



## NICU Experience: Questions from Parents of Babies with Spina Bifida

Babies born with Spina Bifida are delivered at, or immediately transferred to, a hospital that has a Level IV Neonatal Intensive Care Unit (NICU), where surgeons can repair complex conditions including Spina Bifida. The NICU can be a stressful experience for new parents, but being prepared and informed can improve your confidence as you navigate the NICU and prepare to bring your baby home. Some of parents' most common questions are answered here.

### What can I do to prepare for my baby's birth?

Today, most parents learn of their child's Spina Bifida diagnosis at some point during the pregnancy and have time to research and prepare for their baby's birth and NICU stay. Ideally, you will be able to meet with a pediatric neurosurgeon and other healthcare providers who are experienced in caring for people with Spina Bifida long term to discuss your baby's particular diagnosis before your baby is born. Together, the neurosurgeon, maternal-fetal medicine specialist, and you can decide on a birth plan that is safe and preferable for all involved, including choosing between fetal versus postnatal surgery, vaginal or cesarean delivery, when to deliver your baby, and other options.

If possible, schedule a tour of the NICU and speak with the neonatologist, who is the specialist for newborns in the NICU. This visit will allow you to see where your baby will be cared for and to learn more about the NICU, such as:

- visiting hours and guidelines for visits by friends and family
- where you can pump and store breastmilk
- what supplies you should bring for the baby and what is provided by the NICU
- visitor parking permits, overnight rooms for parents, hospital meals, etc.

During these visits, you may also ask about particular policies and preferences that will determine when you will be able to breastfeed or bottle feed, when you will be able to hold your baby and the criteria for discharge from the NICU. Every case is different, and decisions on these matters will vary based on your baby's individual circumstances.

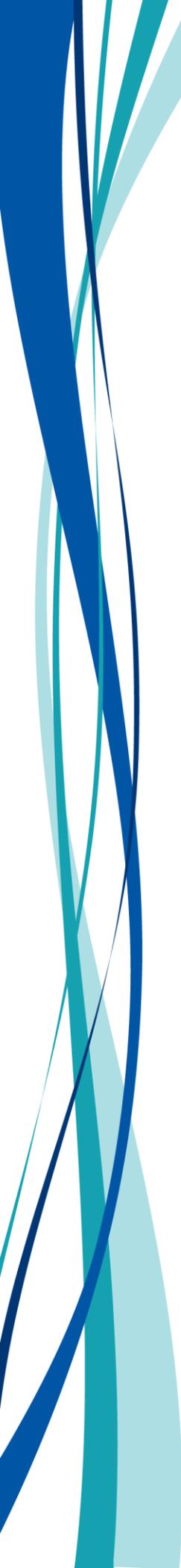
While you wait for your baby's arrival, you may also want to engage in typical activities that take place during pregnancy. For instance, you can take breastfeeding, CPR, and child passenger safety and car seat installation classes offered locally or at your hospital. Allow your friends and loved ones to throw you a baby shower. Take maternity photos.

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Go on a “babymoon” trip. Essentially, take part in whatever activities you would have done if you had not received the Spina Bifida diagnosis. Remember that first and foremost your baby will be just that—a baby whose primary needs will be nourishment, safety and love. He or she may just happen to have additional needs due to Spina Bifida.

### **What do I do if my baby was diagnosed at birth?**

Even with all of today’s prenatal testing and imaging technology, there are still some parents who learn of their baby’s Spina Bifida diagnosis at or shortly after the birth. If you are one of those parents, you are understandably shocked and scared of what this diagnosis may mean for your child. It’s going to be okay. You will need to change some plans about when your baby will come home, and you may need a crash course on Spina Bifida as well as NICU life. But your baby will be well cared for while you learn. Along with your baby’s medical team, the Spina Bifida Association will be a great source of information and support.

