# NICU Guide for Parents of Babies with Spina Bifida

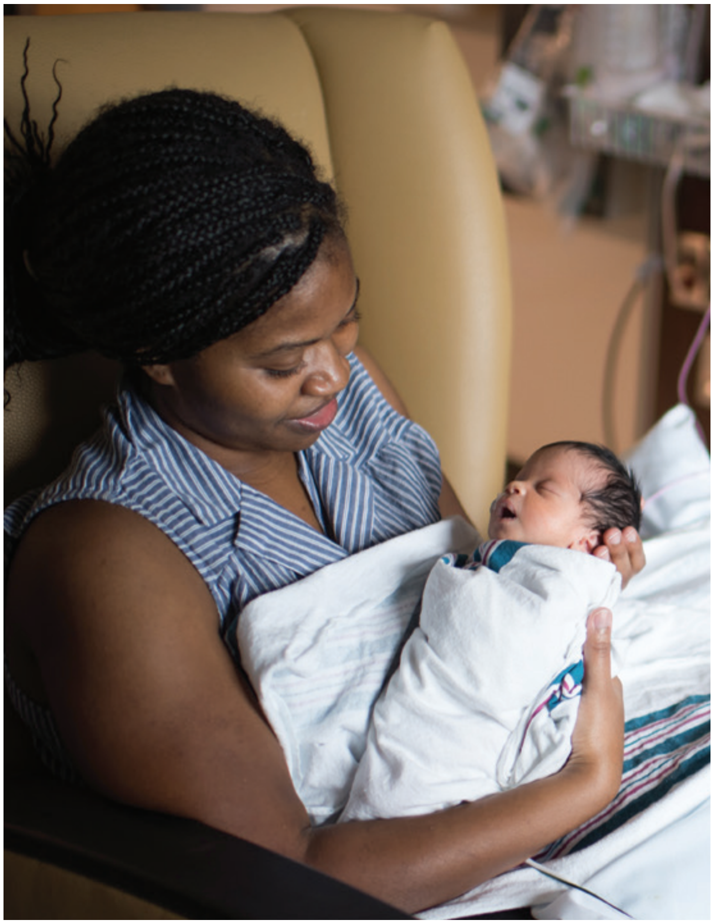
**Babies born with Spina Bifida are delivered at, or immediately transferred to, a hospital that has a Neonatal Intensive Care Unit (NICU) where babies can get around-the-clock specialized care from experts.**

Congratulations on the birth of your new baby! Having a baby in the NICU can be quite a rollercoaster for parents. The joy of finally meeting your baby after months of anticipation is mixed with the stress of having a baby in the hospital and maternal postpartum hormones. Being prepared and informed can improve your confidence as you navigate the NICU and prepare to bring your baby home.

## Preparing

If possible, schedule a tour of the NICU in advance to see where your baby will be cared for and learn about the rules and resources, such as:

- Visiting hours and guidelines for visits
- How to access a lactation consultant and where you can pump and store breast milk
- What supplies you should bring for the baby and what is provided by the NICU
- Parking permits, overnight rooms for parents or nearby accommodations, and hospital meals
- Interpreter assistance
- Policies or preferences about when you can feed and hold your baby
- Criteria for going home



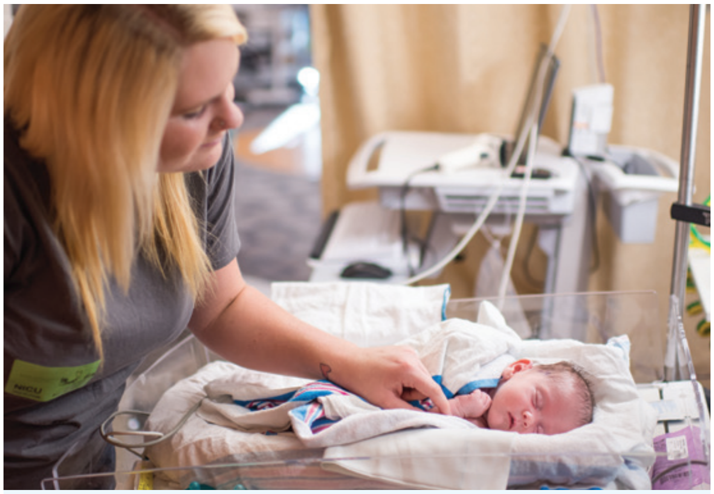
## Diagnosis at birth

**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 birth.** If you are one of those parents, you are understandably shocked and afraid of what this diagnosis may mean for your child. 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.

### What to pack

**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 clothing can get in the way of sensors and wires that monitor their status.**

Although it is not necessary, some parents bring their own personal items and pictures from home to decorate the isolette or crib. 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.



If your baby needs to be moved to another hospital, the other parent or someone else can go along and keep you informed. Ask for the NICU phone number so you can regularly check in with your baby's nurse.

### Seeing baby at birth

**Unless there is a medical emergency, you should be able to see your baby before he or she is taken to the NICU.**

Babies who have already had prenatal surgery will be assessed to make sure the back incision is well healed and the baby is stable enough to be held. **Premature babies** may also need help breathing, feeding, and/or body temperature regulation.

