

**A newsletter for
Sunnybrook NICU
families and their
friends**

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- NICU parents share coping stories & strategies
- Mother's Day & Father's Day
- PREMIE PICNIC June 23!

Something you'd like to see in the newsletter?

We would love to hear from you!

Please email ideas to Kate, the Parent Coordinator, at kate.robson@sunnybrook.ca, or just let me know when you see me in the unit. I'm in Monday, Wednesday and Thursday or by appointment.

Welcome to Sunnybrook

A message for you from the NICU team, NICU graduate families, and the Family Advisory Committee (FAC):

When your baby is in the NICU, sometimes it's hard to remember that YOU also need care. Just as your baby needs attention, and sleep, and kindness, so do you.

We encourage you to take time for yourself, to let your family and friends help you, and to eat well. It's fine if your baby is first on your list, but your own needs matter too!

We wish the best for you and your family.



Thank you to Josee Hartrick, graduate NICU mom & artist, for sharing this sweet drawing with us! See more of Josee's art at <http://jhartrick.blogspot.ca/>

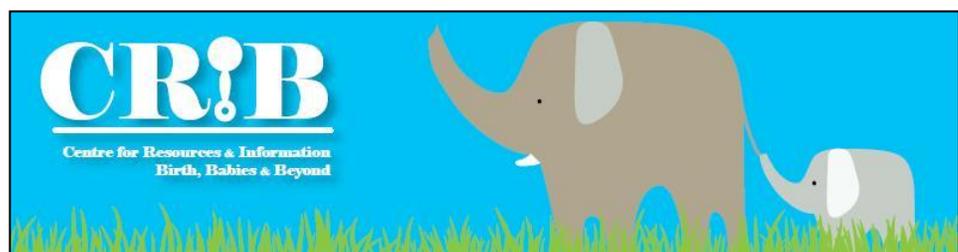
The CRIB

Looking for more information about pregnancy, birth, babies and beyond?

Visit our new Education Centre (also known as the CRIB) to have your questions answered by our knowledgeable

family educators. Explore our materials, including DVDs, books and pamphlets. The CRIB also has computers available for searching online resources.

Visit us in M5-102, or at sunnybrook.ca/CRIB.





Mother's Day & Father's Day

You probably didn't expect to be spending these special days in the hospital, and you may not know exactly how to celebrate. We're here to help!

The Thursday before Mother's Day (May 9th), we will have a special event for moms in the Family Lounge. Our "Milk and Cookies" education sessions before and after Mother's Day will also have a special Mother's Day focus.

On Sunday, we encourage you to spend the day itself in whatever way suits you. You may want to be with your baby in the unit, and have a celebration in the lounge with your family members. You may wish to pamper yourself outside of the hospital. Whatever you do, we hope you enjoy it.

We'll follow a similar pattern for Father's Day. Our unit event will happen the Thursday before, during the day in the Family Lounge. On Father's Day itself, we will leave you to celebrate with your family and friends. We will also schedule a "Dad Night" the week after Father's Day so that fathers who cannot be here during the day can connect with each other.

For event details, please check the parent bulletin board in the parent corridor. You can also speak with Kate, the Parent Coordinator, or email her at kate.robson@sunnybrook.ca.



Expect royal treatment on these special days!

Upcoming events

May 15th: International Kangaroo Care Day

Kangaroo Care (or Skin to Skin Care) is a big deal in our unit, so we'll be joining with other NICUs around the world in a celebration of this life-changing practice.

May 25th: The Linden Fund Pedal For Premies Fundraising Event

The Linden Fund is an amazing charity funded by parents of a premature infant. They raise money for NICUs across the country, and have been very helpful in our unit. For event details, visit <http://thelindenfund.com>



Learn about baby massage

We are so excited to announce we will be holding baby massage classes every month for our NICU families. The classes will be free but we will need participants to pre-register, since there are only 8 available spots per class and we anticipate a lot of interest. Not all premature babies are ready for massage, but parents can use these techniques after discharge or when their babies reach the appropriate gestational age.

Please bring a soft-bodied doll or teddy to practice on; we have some you can borrow as well. If you have been discharged or transferred you are welcome to come back and participate – just let us know.

Our teacher is Cindy McNeely, R.M.T. who has been a Registered Massage Therapist since 1985. As well as having a diverse clinical practice, she has taught in numerous Massage Therapy Colleges since 1988. She began a Perinatal Massage Therapy student program within Women's College Hospital in 1995 which has continued in the new location of Sunnybrook Health Sciences Centre.

