

# TIPS FOR PARENTS OF A NICU BABY



\*The following are general tips based on our experience and not to be a replacement for common sense or a medical professional's advice. Please also see the general tips for parents of a newborn in addition to this list for more tips!\*

## **Before baby is home:**

- Try to find out what most parents who have a baby in NICU end up facing, even after the NICU journey, so you can be best prepared. Also, every baby's NICU stay is different - some shorter and others longer - so be prepared for the unexpected.
- You may or may not be told up front while in the NICU, but if your baby was born very premature, baby should qualify for SSI and subsequently, Medicaid as well - just for qualifying for SSI - automatically.
- Get your baby signed up for SSI as soon as you can. This is a really time consuming process and can be difficult having to jump through the hoops for, but you are much better off getting this out of the way sooner than later. SSI must be approved, so you will have to do a phone interview most likely.
- Even before you get a single hospital bill, make sure you talk to someone in billing and tell ask to see if your baby is covered by Medicaid! All they have to do is look up your baby's social security number. Even if you have not received a Medicaid card in the mail, every bill should be covered by it if your baby was approved for SSI due to premature birth.
- Depending on the NICU stay, how far you live from the NICU, and you/your spouse's work schedule, you'll want to try to stay up to date as often as possible. Figure out a reasonable way for taking turns visiting. Some NICU's even offer video calls with a nurse that is caring for your baby!
- I highly recommend bringing your own food for visits.
- You will likely be pumping milk for your baby while you visit; they should have a pump available in your baby's room, but you'll need to bring your own supplies. Make sure to bring a cooler bag in case you unexpectedly have to take milk home.

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## **Before baby is home (continued):**

- If you have been giving lots of milk pumped to the NICU staff, and you have not been able to keep track of how much was used, be sure to find out BEFORE a visit if they already have enough of your milk on hand for the time being until another visit. If not, they will likely use donated milk or possibly formula if they haven't already been doing that.
- On the same note, if your baby had a very long NICU stay and you were giving them tons of milk over time, there is a rare but possible case that a bunch of your milk was stored in a deep freezer somewhere and forgotten about. Be prepared with a large cooler just in case that happens to be you.

## **After baby is home:**

- If your baby was sent home without any extra medical needs (supplemental oxygen, feeding tube, etc.) then congratulations, I'm so happy for you! If, however, your baby was sent home with special equipment, I understand how hard it can be; try to stay optimistic in light of the hopefully temporary circumstance.
- When you are about to leave the hospital, they should have already went over how to use any medical equipment, but you will want to get yourself familiarized with it at home. Find a clear spot for your baby's bassinet in your room, and make sure that there is sufficient space for walking around the equipment (the wires!).
- If you don't already have a log for keeping track of things, like medical equipment, please download the free resources on our site for logging things for baby. You will want to keep a close eye on everything that has to be ordered so that you don't accidentally run out of anything. Some suppliers will not be able to deliver immediately so always order supplies a week or two ahead of time.

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## **After baby is home (continued):**

- Did you take any parenting courses that were for emergencies? If not, you really should look for videos on giving CPR to your baby and more.
- Does your baby's pediatrician have an after hours number? Keep it handy.
- If you ever notice anything out of the norm (I know it can be tricky, especially as a first time parent), DO NOT HESITATE TO CALL 911. Especially if it is after hours and you can't call a pediatrician. If you don't want to call 911, for whatever reason, please take your baby to the hospital if they have been acting in any of these ways for more than a day:
  - Inconsolable,
  - Unwilling to eat the amount of milk they should be (your doctor should have left detailed notes about this before discharge of baby)
  - Vomiting after eating, even if it is just an ounce or two - if this is happening every time, there is likely an underlying cause for this
  - not gaining weight (this is tricky if you only take baby for pediatrician visit once or twice a month, but you should be able to tell if your baby is losing weight)
  - blue skin, rashes, etc. (if you have tried Aquaphor and other ointments/creams but baby's skin is getting worse, you need to get a medication from doctor. Also, baby may actually be allergic to some ointments/creams - always ALWAYS just test a small spot on baby before covering them in any ointment or cream.
- The above list was not all-encompassing, so please use your best judgment even if you are a first time parent you know your baby better than any doctor. If for any reason you feel like you are not being heard by the doctors, please seek a second opinion from another doctor.