

**I've Just  
Seen a Face**

## Chapter 9

.....

# Birth! What's Next?

### **A Hospital Reference**

*“After You Catch the Baby,  
You Need to Call Us”*

**T**he baby has arrived! Congratulations! A medical professional has probably said, “Your baby was born with a cleft lip and palate.” Some parents heard this phrase weeks or months ago at a prenatal ultrasound. Others learned the news minutes or hours ago, at birth. Yet, here you are, in the hospital, baby in hand. Now, what? What do you do first? What do you do *right now*? Parents and professionals offer the following suggestions.

This is the time to triage, just as the hospitals do. A few tasks can be done now, while you still have hospital resources at your fingertips. Others can safely wait until later. Below, you will find a discussion of three hospital tasks. First, if you have been able to find a cleft team ahead of the birth, you should call them now. If not, this is the time to make initial contact. One cleft-team nurse put it this way: “If the father, partner, or coach is with the mom at the time for the birth, we give them a job. After you catch the baby, you need to call us.” Next, get some help feeding the baby. Then find a lactation consultant, if applicable. You will also find a bonus tip about not learning the news in advance (it’s okay).

## HOSPITAL TASK 1

### *Pick Up the Phone: Call a Team*

Here is a five-minute task that will do a world of good. Parents need to get in touch with a cleft team, a group of specialists who work together to treat a child's cleft lip and/or palate starting at birth (or in some cases, before birth). According to professionals in the field, patients who are treated by teams have better outcomes than those who go to independent providers.

#### **Find a Cleft Team in Your Area**

If you go to only one website, go to the Family Services arm of the American Cleft Palate-Craniofacial Association (ACPA). ACPA Family Services offers reliable information on cleft care and a state-by-state listing of approved cleft teams:

[www.cleftline.org/find-a-team](http://www.cleftline.org/find-a-team)

Why contact these folks now? Many parents and professionals have noticed an information gap between the staff at a birthing hospital and the specialists on a cleft team. Since cleft lip and/or palate occurs in about one in six hundred births, a large birthing hospital may see many cleft-affected babies each year. Some of its staff may know the ins and outs of feeding a cleft-affected newborn and finding the appropriate level of care for her. Wonderful!

A smaller hospital may lack this experience, however, simply from a lack of exposure. One cleft-team nurse in a large city described getting frequent phone calls from birthing hospitals after a baby is born. "Pediatricians call me from outlying hospitals one hundred miles away," she said. Those doctors, she explained, don't always know how to care for a cleft-affected baby in the short term. "I say to them, 'Send me a picture.'" A cleft team can relay information quickly, she continued, to help hospital staff with details on feeding and determining the appropriate level of care in the hospital. If the baby needs the Neonatal Intensive Care Unit

(NICU), the team will confirm it (see more on the NICU in Chapter 10). If the baby belongs in your room, they will confirm that too.

If you didn't know about the clefts in advance of the birth, this is fine. Right now, you need to find and contact a cleft team. The team you contact today may not be the team you choose for your child's long-term care. What matters now is closing the information gap in the hospital. Researching and choosing a team—one that will care for your child over the long term—is a larger task that may be better left for the days and weeks after you get home from the hospital. Then, you can devote some time and careful consideration to making the right choice for you, your baby, and your family (see Chapters 7 and 8 for more information).

Don't want to make the call yourself? One cleft-team nurse suggested that if parents have not connected with a team prenatally, that responsibility could be placed on the staff at the delivery hospital. It is perfectly fine, she said, to ask a staff member: "Could you call the nearest craniofacial center and talk to them?" The key is to ensure that help is on the way in the short term, no matter who makes the call.

One more thing. If you happen to live close to your cleft team, and you contact them right away after the birth, and the timing and logistics (the stars?) are perfectly aligned, you may receive a hospital visit from a person on the team. With a personal visit, the team members can tell you their first impressions of your child's needs. They can connect you with hospital resources, remind you of what to do in the upcoming days, and hopefully, reassure you that you are on the right track. My husband and I received this kind of visit in the hospital, and I'll tell you it made a challenging few days much better.