Along with extensive practice working with pregnant and birthing women, she has taught baby massage for many parents within the home and clinical setting as well as for postnatal groups, public health, and within hospital settings. She has witnessed the important

effects of massaging babies and is thrilled to teach the benefits and techniques of baby massage to parents and healthcare staff. You can reach Cindy by visiting the Trimester website at www.trimesters.on.ca.

There will be a class each month, usually on a Sunday. Email Kate at kate.robson@sunnybrook.ca for details or if you'd like to participate.



Cindy McNeely (L) and one happy baby (R)

Milk and Cookies, every Monday!

Talk and Treats, every Thursday!

When: Every Monday and Thursday from 1-2

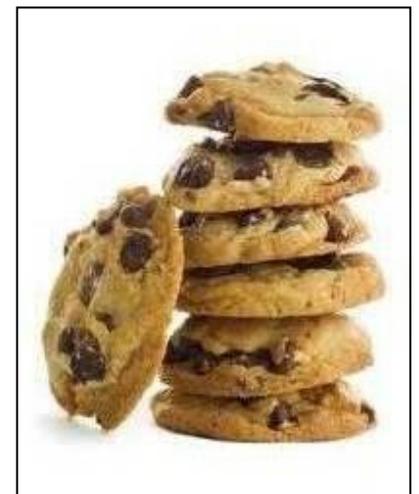
Where: in the Family Lounge

What: You have a standing invitation to these informal family information sessions. They are designed to address your questions and concerns about life in the NICU and beyond.

Come have a cookie and find out what all the excitement is about.

On Mondays, NICU staff members will come to share information about different clinical subjects. On Thursdays, our focus will be more on self care, transfer &

discharge, and the first year at home. If there are specific topics that interest you, let us know! Talk with Luisa King, our Breastfeeding Resource Nurse, or Kate Robson, the Parent Coordinator.



“How did you do it?” NICU Parents share stories and strategies

When you first arrive in the NICU, it's so hard to imagine how the next few weeks or months might roll out. We asked some graduate families to share their stories of how they coped with their stay, and what practical solutions they found.

Josee: “The two things that helped cope the best were keeping a journal, which I love to read once in a while, and making some good fellow mommy friends in the NICU.

Useful things others did for me? Sending prepared food was lovely. My mother also bought me some clothes as I had nothing there. We had many people who wanted to visit and found that overwhelming. My husband made a Facebook page to keep everyone updated without actually having to talk to anyone. I really wanted to just be isolated within my immediate family and the hospital, and my hospital friends. It was nice of everyone else to respect that need for privacy.

When we got close to going home I think was the worst. I think it's because anticipation

really revs up and you become very impatient and all of the weight of the experience starts to feel tangible, likely because you work on autopilot while in the NICU, and suddenly the end is in view, and it snaps you back to reality in a way. Does that make any sense? LOL. We were very impatient with each other (my husband and I) and very frustrated the last two weeks. It really helped to split up for a few nights to each do our own thing. He went to his parents and I stayed in the NICU, of course, because I couldn't leave.”

Heather: “Some refer to it as a rollercoaster, but as an avid runner I like to compare our NICU journey to a marathon. Our son was born at 23 weeks+ 5 days and spent 2 months at the Sunnybrook NICU. Like numerous other NICU moms I pumped around the clock (10 times/day) and commuted up 1 hour per day (one way) to visit our son. To be as efficient as possible I stuck to the same routine. On a typical day I would leave the house after my 8:00am pump so that I could arrive at the hospital by 9:30am. There were never enough hours in the day at the NICU and

family members, who we did allow to visit, would often comment on how busy my days were. When I wasn't pumping, I would participate in Rounds, assist the nurse with handling (i.e. diaper changes), do Kangaroo Care (for at least 2 hours - usually 4 hours a day but depended on how my son's day was going), read children's books to our son and absorb as much information as possible from other parents in the NICU. By 8:00pm, when my husband would arrive at the NICU after work, I was usually mentally drained. I would brief my husband on our son's status over dinner in the Family Lounge and he would stay for a couple of hours while I headed home to pump and get meals organized for the next day. There was never a shortage of frozen meals in our freezer from neighbours and friends, but cooking was comforting for me, and made it easier to come home to an empty house, so I often looked forward to going home to cook a meal. When I was fully recovered from the C-Section I also added a running into the mix, mostly to clear my head after a stressful day. I also found it helpful to keep a change of clothes in my son's room at the NICU as I

did, on occasion, opt to stay over when my son didn't have a great day. It was always nice to put on fresh clothes the next day!

