Better, Faster Recovery from Cleft Lip Surgery

with the Enhanced Recovery after Surgery (ERAS) Program





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, your child, 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 child's 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
Dehydration (dee-hy-DRAY-shun)	When someone loses more fluids than they take in. It means the amount of water in the body has dropped below the level the body needs for health and healing.
Genetics	The study of how parents pass certain genes to their children
Incision (in-SI-zhn)	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 (SOO-chr)	A stitch or row of stitches holding together the edges of a wound or surgical cut.

What is a cleft lip?

The lip forms between week 4 and week 7 of pregnancy. As a baby develops during pregnancy, body tissue and special cells from each side of the head grow toward the center of the face and join together to make the face. This joining of tissue forms the facial features, like the lips and mouth. A cleft lip happens if the tissue that makes up the lip does not join completely before birth. This results in an opening (cleft) in the upper lip.

A cleft lip can be on one side of the lip (unilateral) or on both sides of the lip (bilateral). Orofacial clefts are some of the most common birth differences. A baby can be born with a cleft lip, cleft palate, or both.

A cleft lip could be as small as a tiny notch in the upper lip. It could also be as large as a split or hole that goes up into the nose.

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

Why do cleft lips happen?

The causes of orofacial clefts among most infants are unknown. Cleft lip may be caused by a combination of genetics and other factors. For example, what the mother comes in contact with in her environment, or what the mother eats or drinks, or certain medicines she uses during pregnancy. Cleft lips can occur in any gender or race.

We recommend surgery to repair a cleft lip when your baby is 3-6 months old. Most babies who have a cleft lip have a surgery called cheiloplasty (KY-lo-plass-tee) to repair it. This is done in the hospital while the baby is under general anesthesia (asleep and not feeling pain).

The goals of cleft lip surgery are to:

- Close the cleft.
- Improve the shape and outline of the upper lip and nose.

If the cleft lip is wide, we might other special procedures before the surgery. Cleft lip surgery usually leaves a small scar under the nose.



Baby with cleft lip

Image credit: Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities

Why do babies with clefts have trouble eating and drinking?

Babies with a cleft lip 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 breastmilk to give to their babies. After babies get breastmilk or formula through bottle-feeding, and they are growing well, they can sometimes learn to breastfeed well. 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. 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 lips. 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, stir it gently to fully dissolve lumps. (Do not shake.) Lumps can clog nipple holes. When warming the bottle always remove all bottle parts before warming. This prevents 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 above 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 silicon 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. We call this "priming."
- 13. Then position the baby to feed.
- 14. Burp your baby frequently to reduce discomfort from swallowing air.

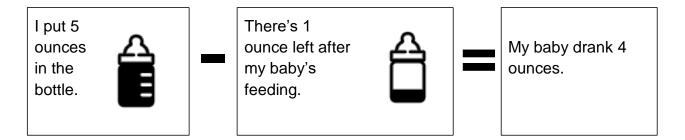
Problem solving

What's happening?	What should I do?		
	Check the collar. It might be too tight or too loose.		
The Feeding System is leaking.	Take the bottle apart and put it back together again. The insert and reservoir may not be connected correctly.		
	Replace the nipple. It might be damaged.		

My baby is sucking but no breastmilk or formula is flowing.	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.	Make sure you're using the correct flow rate. Too fast or too slow can increase spit ups. Remember that infants with cleft lips swallow more air than infants without cleft lips. They're going to burp and spit up more because of this. Spitting up and having breastmilk or formula come out the nose is common.

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

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

When we give your child general anesthesia, there are important rules for eating and drinking before surgery. If you don't follow these rules, your child's surgery may be canceled.

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 hours 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.



When your child wakes up, it's OK to give them something to drink. It's OK to offer formula, breast milk, or clear liquids.

What happens during my child's recovery at home?

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.





Your child's lip is repaired with dissolving stitches. The repair is delicate. It will take 3-4 weeks for the incision to heal.

For it to heal well, put your child to sleep on their back. This will prevent your child from rubbing their lip on a blanket or the crib mattress.



You may gently wipe your child's mouth after feeding with a clean, damp washcloth. 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.



You can bathe your child in the tub as usual.



It's OK to resume **liquids** (and moist, runny foods) 1-2 days after surgery. This includes yogurt, thin cooked cereals, puddings, ice cream, creamed soups, liquid pureed foods, or Stage 1 baby foods. Use only a soft spoon.



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.

Children usually do not eat as much as usual for days or even a week or two after surgery. Most children eat more and "catch up" once they are feeling better. It's important that your child drinks 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, supervise your child's play. **No hard** toys! They could damage the repair. Offer only soft toys or cloth toys. 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 office. 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 may have some mild pain at home. If your child is irritable and not eating or drinking well, they may be in pain. Give your child acetaminophen (Tylenol) around the clock as directed to keep their pain under control. If your child continues with irritability, we have prescribed you a stronger pain medication called Oxycodone (oxy-co-done). Give this medication as directed. We use these medicines to relieve mild to moderate pain and to reduce fever. It is important to take all medicines exactly as prescribed. If your child's pain is not controlled by these medicines, please call us. It's a good idea to schedule a dose of pain medicine around your child's bedtime, especially for the first few days at home. This will help your child sleep better.



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 our office for 2 weeks after surgery, for a follow-up visit if not already scheduled.

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**

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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 lip.

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.

Here's more space to write down your questions and make notes.

