations. To learn more about our team, please visit:

golisano.urmc.edu/craniofacial



What is the Enhanced Recovery after Surgery (ERAS) program?

Enhanced Recovery after Surgery is based on scientific evidence about surgical recovery. We use these standards to get your child back to normal as soon as possible after surgery.

How do we do this?

By changing the way we manage your child's care before and after surgery.

And including **you** as a very important part of the team.

This booklet will:

- Help you prepare for your child's surgery.
- Explain how you play an active part in your child's recovery.



Research shows that your child will recover faster if you do the things explained in this booklet. There are instructions about eating and drinking, physical activity, and pain control. In combination, these things will help your child feel better faster and go home safer and sooner.

Please bring this booklet with you on the day of surgery. Use it as a guide during your child's hospital stay. We may refer to it as your child recovers, and review it with you when you're ready to go home.

Having surgery can be stressful for you and your family. The good news is that you are not alone. We will support you each step of the way, Please ask us if you have questions about your care. We want to be sure to answer all your questions!

Use this space to write down your questions as you go through the booklet. There's more space in the back of the booklet.



Words we use in this booklet

Cleft	A gap or split; divided or partially divided into two parts.
Congenital	Present at birth
Craniofacial (cray-nee-o-FAY-shul)	Applying to the head and face
Genetics	The study of how parents pass certain genes to their children
Incision	Surgical cut
IV (intravenous) (in-tra-VEE-nus)	“In the vein.” A thin, bendable tube that slides into one of your child’s veins. It can stay there for a while. It can be hooked up to tubing that carries fluid or medicine to your child.
Occupational therapist	Specially trained professionals who help patients develop, recover, improve, and maintain the skills needed for daily living and working. A child's main job is playing and learning. Occupational therapists can evaluate kids' skills for playing, school performance, and daily activities and compare them with what is normal for that age group.
Orofacial (or-o-FAY-shul)	Affecting the mouth and the face
Orthognathic (or-tha-NATH-ick) surgery	A surgery performed to move the jaw to correct a condition related to bone structure or growth
Palate (PAL-it)	The roof of the mouth
Speech-language pathologist (SLP)	A highly trained professional who evaluates and treats many types of communication and swallowing problems. This includes speech (how we say sounds and put sounds together) and language (how well we use words).
Suture	A stitch or row of stitches holding together the edges of a wound or surgical incision

What is the palate?

The palate is the roof of the mouth. You can feel your own palate by running your tongue across the top of your mouth. If you open your mouth and look into the mirror, you will see that the palate extends from your teeth all the way back to the uvula (that's the teardrop-shaped piece of soft tissue that hangs down the back of your throat).

The palate:

- Is made of bone and muscle. It's covered by a thin, wet skin that forms the covering inside the mouth.
- Separates your nose from your mouth, like a floor separates the different levels of a house or apartment building.
- Is important for speech. It prevents air from blowing out of your nose instead of your mouth when you talk.
- Is important for eating. It prevents food and liquids from going up into the nose.

What is cleft lip or cleft palate?

A cleft palate occurs when a baby is born with an opening in the roof of the mouth (palate). A baby can be born with a cleft lip, cleft palate, or both. Cleft lip and cleft palate are disabilities that are present at birth (congenital). They occur when a baby's lip or mouth do not form properly during pregnancy. Together, these birth differences commonly are called "orofacial clefts."

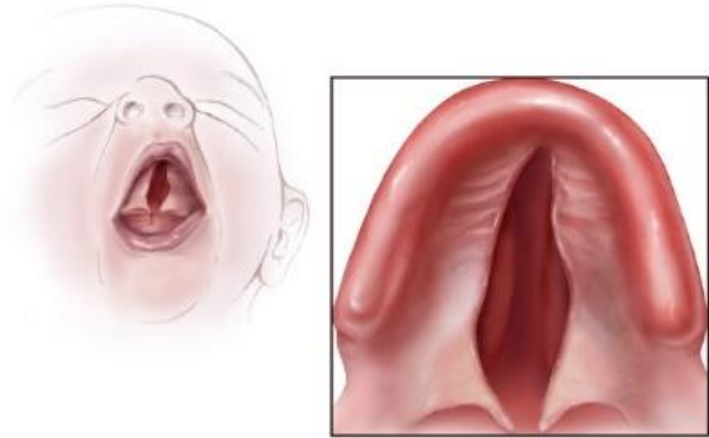
The roof of the mouth (palate) is formed during pregnancy between weeks 6 and 9. A cleft palate happens if the tissue that makes up the roof of the mouth does not join together completely during pregnancy.