Eventually, when we were transferred to a Level 2 NICU, my routine remained the same, except that I was able to spend more time at the NICU as my commute time was a lot shorter.

I think most NICU mom's look back on the experience and wonder have they managed. I think you just find a hidden strength that you never knew you had.”

Dan: “We lived far away from the hospital, and so would come down one day, stay over, go home the next day and sleep at home. Sometimes we felt bad about not being there all day, every day, but we needed to keep things stable for our son at home too. I think you find the way to do the best YOU can, and that's as much as you can do. Feeling guilty all the time will just burn you out. We also took days off when we needed to. When we got transferred things were easier, especially for my wife. Being closer to home made a big difference, although we missed the Sunnybrook team big time.”

Lauren: "We had our little guy at 25 weeks. I was in the hospital every day and night for the first two weeks. I made sure I was at rounds in the morning and met both the day and night nurse in person - I wanted to know who was taking care of him! The first two weeks were extremely stressful, emotional, and filled with ups and downs as I am sure everyone can relate to. During the third week of our journey my husband pointed out that we had another three months to go and it was time to listen to everyone about BALANCE. So we made a compromise. I would take Sunday off for me to run errands, nap, just catch up on life as long as he went! We now each have a "day off" each week. We take care of all the meals and

household chores for the other on their day off so they can focus on what they want to do with their day. This one day completely reenergizes me for the week ahead.

I hope this helps others manage their journey."

Celeste: "The biggest thing for me is that there is no one right way to get through this. Everyone is full of opinions about what you should do, but they don't know you or your situation. So you have to make up your own mind about what you and your own family need. If I wanted to be at the hospital, I was there. If I needed to be home, I went home. That changed when we started getting ready

to take my baby home. I needed to be at the NICU all the time for feeding. I found that hard, but I got through it. I just kept telling myself it wouldn't be forever. Now it all seems like a dream."

Sara: "One thing I didn't know up front that I wish I had known, is that whatever schedule you come up with really only works for a week or two. Then your baby will change and learn something new, or you'll be able to change your pumping schedule, and so everything else will change! So at first you want to be there all the time because you're feeling scared. Then you work out a way of balancing your life better. But then you get transferred and

change everything again! And then your baby is getting ready for home and it all changes again! So I would say don't feel like you have to plan the next three months. Just come up with a plan week by week and change as you go. Living with uncertainty is hard but I think it is a normal part of the NICU experience."

"The depth of the feeling continued to surprise and threaten me, but each time it hit again and I bore it ... I would discover that it hadn't washed me away."

Author Anne Lamott

Your questions answered: When can I start exercising?

Many NICU moms wonder when they can start exercising again after having a baby. The answer is different for everyone, and a lot depends on how you had your baby and what, if any, complications you experienced.

Before beginning any type of exercise, consult with your own

doctor. Your first foray into exercise should be something gentle, like t'ai chi, walking, or gentle stretching (particularly of arms and shoulders).

Once your doctor gives you the all-clear, let your body be your guide as to what exercise you're ready for, and ask yourself why you're exercising.

Take any pressure off yourself related to losing weight. Think of exercise as a means of helping you deal with NICU stress, and for establishing healthy habits for when you're at home with your baby.

This time in your life should not be about setting and pursuing aggressive health

goals, but about doing activities that you like, that get you outside, and that help you relate positively to your body. "No pain, no gain" is NOT a good motto right now!

Focus instead on enjoyable movement, and know that when your body heals, you can resume more vigorous activities.

Protecting your baby from infections

Keeping your baby safe from infections is a team effort, and you and your family are vital members of that team. Here's what you can do to protect your baby.

1. Take off any hand or arm jewelry (rings, bracelets, watches, etc.) Artificial nails must be removed; they harbour dangerous bacteria.

2. Remember **all** hand hygiene moments. Clean your hands after visiting the bathroom, after eating, after entering your baby's room, after touching your phone, after touching objects like books, equipment, or water bottles, and ALWAYS before touching your baby.

3. Cell phones must stay behind the curtain in your baby's room. **Never** use a cell phone while holding your baby. Cell phones are a common pathway for germs. All objects that come in your baby's room should be cleanable with Virox wipes.

4. All your personal items should stay behind the curtained area of your baby's room

5. Please do not bring food or drinks other than water into your baby's room. Flowers and plants also cannot come into your baby's room.

