

The Pee Wee Post

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Surviving the Holidays in the NICU

Here you are in the NICU, and chances are good that you can quickly think of at least a dozen places you'd rather spend the upcoming holidays. But if you know your baby will be here for at least part of this month, here are some ideas to help make the season a little more



MILAN, BORN FULL TERM WITH TRISOMY 18 AND CONGENITAL HEART DISEASE



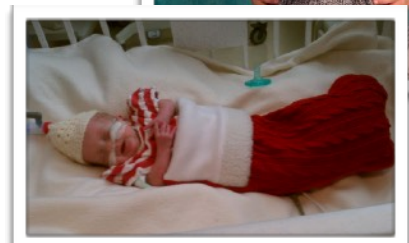
GREYSON, BORN AT 24 WEEKS

1. Bring in a special outfit or blanket for your baby. If he/she cannot yet wear clothes, maybe a festive hat, booties or bib would work. If your baby is stable enough, you might be able to "pose" him or her in a Christmas stocking – talk to your bedside nurse. Take lots of pictures!
2. Write a special letter to your baby. Be sure to include all your thoughts, hopes and dreams. Save it to read every year at holiday time.
3. Bring in some small, non-electric decorations. Maybe a festive bib or "Baby's First Christmas" stocking and some Christmas balls, a small menorah (no real candles!), or any decorations appropriate for the holidays you celebrate, but be sure they are washable or wipeable to prevent the spread of germs. Have siblings make decorations (snowflakes, cards, etc.) Again, take pictures!
4. Print out the pictures you take and bring them to Scrapbooking on Fridays. You can start a scrapbook for your baby with your holiday memory photos.
5. Bring in books about the holidays and read them

to your baby.

6. Don't be afraid to take a day off from the NICU.
7. It's ok to wish things were different. If it helps, think about the special times you will share next year! Plan new family traditions.
8. If a big family gathering sounds overwhelming, just say no!
9. Budget your time and stick to a schedule. If you have other children, you will obviously want to spend time with them, too. Ask friends and family to stop by and visit the baby and/or help entertain your older children.
10. Come to the parent dinners and other groups sponsored by the NICU...there are lots of parents who feel just like you! Our next meeting is January 2 at 6:30 in the NICU waiting room.
11. Take care of yourself. Don't forget to eat right and get plenty of sleep.

For more advice about getting through the holidays see page 3.



WHITNEY, BORN AT 25 WEEKS

What You Need to Know About RSV and the Flu

As you know, NICU parents spend a great deal of time worrying. Even when it's time to go home you have worries that "typical" new parents do not have, simply because you've seen too much. If your baby is going home over the winter months, you have additional concerns: it's cold, flu, and RSV season. These winter viruses can make our fragile babies very, very sick. Here's what you need to know:

RSV (respiratory syncytial virus) is a very common virus. For your average healthy child, RSV is basically a cold (runny nose and fever). But it can make premature and medically fragile babies very sick. Each year, 125,000 babies are hospitalized with RSV. If you go home during the winter, be sure to call your doctor immediately if your baby has the following symptoms: coughing, wheezing, rapid breathing or gasping for breath. RSV symptoms worsen quickly and can be life threatening. If your premature baby contracts RSV during his first winter home, chances are very good he will be re-hospitalized — and that is every NICU parent's worst nightmare!

RSV spreads very quickly by physical contact (shaking hands or kissing an infected person) or even by just being in the same room with someone who is coughing or sneezing. If you are exposed to RSV, you can pass the illness to others, even if you have no symptoms. One of the most important things you can do for your baby is to do your part to keep him healthy:

- *Wash hands thoroughly before touching or holding the baby, and Purell often. Children are very contagious and are exposed to many germs. Make a habit of having siblings wash their hands as soon as they come home from school or daycare. Be sure siblings know how to Purell their hands.

We asked parents of NICU graduates:

What did you do to keep your baby healthy during cold, flu, and RSV season?