### **What should I pack for my baby’s NICU stay?**

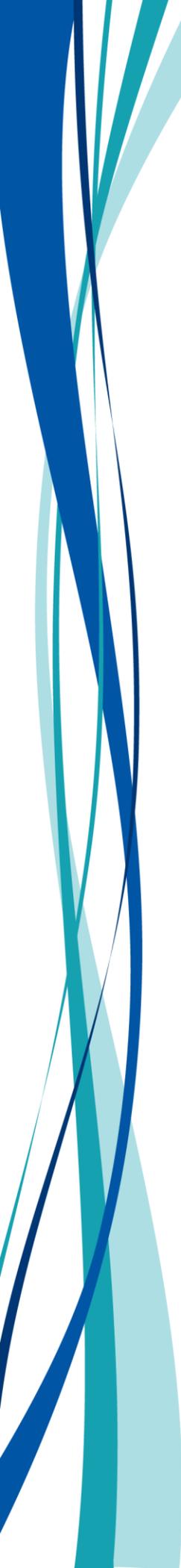
Most hospitals supply diapers, formula (if needed), pacifiers, clothes, and all medical supplies. In most cases, babies who are recovering from surgery will wear only a diaper because they may be connected to monitors with wires and have an IV, and clothing can get in the way. Toward the end of your baby’s NICU stay, it may be more possible for your baby to wear clothing. Although it is not necessary, some parents bring their own personal items and pictures from home to decorate the isolette or crib. This helps remind everyone who visits the bedside that this baby is not just a patient—he or she is someone’s beloved child. Keep in mind that it is very common for these items to be lost during cleaning, so be sure to write the baby’s last name on all personal items and bring only things that can be replaced. The only necessary items to eventually bring for your baby are something to wear home and a car seat.

### **What will my baby’s birth and surgery be like?**

Doctors typically prefer to schedule births for babies with Spina Bifida at some point between 37-39 weeks (compared to 40 weeks for babies without Spina Bifida) so the entire team can be prepared for the baby’s arrival and surgery. Babies who had open fetal surgery are delivered even earlier due to the risk of uterine rupture.

Depending on the doctor's preferences and experiences, as well as the individual health needs of the mother and the baby, some babies may be delivered vaginally. Most are delivered via cesarean section, and mothers and babies who underwent open fetal surgery must deliver by cesarean section.

If the baby is deemed stable at birth, you will be able to see him or her before being taken to the NICU for a full assessment. Babies who have not had prenatal surgery will typically have an operation within 24 to 48 hours after birth (depending on the baby’s



condition and the availability of the pediatric neurosurgeon) to close an open myelomeningocele lesion, thus helping to prevent infection and further damage to the spinal cord. Most closure surgeries take about four hours, but the duration can vary widely depending on the individual baby's case. After surgery, the baby will need to lie on his or her belly with the head at the same level as the back for several days or weeks until the incision is well healed.

### **When will I be able to hold my baby?**

The doctors and nurses should make every effort to allow you to hold your baby as soon as it is safe. In some cases, you can very briefly hold the baby before he or she is taken to the NICU. Sometimes you can hold the baby (carefully wrapped) later that day or the next day before the closure surgery. In the days soon after the back surgery, you may be allowed to hold your baby prone on a pillow on your lap -- only in the NICU or by physician order if you are home, and only for feeding.

In some cases, it could be two or more weeks before the baby can be held. Although this is difficult for parents to imagine, remember that even when babies can't be held, parents can still touch them, hold their hands, stroke those tiny feet, kiss their chubby cheeks, change their diapers, talk and sing to them, and care for them in many other ways. The first time parents hold their baby, even if the baby is two weeks old, will be just as special (if not more) as if it was moments after birth.

### **Will I be able to breastfeed?**

While breastmilk has known benefits for all babies, its antibodies, proteins, and immune cells are especially beneficial to those recovering from surgery and in a hospital setting. Breastmilk is also extremely helpful in managing constipation, which is more common in babies with Spina Bifida. For this reason, from the first day and throughout the NICU stay, mothers will be encouraged to pump colostrum and breastmilk using a hospital-grade breast pump, which is usually provided by the NICU, antepartum floor, or lactation consultant.

In preparation for surgery, the baby may not yet be able to take a bottle. But the mother will be able to store breastmilk in the NICU until the baby is ready to drink either by a nasogastric (NG) tube or bottle. Many mothers are able to start nursing while their baby is still in the NICU, either by standing and leaning over the isolette or by placing the baby on a pillow in the mother's lap. However, some mothers are only able to pump and feed their milk during the NICU stay and later transition to nursing when they get home. Many moms prefer to wear a nursing tank under a loose shirt for easy and discreet pumping and nursing while they are in their hospital room, by the baby's bedside, or in designated pumping rooms.

## How long will our baby be in the NICU?

The average NICU stay for babies with Spina Bifida is about two weeks, but this can vary from a few days to several months depending on the specifics of the baby's medical condition. In some hospitals, babies will spend a few days in the NICU and then be transferred to another floor of the hospital for the remainder of their stay.