6. Please do not give equipment like pumps directly to another parent. Clean and give to a nurse to inspect.

7. Please use the parent corridor to enter and exit your baby's room. For reasons related to safety and to privacy, parents cannot enter the central nursing area in each pod.

8. Please do not visit other NICU baby rooms; we encourage you to connect with other NICU families in the family lounge.

9. You can bring in clean blankets and clothes for your baby. Please do not bring in personal linens for yourself; we have sheets, blankets, pillows and towels here that you can use.

10. Last but not least ... **please never hesitate to ask anyone and everyone, "Have you cleaned your hands?"**

By anyone we mean any staff member or visitor. Everyone in the NICU needs to follow the same rules. By working together, we will all help each other stay clean and stay safe.

A letter for your family and friends

We saw this letter on www.preemieworld.com, and thought it might be useful for some of you to share with your family and friends before you go home with your baby. Feel free to change the wording to suit your own needs. Thanks to Preemie World for giving us permission to share.

Dear Family & Friends,

Our family is excited to be bringing home our preemie and we know you are excited for us as well.

Please know that we greatly appreciate your care and concern throughout our child's stay in the Neonatal Intensive Care Unit (NICU). Thank you for all of your help!

Though our child is leaving the NICU, the professionals caring for our child have been clear that the journey is not over with a simple homecoming. They have advised us that we must be careful in the days and months ahead of us with a number of precautions so that our still-fragile child's immune system and developmental capabilities can develop and thrive.

While we appreciate that everyone is eager to visit, no one wants to see our baby seriously ill and have a re-admission to the hospital. Therefore we ask you to kindly consider these simple and thoughtful requests:

- The baby is going to be on a sort of "lockdown" at home for the time being until our Pediatrician advises it is safe to take our child out of the home for anything other than medical appointments.
- The doctor will be advising us regarding having family and friends over to visit. Believe us when we say that we hate having to turn people away, but we have to be careful for our child's sake.
- If we are able to have you over, please make sure that you are 1) healthy, 2) not smoking before or while visiting with us and 3) prepared to wash your hands upon entering the house.
- If you are assisting us with taking care of the baby, please note that we are following doctor's orders regarding safe sleep and the guidelines to prevent Sudden Infant Death Syndrome (SIDS). This includes laying the baby down on his/her back to sleep, with no pillows, blankets, stuffed animals or other objects in the sleep environment.

We greatly appreciate your understanding with this matter. Should you have any questions regarding these requests, please talk to us.

Thank you for your support!

Dad night and Date Night!

Once a month, a graduate NICU dad comes to host a **special pizza night for dads**, uncles, big brothers, and grandpas.

The NICU can be a pretty female place at times, and dads need an opportunity to connect as well. Don't be shy!

Also, starting in May, we'll be hosting a monthly **"Date Night" for NICU**

families. Bring your partner or a close friend, and come to the Family Room for a nice dinner and some quality together time.

Both events always start at 7pm, and are always in the Family Room. We'll post the specific dates on the bulletin board in the Family Room, on the Parent Coordinator's door, and in the parent corridor.



When the moon hits your eye like a big pizza pie

The next Preemie Picnic: JUNE 23, 2013

We celebrated our annual Preemie Picnic on June 24th, and now we're planning the next one! Whether you spend five months or five minutes in our NICU, you have a life-time invitation to this event.

Our next picnic will be on Sunday, June 23, from 12-4. It's at McLean House Park just north of the hospital, behind the Estates of Sunnybrook.

We've got bouncy castles, yummy food, a great band, and fun activity stations all lined up.

The Picnic happens rain or shine, but we have it on good authority that it's going to be a beautiful day. Can't wait to see you all!



Precious handprints



Enjoying the show!

What is Family Centred Care?

Sunnybrook NICU

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416-480-6055
Location: M Wing,
4th Floor, Bayview Campus

Newsletter Editor and
Parent Coordinator:
Kate Robson

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The model of care offered in the NICU at Sunnybrook is known as "Patient and Family Centred Care" (or P&FCC). It means that you and your baby/babies are at the centre of the circle of care. Families are a key part of the care team and should always be treated as

such. That is why NICU staff members make a point of telling families you are not visitors – you have a right to be here.

The core concepts of P&FCC are:

- Respect and Dignity
- Information Sharing
- Participation
- Collaboration

We want you to be a part of the team, and we will help you in whatever way we can.

To learn more about Patient and Family Centred Care, visit the Institute for Patient and Family-Centred Care at <http://ipfcc.org>.