I kept my daughter inside during the entire flu season. It was very challenging to do this but I could not assume the risk of her getting the flu or RSV. **In addition, I had all visitors wash their hands upon arrival and made sure they had their flu shot.** It may have seemed like a lot, but I believe it kept my daughter who was still extremely fragile at the time healthy." **-Brandi, mom of Leah**

"One of the hardest days in the NICU was when I couldn't go visit Gus because I had a cold. I had never missed a day with him and the loss that day was painful. But it was the right decision for him. I learned that in this instance, loving my baby and doing what was best for him meant sacrificing my own needs to be with him." **-Carter, mom of Gus**

"At the advice of our pediatrician, we kept Catherine at home for her first winter and limited visits to close family. We made everyone aware of this decision several weeks before she came home so that no one was surprised by these restrictions. Our friends and family were extremely supportive. It was a long winter, but the peace of mind of having a healthy baby was worth it. When we were finally able to show her off to everyone in the spring, I was able to enjoy it without worrying as much about germs." **- Megan, mom of Catherine**

- *Keep your baby away from crowds. This is very important....no family reunions, parties, shopping malls, church nurseries or large daycare settings during that first winter home. This can be hard, because you want to show your baby off! But never forget how hard your baby worked to get home. It is not worth it to risk re-hospitalization. There will be other opportunities to introduce your baby to family and friends.

- *Keep people with colds away! Put a sign on your door asking friends to call before visiting, so you can be sure they are well.

- *Do not smoke around your baby or allow smokers to hold your baby without properly washing hands and arms and putting on a clean, smoke-free shirt. Smoke lingers on clothing and in hair and can disrupt your baby's breathing. Please speak with your Social Worker if you would like additional information about the effects of smoke on preemies.

There is a monthly RSV vaccine called Synagis, which is available for at risk babies. If your baby is in the high risk group, he or she will receive a first dose of Synagis before discharge and follow-up injections from your pediatrician. Please speak with your baby's doctor or nurse to find out if your baby qualifies for Synagis injections.

Finally, everyone in your house and anyone who will be caring for your baby should receive a flu shot. The flu, like RSV, can put your baby back in the hospital. Your baby is too small to receive a flu shot, but you can and should!



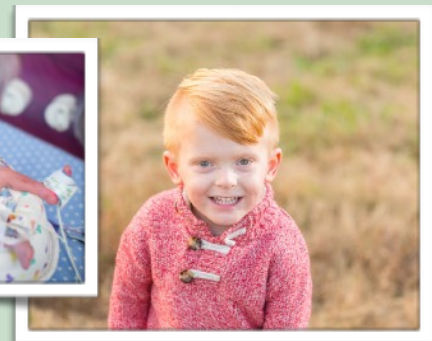
We asked parents of NICU graduates:

What did you do to make it through the holidays in the NICU?

“Do whatever you feel comfortable with for your holiday. If you want to spend it alone in the NICU with your baby, do it. If you want to go home and celebrate with your entire family, do it. No judgment. No worries about what anyone thinks. I spent all day with my baby and the night with my family. I had time for everyone and it made me feel happy that I hadn't left my baby out of my celebration. I didn't give a time when I would be home so I wasn't rushed with my son. That was most important to me.” -**Leah, mom of Greyson**

“While having a baby in the NICU over the holidays is extra hard, remember to take time to still celebrate with your family and friends.” - **Krystie, mom of Whitney**

“Gus wasn't even supposed to have been born yet at Christmas, so it was especially hard not focusing on what I had dreamed Christmas 2013 to look like. We spent Christmas morning with family and the remainder of the day in the hospital with Gus. I won't pretend it was easy, but **we talked a lot about what “next Christmas” would be like. We talked about traditions we wanted to start as a family.** We looked forward to the future and tried not to be sad that we weren't spending Christmas at home as a family.” -**Carter, mom of Gus**



GUS, BORN AT 26 WEEKS

“We made our time at the NICU as festive as possible by decorating Milan's space. **Having family visit helps maintain a sense of normalcy even while being away from home during the holiday.** Hold on to your joy!” -**Yolanda, mom of Milan**

Famous Preemies

Your baby may be small now, but you never know what the future holds! The following famous people were all born prematurely, so THINK BIG!

- Isaac Newton
- Mark Twain
- Winston Churchill
- Napoleon Bonaparte
- Renoir
- Albert Einstein
- Daniel Webster
- Sidney Poitier
- Richard Simmons
- Stevie Wonder
- Theodore Roosevelt
- Anna Pavlova

Happy Holidays from the CHKD NICU Family Advisory Council! Feel free to cut and post this door sign at your home during RSV and Flu Season!

Welcome to Our Home!

Our Child is Medically Fragile. Please:

- Make sure your vaccinations are up to date
- Wash your hands thoroughly
- Do not visit if you or someone you have been around has been sick in the past 2 weeks
- Do not expose my baby to smoke or second hand smoke

**Thank you for helping us
keep -----
healthy!!! ♥**