## What other procedures do babies with Spina Bifida need while in the NICU?

Sometimes a baby who is born with moderate to severe hydrocephalus will also receive a shunt (a long, thin tube that diverts extra cerebrospinal fluid from the ventricles of the brain to another part of the body, usually the abdomen) during the initial back closure surgery. But in most cases, the pediatric neurosurgeon will perform surgery to close the back, and then wait and watch carefully to see if the baby shows signs of needing an intervention for hydrocephalus. These symptoms may include increasing ventricle size, "sunsetting" eyes, vomiting, excessive sleeping for a newborn, or the leaking of cerebrospinal fluid from the back incision. Some babies will receive a shunt or another procedure called the Endoscopic Third Ventriculostomy (ETV) before they leave the NICU. Others may be several months old before they need an intervention for hydrocephalus. And still others will never need an intervention for hydrocephalus.

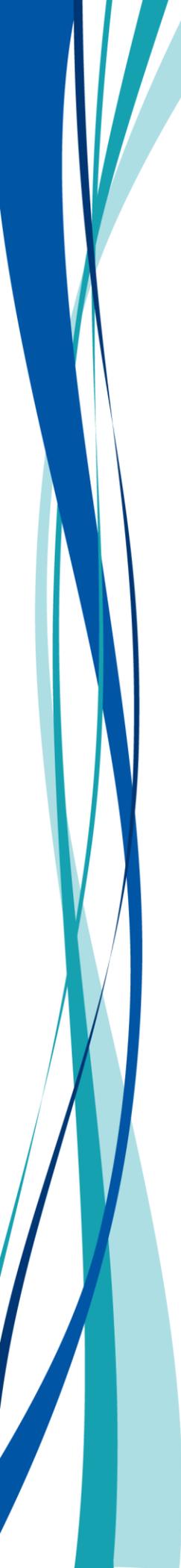
While the baby is in the hospital, doctors may order different procedures and tests. These could include:

- Magnetic resonance imaging (MRI), computed tomography (CT) scan and/or cranial ultrasound to monitor the ventricles in the brain
- Renal ultrasound and perhaps VCUG (Voiding Cystourethrogram) to assess bladder function and kidney health.
- Parents of boys may request for their sons to be circumcised while still in the hospital.

Other procedures may also be necessary depending on the baby's needs.

## What specialists will treat my baby while in the NICU?

One of the most important first lessons parents will need to learn is to identify each of the specialists and what they do. There may be many physicians, residents, interns, students, nurses, and therapists coming in the room throughout the day. This can be overwhelming and confusing until you figure out who makes the decisions, who can answer your various types of questions, and at what time each of them makes their daily rounds.



The **neonatologist** will likely make daily rounds to check the overall health and progress of your baby. You can ask this specialist about feeding, weight, growth, and other general baby care questions.

The **neurosurgeon** is a very important member of the baby's team from day one and throughout the baby's life. This will be the go-to person for any questions about the back closure surgery, signs of hydrocephalus, and neurological function.

A **urologist** will likely be involved in the baby's care in the NICU and also long term. Most NICUs catheterize babies born with Spina Bifida for at least the first few days to help assess and monitor bladder function and decide whether catheterization should be continued after discharge. Pediatric urologists are often the specialists most knowledgeable about bowel function in babies with Spina Bifida. (Gastroenterologists also specialize in bowel function, but are often less familiar with the treatment and management of bowels affected by Spina Bifida.)

An **orthopedic surgeon** may stop by to assess the baby for clubbed feet or other orthopedic concerns. Most orthopedic issues will be treated later on during follow-up care.

Sometimes a **physical therapist** will visit to do some stretches on the baby and provide parents with initial exercise ideas until early intervention services can begin at home.

**NICU nurses** also play a critical role in your baby's day-to-day care. Because the interaction between parents and babies is important and builds the parents' confidence in their ability to care for the baby after discharge, NICU nurses can help teach you how to safely take over the routine care for your baby. Each baby in the NICU is assigned to a nurse who typically cares for one to four patients per shift. Most babies are placed on a feeding and assessment schedule, and your nurse will be able to tell you when your baby is scheduled for an assessment (usually every three to four hours). That is an excellent time to get a better look at your baby, watch what the nurses do, and ask questions as you observe your baby. You can also ask your baby's nurse for suggestions on how to navigate the hospital system and to whom you should direct your questions when you are unsure of any aspect of your baby's care.

