

# Kaiser NICU – Santa Clara

Parent to Parent Guide

*Helpful Tips from Another NICU Parent*

## INTRODUCTION

Welcome to the Kaiser – Santa Clara NICU. While I'm sure you never expected your little one to end up here, if you are reading this it's because, like me, you also have a baby in the NICU. The first thing you should know is that the Santa Clara NICU is top notch. The team of nurses, doctors, administrators and specialists that will care for your little one over the coming days or weeks really do know what they are doing. Not only are they caring for your baby, but they are also here to help you through this journey. Get to know them, ask questions and most of all be involved in your baby's care. The road you are about to embark on may be a bumpy one, things in the NICU can change often, there *will* be ups and downs. The best advice I can give is take things as they come, try to stay optimistic and utilize the support both provided by Kaiser and your family and friends, it's they who will help make all this a bit easier.

My daughter spent 98 days with the Santa Clara Kaiser NICU. During this time the staff became our extended family. So rest assured this parent-to-parent guide was created by someone like you, a parent of a NICU baby. It's designed to provide you, with some helpful tips to guide you along your journey. If you're new to "our world" it can be an overwhelming time for you right now, please know that you are not alone. I hope this guide can help answer some of your questions and help make your journey a little easier.

*Disclaimer: This is a guide from a NICU parent, it's designed to help answer some of the common questions I had when I was new to NICU. The advice in this guide should not take the place of first hand advice / instruction that you will receive from the licensed staff that is caring for your baby.*

## WHY IS MY BABY IN NICU?

There is no good answer to this question. Unfortunately, it just happens, no one can explain it. The important thing to remember is it's not your fault and you probably couldn't have stopped the outcome. Your baby needs you right now, so instead of asking the "why me" questions focus on the "how can I help my baby".

## YOUR FIRST DAYS

The first days of your baby's arrival at the NICU will be a whirlwind. In addition to recovering from birth, which is an experience all it's own, you will need to brace yourself for the idea that your precious gift won't be leaving the hospital with you when you are discharged. He/she may be staying in the NICU a few weeks or a few months depending on his/her specific needs. On the bright side, you will have a bit more time to recover from the birthing process. Also, by the time your baby comes home you should be well versed in how to bathe, feed and take care of your little one... something most parents take weeks to master.

In addition, you will be adjusting to being a NICU parent. You will have a lot of information coming at you in a lot of different directions. You will receive information from the NICU staff, Social Workers, Patient Coordinators, Lactation Specialists and even other NICU parents, all wanting to help acquaint you with the NICU. It will be next to impossible to keep all the information straight. I found it useful to carry a notebook with me so I could write down questions as they popped in my head. I also took business cards from everyone I met. I stapled them to a piece of paper and made a note of what they do so when the time came that I needed their services I didn't have to remember who did what.

To top everything off, you will have a lot of different emotions running through you. You will feel joy about being a parent. Added to that will be concern and fear about your baby – is he/she going to be OK? You will be upset about being in the situation you are faced with. In fact, you will be working yourself through the 5 stages of grief identified by Elizabeth Kubler-Ross as noted below

- **D**enial (this isn't *happening* to me!)
- **A**nger (why is this happening to *me*?)
- **B**argaining (I promise I'll be a better person *if*...)
- **D**epression (I don't *care* anymore)
- **A**cceptance (*I'm ready* for whatever comes)

It is highly likely that you will move back and forth through these stages during your baby's stay in the NICU and possibly even after he/she comes home.

You will watch other parents interact with the staff and their babies with ease and wonder why they look so comfortable with the situation. Chances are those parents have been at the NICU longer and I can bet they had the same emotions running through them when they first arrived. If you are feeling overwhelmed, it's OK to ask for help. The NICU staff can help get you in touch with support groups, a counselor or even other parents who have been through what you are going through.

## **YOUR BABY'S FIRST DAYS**

Your baby will be adjusting to living outside of your belly. He/she may need assistance to make the transition from living in utero to living in our world. Depending on your baby's condition he/she may need breathing assistance. More than likely he/she won't be eating right away and will be placed on antibiotics as a precaution. The doctors will be following your baby closely and will alter any care as needed.

The first 24 to 48 hours of your baby's life is referred to as the "honeymoon" period. This is because as your baby adjusts to his/her new surroundings he/she doesn't typically show any complications of birth. Hopefully your baby will be fine, but you should brace yourself for the idea while although he/she is responding well upon birth that his/her condition could change at a moment's notice. Unfortunately this is part of the "bumpy road" you are about to embark on.