## HOSPITAL TASK 2

### *Get Some Help Feeding the Baby*

A parent's first task in caring for any baby is to feed her. As you may already know, a cleft-affected baby may require special care

with feeding because of her unique anatomy. A baby born with cleft lip only—with no involvement of the palate—may be able to breast-feed and bottle-feed normally or near normally. A baby born with cleft palate, however, cannot make a perfect seal between the mouth and the nose and, therefore, cannot create suction. Unfortunately, in almost all cases, the presence of cleft palate rules out breast-feeding or sucking from a regular baby bottle.

Some mothers feel sadness and loss at not being able to nurse (see Chapter 15 for more discussion on this topic). Many parents also feel overwhelmed with the task of feeding, including handling a special bottle and reading a baby's physical cues. But don't worry—you will have time to process your feelings, absorb this information, and hone your skills in the upcoming weeks and months. In the meantime, it may be helpful to take advantage of the resources available in the hospital.

**Find an Expert.** While you are still in the hospital, the best way to get started is to seek help from a feeding specialist, and if your baby was born with a cleft palate, get your hands on a special bottle. A feeding specialist at a hospital can usually supply you with such a bottle (if you don't have one already) and give hands-on instruction on how to get started with it. Job titles vary; this person may be referred to as an occupational therapist (or "OT") or a speech-language pathologist (SLP), may work on a newborn feeding team or may be linked with the NICU. Title aside, this specialist offers expertise in feeding newborns with special needs. They can help you learn to feed your baby *right now*—that is, during the time directly following birth, until you meet with the specialist on your child's cleft team. (Note that while many cleft parents said that CLP did not affect the type of formula they used, it is always best to consult with your baby's pediatrician about this choice.)

**Find a Bottle.** Special baby bottles, sometimes referred to as special-needs bottles or cleft-palate feeders, allow a caregiver to

feed a baby born with cleft palate. They can also be useful for babies born with isolated cleft lip (cleft lip only—with no cleft palate), depending on specific anatomy. There are four such bottles currently on the market: the Enfamil Cleft Lip/Palate Nurser by Mead Johnson; the Medela Special Needs Feeder by Medela (formerly called the Haberman Feeder); the Pigeon Bottle by Respironics; and the Dr. Brown's Specialty Feeding System by Dr. Brown's. Each of these bottles has different features and characteristics—and can be purchased online or obtained from a feeding specialist in the hospital (as mentioned). In any case, it is worth repeating: a baby born with cleft palate will not be able to draw milk from a regular baby bottle. (For more information on feeding, see Chapters 12 through 16.)

**Find Even More Help.** Once you've gotten started with a special bottle and had an instructional session with an OT or other feeding specialist in the birthing hospital, don't hesitate to ask for a repeat visit. The key is to get as much help as possible during your stay in the hospital—from an OT you have already met or, perhaps just as useful, from another OT starting a new shift. Remember, some specialists in birthing hospitals have more experience with CLP than others. What's more, each specialist offers a slightly different method, feel, or way of explaining things. For a hands-on technique like feeding a baby, the right explanation can make all the difference.

**Lean on the Team.** If you don't find a groove with any of the OTs at the hospital or with feeding your baby in general, fear not. The feeding specialist on the cleft team, typically a nurse, clinical nurse specialist, or speech-language pathologist, will not only serve as a family's point person for feeding during the baby's first year, but according to many cleft parents, will act as a teacher, troubleshooter, and a wonderful source of support and encouragement. Expert help is at the ready, regardless of what you learn—or don't learn—in the hospital. (This is another reason to pick up the phone and call a team.)

Remember: feeding a cleft-affected baby requires special equipment and assistance. But it often requires trial and error, time, and patience as well. Feeding can be a specialized affair. If you don't get the hang of a particular bottle or feeding system right away, keep at it. Specialists on cleft teams will assure you: these bottles can do the job. You can do the job! This task is doable.

### HOSPITAL TASK 3

#### ***Pumping Milk? Find a Lactation Consultant***

Nursing and pumping breast milk can pose all sorts of unforeseen challenges to a mother. Clefts may add a few more. If you plan to breast-feed your baby (for a baby with an isolated cleft lip) or pump breast milk, it may be helpful to find a lactation consultant at your hospital.