For some babies, both the front and back parts of the palate are open. For other babies, only part of the palate is open.

Clefts occur because something in the environment or genetics (a family trait) has affected facial development. It is often difficult to determine the exact cause of a cleft. Clefts occur in all racial and ethnic groups.

Facial clefts occur in about 1 of every 600 births in the United States. They are one of the most common birth differences.

Children with a cleft palate often have problems with feeding and speaking clearly. Ear infections can be a problem, too. They also might have problems with hearing and with their teeth.



Surgery to repair a cleft palate is recommended within the first 18 months of life or earlier if possible. Some children may need other surgeries as they get older. These might include:

- **Speech surgery:** Children can develop speech problems even after the palate has been repaired. At your regular appointments with the cleft team, the speech-language pathologist (SLP) will carefully listen to your child's speech. The SLP works with the doctor to decide if another surgery is needed to improve speech.
- **Orthognathic surgery:** Some children with cleft palate need this surgery to realign the jaws and teeth when they're older. It's done when the child is finished growing.

If the split is not fixed, the child may develop problems with eating, swallowing, talking, and sometimes with hearing. Examples of such problems include food or liquids coming out from the nose while eating, repeated sinus and ear infections, and poor speech that is hard to understand. If the cleft involves the bone of the upper jaw, the child's teeth may also be affected. This can alter the child's ability to chew.

One of the first problems a baby with cleft palate might have is difficulty breathing or eating. Cleft palate usually makes breastfeeding difficult because the infant has difficulty sucking properly. The palate prevents food and liquid from going up the nose when swallowing. To prevent liquid from passing into the nose of a newborn baby with a cleft palate, use a bottle with a special nipple to feed the baby breast milk or formula.

Why do babies with clefts have trouble feeding?

Babies with cleft palate have trouble feeding because of the opening between the nose and mouth. It's hard for them to produce suction to get milk from mother's nipple or pull milk out of a bottle. It may look as though they are sucking, but most of the time they will not be able to get enough nutrition on their own. It's like trying to drink from a straw with a hole in it. You have to suck hard and you get very little out the straw.

Moms can still have skin-to-skin bonding time, breastfeeding experiences, and can pump to provide to the baby with breastmilk. Once their nutrition is provided through bottle feeding, and they are growing well, they can sometimes learn to breastfeed more effectively. If you choose this path, discuss it with the baby's surgeon. Follow up after your baby goes home with UR Medicine Breastfeeding at (585) 276-MILK.

Pacifiers can also be frustrating for infants with cleft palates. Babies cannot create enough suction to hold on to them. Moms can use their breast to sooth the baby after the baby has fed or any time the baby is upset.

We recommend using Dr. Brown's Specialty Feeding System for infants with cleft palates. The Feeding System uses a special bottle. It allows the infant to squash the nipple and get breastmilk or formula even though they cannot suck it out on their own.

Dr. Brown's® Specialty Feeding System

www.drbrownsbaby.com/medical/products/specialty-feeding

Dr. Brown's Specialty Feeding System is a ready-to-use bottle system. It will not work without the INSERT, RESERVOIR, and INFANT-PACED FEEDING VALVE®. The bottle system, nipples, and Infant-Paced Feeding Valve are all BPA and latex free.

How to use Dr. Brown's Natural Flow® Bottle System

1. Fill the bottle to the desired level. The vent will not work properly if you fill the bottle above the FILL LINE WARNING.
2. If you're using breastmilk, thaw it as recommended. Or warm it in the bottle in a warm water bath. If you're using formula, it should be stirred gently (not shaken) to fully dissolve lumps. Lumps can clog nipple holes. When warming the bottle always remove all bottle parts before warming to prevent the vent from leaking fluid if gas forms during warming.

Shaking the bottle may cause the internal vent system to separate and the bottle to leak.

Do not warm the liquid beyond body temperature of 98.6° F (37° C). Always test temperature of liquid before feeding baby. Never warm a bottle in the microwave due to risk of burning.

3. Insert the plastic valve into the nipple.

NOTE: Before using the silicone nipple for the first time, boil it in water for 5 minutes.



4. Make sure the valve is even with the nipple.



5. Insert the nipple into the nipple collar.



6. Make sure the nipple is fully seated.



7. Snap the reservoir fully onto the insert.



8. Place the reservoir into the bottle.



9. Make sure the insert makes full contact with the top of the bottle.



10. Place the nipple collar loosely on the bottle.



11. Be sure to tighten the collar snugly before feeding. Do not over-tighten.
12. Pinch the nipple. Tip the bottle upside down and release the nipple to fill it with milk or formula.
13. Then position the baby to feed.
14. Burp your baby frequently to minimize discomfort from swallowing air.