## **THE STAFF**

There is an entire team behind you working to make your baby's journey as smooth as possible:

The NICU Doctors: There is a team of five (5) main doctors that will oversee your baby's case on a day-to-day basis. These doctors are specially trained to deal with the needs of NICU babies. The team will rotate the point doctor for your baby every two weeks. This allows each of the doctors to stay involved in the care of your baby. In addition to the core team there are other doctors who help cover the overnight shifts who also are involved with your baby's care as needed. Any one of the doctors can help answer your questions. You can request to talk with them at any time. In addition, don't be surprised to receive a call from them from time-to-time to update you on your baby's condition, especially if they missed you at the bedside.

The NICU Nurses: The NICU nurses have special training to deal with the needs of your baby. Their main mission is to help care for your baby while helping you, the parent, through the journey of getting your baby home. The nurses work in teams, which helps your baby with continuous care. The team assigned to your baby will come to know your baby's needs and respond accordingly. They will be your "rock" during this trying time. They will be your teacher, your champion, your guide through the journey. They will become an extension of your family. That said, there will be times that your baby will

have a nurse not from his/her normal team. Rest assured that all the NICU nurses are great at communicating the needs of your baby to another and will take great care of your little one.

Social Worker: You will have a Social Worker assigned to your baby who will check in with you from time to time. This person is there to help you with any type of support you need. They can refer you to support groups and/or counselors. They can help with insurance coverage questions. They will also help coordinate meetings between specialist, doctors and you. In addition, if your baby qualifies for state or federal assistance they can help provide information about those services.

Patient Coordinator: The Patient Coordinator will help coordinate special services for your baby. They will arrange for you to have a hospital grade breast pump and the monthly renewal if needed. They will also help with the follow up care for your baby once he/she is discharged

Developmental Specialist: The developmental specialist will observe your baby shortly after he/she is born. Based on your babies evaluation the specialist will write up a plan of care to help you and the nurses interact with your baby. This allows your baby the interaction that his best suited for him/her. These evaluations will be repeated every few weeks while your baby is in the NICU and the plan of care will be modified accordingly.

Nutritionist: The nutritionist works with the doctors to ensure your baby is getting the nutrients needed to grow. They will review your baby's progress daily and make recommendations regarding any added supplements that may be required.

NICU Management Team: The NICU Management team ensures that the I's are dotted and the T's are crossed. They help make the unit run efficiently. They will become familiar with your baby's case and will stop by the bedside from time to time to ensure you are receiving quality care.

NICU Clerk: This is the person who actually lets you into the NICU when you arrive in the main lobby. In addition, this person works with the Management staff, doctors and nurses to make sure that the unit runs effectively. When it's time for your baby to be discharged they will help to set up follow up appointments, etc.

In addition to the people noted above, there are also respiratory therapists, occupational therapist, lactation specialist, pharmacist and specialist (neurological, infection, etc) that are all working together to support your baby's needs.

## **VISITING THE NICU**

The NICU offers you 24-hour access to your baby. You may visit your baby as much as you like, however no one expects you to be at your baby's bedside 24/7. While not

required, it's helpful to visit your baby on a schedule. This allows the nurses to plan for your visit, especially if your baby is eating and you'd like to be involved in his/her care.

While the NICU is available around the clock there, are a few times when you will be asked to leave your baby's bedside as noted below. When asked to leave you may wait in the outer pod area and your nurse will let you back in once complete.

- Daily during nurse shift change
  - 7:00am to 7:30am
  - 3:00pm to 3:30pm
  - 11:00pm to 11:30pm
- Wednesday mornings from 10:30am to 11:00am – this is when “the staff” as noted above has rounds (they review each baby's case)
- Ad hoc: Medical Procedure (i.e.: IV stick, eye exam, etc) being performed on your baby.
- Ad hoc (rare): Surgical Procedure being performed on another baby in your pod.

## **ACCESS INTO THE NICU**

When your baby is first born your baby will be assigned a medical record number and banded. At the same time you will also be banded allowing you access to your baby. For the first few days in the NICU you will be required to show your nurse the band (preferably still attached to your wrist) before they will let you in the pod. It is wise to also have a photo ID on file with the NICU which can be a nice alternative to the band, especially if your baby has a lengthy stay.

## **VISITORS**

At all times only two visitors are allowed at the baby's bedside at once. One of the visitors must be a banded parent/guardian. While it's understandable that you want to “show off” your new bundle of joy, it is best to limit visitors to close family members (for example grandparents) for a number of reasons. First of all, your baby needs rest. Too much stimulation can have an adverse effect on him/her. Secondly, you're baby will have neighbors, and depending on their conditions a lot of excess noise could be troublesome to them. Thirdly, the NICU is a sterile environment so it's best to minimize germs if possible.

Young visitors should be limited to siblings only. Upon arrival you will be asked if the sibling has been sick recently. In addition, siblings will need to be kept under parents'

control. If the young visitor is making a lot of noise (yelling, crying for parents attention, etc.) you will be asked to remove them.