Babies who have **postnatal surgery** typically have their back closure operation within 24 to 48 hours after birth. Sometimes you can hold the baby (carefully wrapped) before the closure surgery. In the days soon after back surgery, a nurse may help you hold your baby prone or side lying on a pillow on your lap. You will be allowed to hold your baby as soon as it is safe.

Even when babies can't be picked up, parents can still hold their hands, touch their little feet, kiss their cheeks, change their diapers, talk and sing to them, and care for them in many other ways. The first time parents hold their baby, no matter how long it takes, will be just as special (if not more) as if it was moments after birth.

## Feeding

Whether by breast or bottle, feeding your baby is a special time for you to bond with him or her while in the NICU. In preparation for surgery (or for other reasons), your baby may not be able to nurse or take a bottle at first, but the NICU will safely store your milk to be given by bottle or nasogastric (NG) tube later. Parents are encouraged to pump colostrum and breast milk using a hospital grade breast pump, which is usually provided by the NICU, antepartum floor, or lactation consultant. While breast milk 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. Breast milk is also helpful in preventing constipation, which becomes common in babies with Spina Bifida later on, after starting solids.

**Some parents are able to start nursing while their baby is still in the NICU, either by standing and leaning over the isolette or on a lap pillow; others pump and feed during the NICU stay and transition to nursing when they get home.**

For those who formula-feed, work with your neonatologist or pediatrician to find the most appropriate formula for your baby. Due to slower moving bowels, some babies with Spina Bifida do best with a "gentle" formula.

## Length of Stay

**The average NICU stay for babies with Spina Bifida is about two weeks, but this can vary from a few days to several weeks 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.

## Specialists

There will be many providers visiting your baby every day. This can be overwhelming and confusing to parents until they learn what issues each specialty focuses on, whom to ask questions about which body system, who makes decisions, and when each specialty rounds for the day.

- 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 your child'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 at home.
- An orthopedic surgeon may assess the baby for clubbed feet or other orthopedic concerns, but most orthopedic issues will be treated later on during follow-up care.
- NICU nurses perform routine checks of your baby every few hours. This is an excellent time to ask questions and learn about caring for your baby's needs. They will help you start to take over the care so you are confident when you take your baby home. You can also ask your baby's nurse questions about navigating the hospital system and to whom to direct your questions if you are unsure.

Other specialties will be involved as needed during the initial hospital stay to meet with the family, answer questions, and consult with the primary care team. Parents rely on the expertise of their babies' specialists, but remember that you are an equal member of your child's care team and your questions and concerns matter.

# Going home

**The NICU experience is often described as "one step forward, two steps back." One day the baby could make great progress and the next day have a setback. One week you may be discussing plans to go home, and the next week those plans could be delayed. Try to take it one day at a time.**

Before going home, babies may need to receive a hearing test, newborn screening for certain medical conditions, and pass a car seat test. Babies should be eating well, gaining weight, regulating body temperature, and be generally healthy enough to go home. Parents may need to watch hospital-required education videos about Shaken Baby Syndrome, baby CPR, and other topics. In addition, babies with Spina Bifida often need certain tests while in the NICU. These could include:

- Magnetic resonance imaging (MRI), computed tomography (CT) scan and/or cranial ultrasound to monitor the size of the ventricles in the brain.
- Renal ultrasound and perhaps VCUG (Voiding Cystourethrogram) to assess bladder function and kidney health.

Parents of boys may request circumcision while still in the hospital, and other procedures may also be necessary depending on the baby's needs.

Your baby's team will make sure the back incision is healing well, hydrocephalus (if present) is stable and parents recognize the signs of hydrocephalus, and the bladder is voiding well or that parents have been taught how to catheterize.

Most babies go home in a typical infant car seat, but sometimes the medical team prefers for the baby to lie on his or her back or side in a special car bed. These are often provided by the hospital or paid for by insurance.

At discharge, the social worker and/or nurse will help you set up follow-up appointments with the Spina Bifida Clinic or individual specialists and order any needed supplies such as catheters. They can also make referrals to your state's early intervention program and help you apply for benefits such as Supplemental Security Income (SSI) and Medicaid.

# Ongoing Support

Even after leaving the NICU, you will have a team of specialists to help you and your baby, and you will continue to build this team over the years. The Spina Bifida Association will also be a helpful resource for information, connections to the community, and support throughout your baby's lifetime.

SPINA BIFIDA ASSOCIATION

**Our mission is to build a better and brighter future for all those impacted by Spina Bifida.**

# Additional information

## For more information and lifelong support, connect with the Spina Bifida Association at:

*spinabifidaassociation.org*, or by contacting the SBA National Resource Center at **(800) 621-3141, ext. 800** or *sbaa@sbaa.org*.

**If you're an expectant parent, scan for more information and resources just for you.**

The Spina Bifida Association would like to acknowledge and thank the Spina Bifida "Diagnosis to Three Months" working group who contributed to this project. Among this group are distinguished clinicians, adults with Spina Bifida, parents of children with Spina Bifida, and SBA chapter leaders.

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