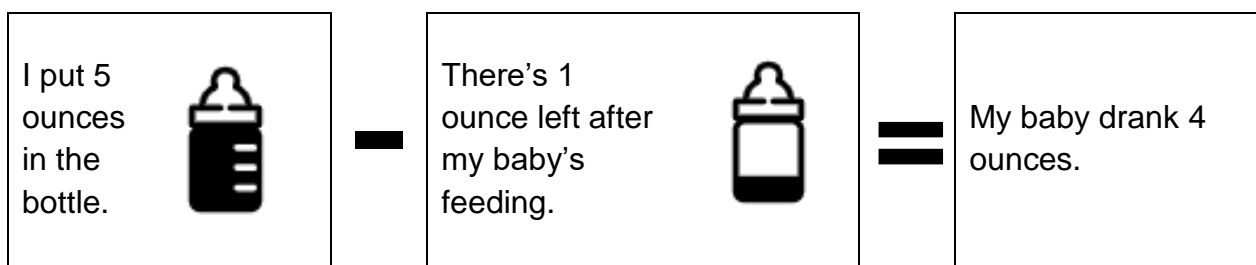
Problem solving

What's happening?	What should I do?
The Feeding System is leaking.	<ul style="list-style-type: none"> • Check the collar. It might be too tight or too loose. • Take the bottle apart and reassemble it. The insert and reservoir may not be properly assembled. • Replace the nipple. It might be damaged.
My baby is sucking but no breastmilk or formula is flowing.	<ul style="list-style-type: none"> • Did you remember to prime the bottle? Check to see if you can pull breastmilk or formula into the nipple by squeezing it, turning the bottle upside down, then releasing the nipple. • There may be something blocking the valve. Wash the valve and try again.

My baby is spitting up.	<ul style="list-style-type: none"> • Make sure you're using the correct flow rate. Too fast or too slow can increase spit ups. • Remember that infants with cleft palates swallow more air than infants without cleft palates. They're going to burp and spit up more because of this. Spitting up and having breastmilk or formula come out of the nose is common.
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How much did my baby drink?

You know how much you put in the bottle to start. Measure what's left in the bottle when your baby is done feeding. Subtract the amount that's left from the amount you started with. The difference is the amount your baby drank during the feeding.



To measure what's left in the bottle:

1. Loosen the ring
2. Leave the assembly mostly together, just loose.
3. Push your thumb nail down on the nipple to push the valve out of the nipple.
4. This will allow the breastmilk or formula to drain from the nipple into the bottle but keep the valve from falling in.

Note: You'll need a syringe to measure amounts less than 30 cc.

How do I clean the Feeding System?

1. Gather everything on a clean work surface.
2. Wash your hands well.
3. Take the Feeding System apart.
4. Wash all parts thoroughly in hot water and detergent. Use the brush supplied with the system on all holes, in the insert and reservoir.
5. Rinse parts thoroughly, making sure that the nipple hole is clean and clear.

6. If you use a dishwasher, keep all parts in the top rack only.

Where can I buy Dr. Brown's Specialty Feeding System?

The best place to buy kits and supplies is Amazon (see QR code below). You can also buy kits and supplies from other places including Target, BuyBuy Baby, and Walmart.



urmc.rochester.edu/childrens-hospital/craniofacial/feeding-cleft

How do we prepare for surgery?

1 day before surgery



Pack a bag for your child. It should include:

- Pajamas and slippers
- Favorite comfort items, such as a blanket or pillow, stuffed animals, and books.





Remember to bring:

- List of your child's allergies
- List of your child's medicines
- Emergency contact numbers
- Insurance card
- Any other important billing information

On the day of surgery

After midnight	Stop feeding solid foods .
6 hours before arrival	Stop feeding baby formula .
4 hours before arrival	Stop feeding breast milk .
It's OK to give your baby clear liquids up to 1 hour before arrival.	

After surgery






	Your child will be sleepy for several hours. Your child will have an IV in place for giving fluids and pain medicines.
	<p>We place no-no® Pediatric Arm Immobilizer restraints on the arms of infants and young children following cleft lip and cleft palate surgery.</p> <p>These restraints are important because they prevent children from bending their elbows and touching surgical repairs.</p> <p>Your child should wear the restraints until we tell you it's OK to remove them, which is usually on the day after surgery.</p>

What happens during my child's recovery at home?

It's common for children to have blood-tinged saliva (spit) for a day or two after surgery. If your child has any vomiting after the surgery, this too may have blood in it. This is normal.