Finally, don't forget to remind your visitors to only visit the bedside of your baby. It's tempting to ask questions or want to view the other babies in the pod, but due to privacy laws this is forbidden.

## **GET INVOLVED WITH CARE**

It's important to become an involved parent when it comes to caring for your baby. The nursing staff will encourage you to take part in taking the baby's temperature, changing his/her diaper, feeding and bathing. In fact, you have to show adequate strengths in each of these tasks before your baby is discharged from the NICU.

More importantly, you need to bond with your baby. As a mother, your baby already knows your voice and even can sense your touch. It's different than any other. As a father, your baby will come to know your voice and touch. The touch and love of a parent is different than the working touch of a nurse. It's soothing to the baby. The nursing staff will teach you the best way to interact with your baby. In addition, depending on your baby's case, there may be times when your baby should/should not be interacted with. Follow the guidance of your nurse until you get comfortable enough to read the signs yourself.

When your baby is stable enough you will be encouraged to provide your baby with kangaroo time. This is when the baby is placed on your chest skin-to-skin. Kangaroo time benefits both you and your baby. If you are breastfeeding it will help with your milk production. It is also a time for the two of you to bond and become familiar with each others touch. In addition, typically your baby will fall into a deep sleep which helps with the baby's development and digestion. Kangaroo time is a quiet time, its best to just hold your little one close (the occasional kiss and whisper is fine). The key is to remember to allow yourself enough time to perform this task. You should plan on being able to hold your baby for at least an hour with an additional ten minutes of bedside consoling to allow the baby to smoothly transition from your chest back to bed.

Finally, be your baby's activist. While the nursing staff will come to know your baby, you will know him/her best. The more time you spend with your little one the more in tune you will become with his/her cues. You will know if he/she looks OK, is in distress, etc. Speak up and be the voice for your baby – the *staff* will listen!

## **MAKE THE SPACE YOUR OWN**

The NICU receives wonderful support from charity organizations such as Project Linus, which provides handmade blankets and hats to patients. It's very likely you will arrive to visit your baby and he/she will have a special blanket or hat in place. These items will

become yours to take home and use in the future. The nurses will also encourage you to bring in your own blanket, small toy or pictures for your baby. By doing so you personalize the space allowing you to make a home away from home for your little one. When personalizing the space, bring items that won't interfere with your baby's care. Remember that you will need to switch out the items from time to time to keep them clean.

## **CLOTHING**

When your baby is ready for an open crib he/she will be put in a hospital issued t-shirt and hat to help keep him/her warm. If you'd like, you may bring in clothing for your child. The best clothing is long sleeve button down sleepers. This will allow your baby to stay warm, while also allowing the leads (wires) to be easily accessed as needed. Remember that your baby will grow fast so you don't need a ton of clothes. Three or four sleepers should be sufficient (depending on how often you want to wash).

## **SPECIAL ITEMS**

The NICU will provide your baby with his/her basic needs (diapers, food, medicine). However they can't always provide pacifiers for your baby. Depending on the gestational age of your baby the regular pacifier found in your local store may be too big for his/her mouth. My little one loves to suck, and I was able to find premiere pacifiers, online at [www.preemiesrus.com](http://www.preemiesrus.com). As with any other personal item you bring to the NICU you will be responsible for cleaning them. If they fall on the floor, they need to be taken home and cleaned – so remember to buy extras. I'd recommend 6 to 8 pacifiers to start – they sometimes get lost in the bedding when changed and can always be used when your baby is home.

## **PICTURES**

Take lots of pictures of your baby. He/she will grow and change so quickly and you can never get these days back. When you look back at the pictures you will be amazed to see the progress your baby has made. A picture timeline will speak millions about your baby's progress and it will be a great story to share with your little one when he/she grows up. Whether you view this time in your life as good or bad, it's an important time, and it should be documented.

## **BREASTFEEDING / PUMPING**

We've all heard about the benefits of breastfeeding. I believe it's a personal choice but if you are going to do it, here is some information you will need to make life a bit easier.

Depending on your baby's condition he may/may not be ready to breastfeed right away, if this is the case you will need to pump and store your milk until he/she is ready. When you leave the hospital you will most likely have a hospital grade breast pump issued to you. Depending on your insurance coverage you may have a co-pay for the use of the machine. The rental is a 30-day assignment which can be renewed while you baby is in the NICU. The NICU patient coordinator can help you renew the rental. Once the baby comes home you may keep the pump by switching the rental to a private pay.

Approach pumping as you would feeding your baby – get on a schedule. To keep your milk production going it is important to pump at least 6 to 8 times per day (especially if you are first time mother). It may take a few weeks for your supply to come in – DON'T give up, even if you get 1-ounce a pump, its still better than nothing. I would recommend that you wake up at least once a night to pump. Just think of the need to wake up as training for when your baby comes home.