***Learn about Breast-Feeding (Isolated Cleft Lip).*** A lactation consultant in the hospital will be able to show you special ways to position the breast tissue to accommodate the wide opening of the baby's upper lip. She may also make recommendations on suitable accessories or techniques to help minimize the leakage of air, a common problem for babies with isolated CL.

***Learn about Exclusive Pumping.*** A lactation consultant can also offer practical instruction related to *exclusive pumping*, the act of squeezing (or *expressing*) milk from the breast to deliver to the baby through another means (usually a bottle). She may give advice on techniques and accessories and provide information on how to rent a hospital-grade breast pump, a must-have if you plan to pump milk.

It is important to note that *exclusive* pumping is different from the more common practice of *supplemental* pumping. With *exclusive* pumping, the baby never feeds directly from the breast—in this case, because they are unable to draw milk. And because a single person may or may not be able to pump milk and bottle-feed

at the same time (depending on a few factors), the mothers (and families) who take on this extraordinary endeavor will nearly double their time commitment to feeding the baby. So, while exclusive pumping requires time and special equipment to start, it also requires determination and, as many parents have mentioned, logistical and emotional support.

If you make a meaningful connection with a particular lactation consultant, don't forget to ask if they accept calls after you return home. These specialists rotate shifts and may not be in the hospital from one day to the next. Does this person have a direct number? Would it be possible to return to the hospital in the upcoming days and weeks for another in-person consultation if necessary? Many hospitals also have 24–7 hotlines for feeding specialists and/or lactation consultants who can help with the critical few days following your return home.

### BONUS TIP

#### ***For Parents Who Learn the News of CLP at Birth***

It's okay to feel overwhelmed at not learning this news in advance. Parents who found out about their baby's clefts prenatally have had some time to prepare for birth, logistically and emotionally. Those who learned at birth are still processing the news. Many feel shocked. "I was so traumatized in the hospital," said one mother about the few days after learning the news of her son's CLP. "We had all these friends who wanted to visit, and we were such a mess."

As upsetting as the news may feel, it is important to know that medical professionals, particularly those on the cleft team, are ready to help—whenever you happen to contact them. You have not missed the bus. One mother, Amanda, recalled receiving questions from friends and family about how she felt to have learned the news of her son's condition at birth rather than via prenatal ultrasound. "A lot of people say to me, 'I bet you were mad that you didn't know the news in advance,'" she said. Despite those comments—and

despite her rush to learn about cleft care following her son's birth—Amanda felt okay about the situation and the way she learned the news. “You know what?” she continued. “After the birth, we found out what we needed to know.” There is time.

The act of giving birth itself can feel momentous and overwhelming, clefts and other news aside. And the hustle and bustle of a birthing unit or NICU can heighten those feelings. Whether you learned the news in advance or are just finding out now, the key is to do your best to get the help you need—whenever that may happen—so you will also have time to rest, recover, and get to know your newest family member.

## Chapter 10

.....

# Birth and the NICU

## Speaking Up for Appropriate Care

The Neonatal Intensive Care Unit, or NICU, is an area in a hospital where some babies go directly after birth for help with extraordinary health needs. A NICU (often pronounced “NICK-you”) provides sophisticated equipment and specially trained staff who can help babies born with low birth weight, breathing problems, infections, and other special medical concerns.

Many expectant parents wonder whether a baby born with cleft lip and palate will need to go to the NICU after birth. The short answer? Probably not. The longer answer? Maybe—it depends on several factors. We'll explore some of those factors here. The most important advice from professionals on cleft teams, however, is for parents to know about the notion of *appropriate care* in the hospital—the concept of seeking just the right amount of medical intervention—and to speak up and ask questions on behalf of your baby to make sure that happens.

### Why the NICU?

The professionals I spoke with on cleft teams have explained that, in most cases, babies born with CLP will not need to go to the NICU. “I tell parents that if there are no other issues, they should expect normal everything,” commented one clinical nurse specialist. “For a cleft only, most of the time, you would not end up in the NICU.”