For a week or two after surgery, your child may need extra attention and understanding. Don't worry about "spoiling" your child during this time. It is OK to respond to your child's need for extra holding and comforting.



	<p>Your child's palate is repaired with dissolving stitches. The repair is delicate for several weeks after surgery.</p> <p>To heal well, nothing hard should go into the child's mouth.</p>
	<p>You may offer your child a small amount of water after eating or drinking to wash out the mouth and keep things clean. Otherwise, no wound care is needed.</p>
	<p>You can bathe your child in the tub as usual.</p>
 	<p>It is OK to resume liquids 1-2 days after surgery. This includes yogurt, thin cooked cereals, puddings, ice cream, creamed soups, thin pureed foods, or stage 1 baby foods. Use only a soft spoon. Do not allow the spoon to enter deep into the mouth.</p> <p>It is OK to resume soft foods 2-3 days after surgery. This includes soft cooked fruits and vegetables, noodles, cereal soaked in milk, and bananas. Use only a soft spoon. Do not allow the spoon to enter deep into the mouth.</p> <p>No hard food is allowed for 6 weeks after surgery... no chips, hard cereals, cookies, or toast.</p> <p>Children usually do not eat as much as usual for days or even a week or</p>

two after surgery. Most children eat more and “catch up” once they are feeling better.

It’s important that your child gets enough liquids every day to stay hydrated. You’ll know your child is getting enough to drink if they have a moist mouth, tears in the eyes when crying, and urinate regularly.



For 6 weeks after surgery it is important to ensure that all play is supervised so that **no hard toys** are at risk of damaging the repair. Only soft toys or cloth toys should be used.

Generally, most children are ready to return to daycare about 2 weeks after surgery. If you have concerns or questions about when your child can return, talk with our team. It’s important to review the drinking, eating, and activity restrictions with the daycare. Make sure they have enough supervision to enable a safe environment for healing.

Your child can walk or play calmly after surgery.

They should not run or engage in rough play (like wrestling or climbing) or play with “mouth toys” for one to two weeks after surgery. Your child’s doctor will advise you when your child can safely return to regular play.



Your child may have some mild discomfort at home. If your child is irritable and not feeding well, they may be in pain.

We recommend you give your child pain medication every 3 hours. It is best to alternate acetaminophen (Tylenol) and ibuprofen (Advil/Motrin). An example is provided below, which you can use to keep track of how often your child should get medication.

	Dose	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Tylenol								
Ibuprofen								
Tylenol								
Ibuprofen								
Tylenol								
Ibuprofen								
Tylenol								
Ibuprofen								

If your child's pain is not controlled by these medicines, please call us. We may need to prescribe a stronger medicine.



Keep track of your child's poops (bowel movements). They should return to previous bowel habits. If not, they may be constipated.

Call your child's pediatrician or our office if you think your child is constipated.



Please make an appointment with your surgical team for 2 weeks after surgery, for a follow-up visit.

After this visit, we probably will see you again in about 3 months.

Call us if:

- There's redness, increased swelling, drainage, or bleeding from the incision.
- The suture line comes apart.
- Your child has a fever higher than 101.5° F (taken in the armpit).
- Your child has pain that doesn't get better after you've given the pain medicine.
- Your child is not drinking liquids.
- Your child is vomiting.
- Your child has trouble breathing.



**(585)
275-1000**

Information and Resources

- **Golisano Children’s Hospital Family Resource Library**

libraries.urmc.edu/gch

Monday-Friday, 9 a.m. – 5 p.m.

Golisano Children's Hospital

1st Floor, Room 1-1177

Phone: (585) 275-7710

A librarian can help you:

- Find reliable and helpful health information
- Set up and use MyChart
- Provide a quiet space to read or relax
- Borrow books
- Connect to the Internet using your own device
- Use an iPad or use our PCs

- **Centers for Birth Defects Research and Prevention**

cdc.gov/ncbddd/birthdefects/cbdrp

Collaborates on large studies to understand the causes of and risks for birth defects, including cleft palate.

National Birth Defects Prevention Study

cdc.gov/ncbddd/birthdefects/nbdps.html

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)

cdc.gov/ncbddd/birthdefects/bd-steps.html

- **American Cleft Palate-Craniofacial Association (ACPA) Family Services – Resources for your cleft journey**

cleftline.org/family-resources

ACPA Family Services provides crucial information for parents and families, including: Educational Materials, Feeding Your Baby, and Community Support.

- **The Cleft Lip & Palate Foundation of Smiles**

cleftsmile.org

Provides information and support for individuals and families with cleft lip or palate.