Milk can be stored in the fridge for 48 hours or in the freezer for 3 to 6 months. The best way to store your milk is in breast pump bags. You can find these bags at the local grocery store in the baby section, Target or Babies R Us. They come in a package of 25 (which will last a few days if you are pumping consistently). Each time you pump you should use a new bag. The NICU will provide you with special baby labels for your milk. When storing the milk, make sure you label the bag before you freeze it (otherwise it won't stick). Don't forget to note the date, time of pump and the date of freezing. I found it best to group two day's of pumps together in a 1-gallon freezer bag. I'd date the outside of the gallon bag. When the nurses asked for milk I'd bring the oldest bag first.

The NICU has a few hospital grade pumping machines available for you to use while you are visiting your baby. They provide the pump, but you will need to bring your own supplies (shields, connectors, bottles and storage bags). I always found it hard to leave my baby's bedside when I was visiting so I ended up bringing my pump with me when I visited, I could plug into the baby's station, pull the curtain and pump while I watched my baby rest.

If you need support learning to pump correctly plan a visit to the Newborn Club in the medical office building, they are a big help. Once your baby is ready to try to breastfeed ask for a lactation consultant to come by and give you pointers. The nurses can also help get you started.

## **WHEN THE BABY IS READY TO COME HOME**

The NICU staff won't discharge your baby until they feel he/she can successfully make the transition from hospital to home. The discharge process is about five days long, and if you've been involved with your baby's development you should be able to gauge when that time nears.

To be discharged your baby must be stable, eating from a bottle and preferably off breathing support. In addition they must have 5 days with no apnea (heart/breath stops) episodes. He/she will have a hearing screen and a car seat test and possibly even some of his/her vaccinations depending on discharge age before he/she goes home.

To be discharged the parents must be signed off on baby care (diaper change, temperature, suction bulb use, feeding, etc). The nurses will walk you through each of these milestones. In addition you will need to complete CPR training. At a minimum you will need to attend the 15 to 20 minute lesson provided by the NICU, however I'd encourage you to get CPR certified through the American Red Cross. They have a great infant/child class that offers real time practice on dolls.

Just before your baby is ready to come home you will be offered a "rooming in" night. This is when you stay at the hospital in one of the patient rooms with your baby. You provide the baby with 100% care, the NICU nurses only provide you with milk as needed. The benefit of this room in is you have the safety net of the NICU for a night should anything go wrong. It is also a great time to ask any questions that may arise when you are taking care of your baby on your own. You won't get much sleep, but you will feel more at ease when you take your baby home.

Before you leave the hospital you will need to pick a pediatric doctor for your baby. Any follow up appointments, home health visits or specialist appointments will be requested and possibly even scheduled for you.

## **WEBSITES OF INTEREST**

There are a number of websites about NICU babies – most talk to premature births. Some that I found useful are listed below:

[www.preemiesrus.com](http://www.preemiesrus.com) – pacifiers and baby supplies  
[www.preemie-clothes.com](http://www.preemie-clothes.com) – they have some NICU specific clothing  
<http://www.dds.ca.gov/EarlyStart/ESHome.cfm> - Information on Early Start Programs  
[http://www.kidshealth.org/parent/pregnancy\\_newborn/medical\\_problems/preemie\\_home.html](http://www.kidshealth.org/parent/pregnancy_newborn/medical_problems/preemie_home.html) - overview of a preemie's homecoming  
[http://www.zerotothree.org/site/PageServer?pagename=par\\_parents](http://www.zerotothree.org/site/PageServer?pagename=par_parents) – information on babies development (cognitive and physical)

Here are a few other websites that may be of interest

<http://www.scv-redcross.org> – Santa Clara American Red Cross  
<http://www.schwans.com/> - Food home delivery, great for those days when you just don't have time to cook.  
<http://welcomeaddition.com/> - Similac Welcome Addition Club – if you register they send formula samples  
<http://verbestbaby.com> – Good Start New Baby information – if you register they will send you samples and baby development information

## **IN CLOSING**

I hope you found this guide helpful. Overtime you will find that a lot of the information provided is very similar to the information provided by the NICU staff. Again, the guide should be used to provide you with an additional tool to make your time at the NICU easier, but it should never replace the real-time information you will receive from the professionals.

Your baby's stay in the NICU will have its good and bad moments. Try to stay positive and as optimistic as possible. Seek out others to help you through this tough time. Utilize the strength that gets you through the day be it your faith, family, friends, the NICU staff and other NICU parents. Ask for help – its OK! You are not alone, and you will make it through this life challenge.

I wish you all the best!