Other specialties will be involved as needed to meet with the family during their initial hospital stay, answer questions, and consult with the primary team. These may include occupational therapy, plastic surgery, nephrology, respiratory therapy, pulmonology, cardiology, nutrition, neurology, wound care, genetics, speech therapy, general pediatrics, developmental behavioral pediatrics, rehab medicine, Spina Bifida clinic coordinator, and others.

Remember that you are an equal member of your child's care team. Your concerns matter and your questions need to be addressed. As the parent, you rely on the expertise of the medical team, but you ultimately make decisions for your baby.

## What resources will be available to us?

Ideally, you will have learned about the resources available at your hospital when you toured the NICU during the pregnancy. Some hospitals have a limited number of parent suites, but many are located near Ronald McDonald Houses or similar temporary housing facilities that allow parents to stay close to the hospital. Some hospitals provide meals for nursing mothers. Lactation consultants can help establish breastfeeding and pumping routines and troubleshoot problems.

You should always feel free to ask for a social worker to help you identify resources and solve problems you experience. A social worker should also help you apply for benefits such as Supplemental Security Income (SSI), Medicaid, and any other government assistance programs for which you might qualify. Even if you do not believe you qualify for SSI based on your income, it is always a good idea to apply because you may receive a one-time payment for the time period your child was in the NICU. Additionally, your denial letter may help when applying for other benefits at a later date.

In some areas, parents with babies in the NICU receive visits from other parents of children with Spina Bifida, representatives of their local Spina Bifida Association chapter, a mentor for parents with babies in the NICU, or on-site parent support groups.

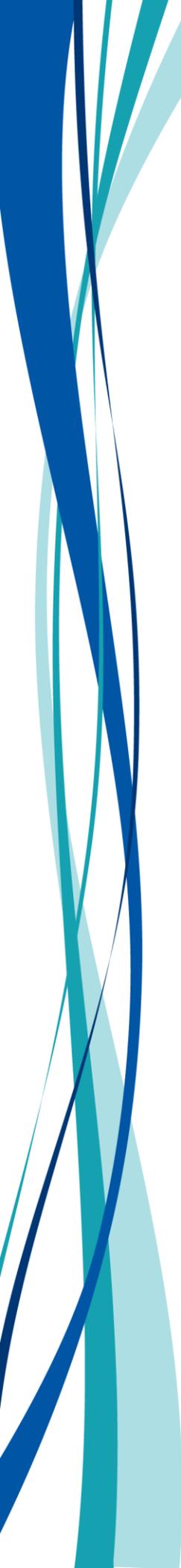
Other resources may include child life specialists to help with siblings, parking or transportation financial assistance, translation services, and others as available and needed.

## What are the criteria for being discharged?

All babies receive a hearing test and newborn screening for certain medical conditions and must pass a car seat test before leaving. Most babies go home in a typical infant car seat, but occasionally the medical team is not comfortable with the baby lying on his or her back for prolonged periods. In this case, a special car bed may be needed, and these are often provided by the hospital or paid for by insurance.

Parents must usually watch the hospital-required education videos about preventing shaken baby syndrome, how to do CPR, and other selected topics. The neonatologist will want to make sure your baby is eating well, gaining weight, regulating his or her own body temperature, and is generally healthy enough to go home. The urologist will ensure that the baby has had all necessary tests and is voiding well on his or her own, or that the parents have been taught how to catheterize. The neurosurgeon must be certain that the baby's hydrocephalus (if present) is stable and, along with the plastic surgeon (if involved), that the back incision is well healed. Parents must be educated on recognizing the signs of hydrocephalus and when to call the doctor or return to the hospital.

At discharge, the social worker and/or nurse will help you set up follow-up appointments with the Spina Bifida Clinic or individual specialists, as well as order any needed



supplies such as catheters. They can also make referrals to your state’s early intervention program and other needed resources.

Many parents describe their baby’s time in the NICU as “one step forward, two steps back.” One day the doctors may be discussing discharge, and the next day there could be setbacks that delay plans. Everyone could be worried about the baby one morning and by that night the baby is well enough for the NICU care team to determine that the baby can be discharged the next morning.

Unfortunately, this is a normal NICU experience, and even the most flexible parents can become flustered by the instability of their best laid plans.

### **What is it like to bring the baby home?**

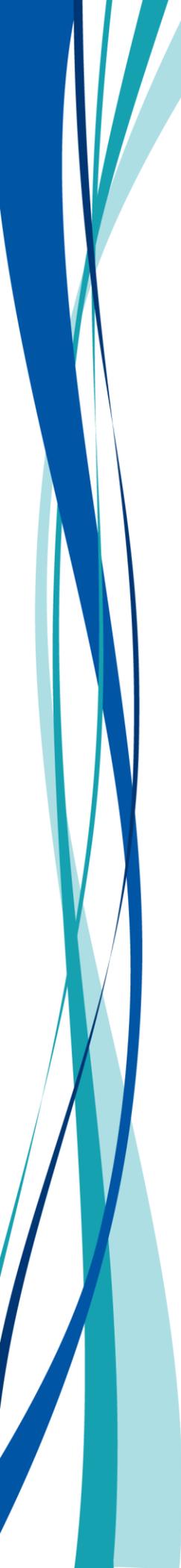
Parents spend the entire NICU stay learning how to care for their baby and looking forward to bringing their baby home. But when discharge day arrives, their excitement and relief can also be mixed with anxiety. For the first time, there won’t be round-the-clock healthcare providers to care for your baby, answer your questions, and calm every fear. First-time parents realize (as all first-time parents do) that they will be solely responsible for caring for their baby, and those with other children at home worry about how they will care for the new baby along with their other children. These are all very normal fears. It may not be easy, but you can do this! You will do whatever is necessary for this precious baby whom you love so much already.

The first day home will hopefully feel like a huge relief. You did it! You made it through the hardest parts of having a baby with Spina Bifida—the pregnancy and the NICU. There may be challenges ahead, but for now your family is all under one roof, and these are the days you have been dreaming of for months or even years.

Of course it can also be a big adjustment. There will be people to call, appointments to make, prescriptions to fill, diapers to change, and a schedule to keep. Many parents say one perk of their baby being in the NICU is that he or she is already on a three-hour feeding schedule, which is often maintained at home. Friends and family may be eager to visit you and the baby during the first few days at home, but you should protect your time as best as possible so that you can rest and begin recovering physically and emotionally from your stressful experience in the NICU.

### **What will the first weeks and months at home be like?**

For any parents of newborns, the first few weeks at home are a blur of feeding, changing, washing bottles, first pediatrician appointment, sleepless nights and ultimately, falling in love with your baby. It is very much the same for babies with Spina Bifida, but there can be some additional tasks and challenges.



Some parents will learn to catheterize their baby's bladder, which can be daunting at first, but becomes second nature after only a couple of weeks. Some babies come home with perfectly healed incisions, but others still need wound care—either by the parents who have been trained in the NICU or by a home health nurse who visits the home. It can be stressful to monitor the baby's head circumference and watch for signs of hydrocephalus or shunt malfunction. And as the weeks turn into months, parents need to be aware of signs of constipation. As anxious as you may be about health concerns, it is equally important to focus on bonding with your baby. Enjoy and love your baby while getting used to your new normal with a new family member. Cuddle, sing, read aloud, and spend time with your baby. In time, you will likely see just how much your baby is like any other baby, rather than focusing on the Spina Bifida.

At about the three-month mark, or sooner if there are concerns, your baby will need to see the Spina Bifida specialists. The neurosurgeon will continue to monitor for hydrocephalus and check neurological outcomes to date. The urologist will probably want tests to check bladder function. The orthopedist will examine the baby's legs and begin treatment in the case of clubfoot. The pediatrician and in some cases rehab medicine doctors will help monitor function, growth, and development. You may also begin assessments and treatment by your state's early intervention program, which may include physical therapy, occupational therapy, developmental intervention and more. Early therapies can help your baby stay on track developmentally, and the programs are typically beneficial to the whole family.

Very soon, you will be the expert on your child, their biggest cheerleader, and their best advocate. Learn all you can from doctors and research, and find local and online communities of parents with children who have Spina Bifida. Try to enjoy and love your baby today instead of worrying about what tomorrow will bring. You don't have to solve the next 18 years of challenges right now. Focus on today and what your baby needs right now. Most of the time, all your baby really needs is you.

## Contributors

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**Members of Spina Bifida Kids**, a [Babycenter.com](http://www.babycenter.com) message board for parents and newly-diagnosed parents of children with Spina Bifida.

### **Spina Bifida Association**

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**CONNECT2NICU Family Advisory Committee**, whose role is to ensure that the decisions and direction of the organization are relevant to the families and communities they serve.

