

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

In this Issue:

- Why your touch is magic
- Can music help make milk?
- Milk & cookies every Monday

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 graduate families of the NICU at Sunnybrook and the Family Advisory Committee (FAC):

A recent study showed that spending 5 minutes in a garden or other natural place significantly reduced stress levels. What does this mean for you? It means that, though it is really important for you to

spend time in the unit with your baby or babies, it's also good for you to take time for yourself outside. Sunnybrook has beautiful gardens and trails close by, and we encourage you to explore them.

Make a pledge that you will do something kind for yourself every day. Walk among the flowers, meet a friend for a picnic, eat

something delicious ... do what is comforting for you. Here's a quote to remind you about making the best of the season.

"A perfect day is when the sun is shining, the breeze is blowing, the birds are singing, and the lawn-mower is broken." *James Dent*

We wish the best for you and your family.

Reading to your baby

Some interesting research confirms that reading to your baby in the NICU will benefit both your baby and yourself.

A study from the McGill University Health Centre showed that parents who read to their preemies felt a closer bond to their babies, and were twice as likely to keep reading regularly to their babies once

home. Regular reading helped promote listening and memory skills and stimulated developing senses.

Another study from Brigham & Women's Hospital showed that when babies heard their parents' voices, they had fewer cardiorespiratory events. Parental voices are very familiar and soothing to babies, which may account for

this finding.

While many parents read childhood classics to their babies, it doesn't really matter what you read. You can read your favourite book or magazines, or make up your own stories. The thing to remember is that your voice is good medicine for your baby.



Why your touch is magic

You may have seen posters around the unit that say "Your Touch is Magic." All of the parents and babies featured in these posters are graduates of this NICU.

Many parents, when we first see our babies in the NICU, are afraid to touch them. They look so small and fragile! But our babies need our touch to grow and thrive. Not all babies are ready for every kind of touch; your nurse will be your best guide to what kind of touch is appropriate for your baby.

In many cases, the first kind of touch that a baby will experience is called "hand-hugging." To hand-hug your baby, clean your hands thoroughly and then gently but firmly cup your baby's head and bottom with your

hands. Usually preemies don't like light strokes; they prefer a steady, solid hold. If you have any questions about hand-hugging don't hesitate to ask your nurse.

You'll also see many babies in our posters getting "kangaroo care", also known as skin-to-skin care (STS). Babies thrive when they get regular STS with both mom and dad. STS helps a baby's brain develop, helps him or her regulate breathing and heart rate, and also helps parents too. Parents who hold their babies report lower levels of depression and moms who hold their babies often produce more breast milk.

If you would like to hold your baby, let your nurse know. It is the transfer from incubator to parent that is most

bothersome for your baby, so make sure you're ready to stay put with your baby for a good long time. Always pump and visit the washroom before settling down for a cuddle.

If your baby is not stable enough to come out, ask your nurse about modified Kangaroo Care. This technique involves taking the top of the incubator off and letting the parent come over the baby. The sessions

can't last as long as traditional STS but have a similar positive impact on both baby and parent.

It also helps to talk about your plans and hopes for the day early with your nurse or with the team during rounds. They can help you find the best time for whichever technique works best for your baby and you that day.

Happy cuddling!



You're invited to Pizza Night



Our pizza nights, hosted by grad dads, are a hit! We will be continuing these for the next few months, and encourage all family members to attend.

While the idea of our dad-hosted pizza night is to create an opportunity for NICU fathers to meet each other, the event is open to all. Don't be shy!

Pizza nights start at 7pm and are always in the Family Room.

Dates will be posted on the parent bulletin boards in the parent lounge and parent corridor, and also on the board on the office of the Lactation Consultant/Parent Coordinator.

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.

Dates of classes will be posted on the parent bulletin board.



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

Can music help make milk?



Pump up the volume!

The journal *Advances in Neonatal Care* just published a fascinating new study about an interesting way to boost milk supply.

Mothers were given audio recordings to listen to; some of the recordings had music and words, some had just words, and some had just music. Also, some mothers had

photos of their babies to look at while pumping.

The results show that listening to music while pumping can help boost milk supply. Listening to spoken word relaxation programs was also helpful, but the best combination of all was when mothers listened to music and looked at

pictures of their baby at the same time. In those cases, not only did the mothers produce more milk but the fat content of the milk was higher!

Why not give it a try yourself? See what happens when you add music and photos and pumping together. Let us know if it works for you.

The Self-Care Pledge

Probably every NICU parent gets told at some point, "You have to take care of yourself." It's one of those things that is easy to say, but hard to do.

How can parents think about ourselves when our babies are in the hospital? How can we fit in time for self-care when we have so much to do? We come to the hospital, pump, take part of rounds, take care of each other, take care of other children or family members, and take care of the parts of our lives that are not at the hospital. If we're very lucky we might find an odd hour here or there to sleep.

We asked graduate parents for some self-care tips, and they had lots of ideas to share.

- Take care of your diet. It's too easy to eat garbage.
- Give yourself breaks throughout the day. Get outside for at least 15 minutes.
- Ask friends for help. Don't be too proud! Ask people to make meals.
- Keeping a journal really helped me. I also loved doing scrapbooking and other crafts.
- Treat yourself to little luxuries now and then.

Like a new lipstick or something yummy from the Second Cup.

- Watching soaps in the Family Room.
- Connecting with other parents. I joined Facebook groups and went to the drop-ins at the hospital. It helps to talk to others in the same boat.

You can see some common threads running through these tips: the importance of connecting to others, of maintaining some healthy habits, and giving yourself breaks from the NICU environment. What is soothing for one person might not be for another, so it's very important to find what works for you.

There are some things, though, that are helpful for just about everyone. One of the first things to go out the window after you've had a baby, especially if you've had a preterm or sick baby, is exercise. However, just 15 minutes a day of movement is enough to start producing endorphins. Talk to your doctor about what kind of exercise you can do; if you've had a C-section, for example, you really need to be careful about certain movements. Once your doctor gives you the go-ahead, do what you enjoy. Take a walk on

one of Sunnybrook's trails, or simply explore some different areas of the hospital. (There's a library branch in the Veteran's Wing, in case you're interested.) You might enjoy t'ai chi, yoga, or other gentle forms of exercise.

Many parents have found meditation and breathing exercises very effective; there are many websites devoted to meditation and excellent free podcasts and videos as well.

Another thing that is good for everyone, including your baby, is for you to interact with your baby. Your presence and your involvement will not only help your baby do better, but will help you manage the experience better. Sometimes parents stay away

because of fear or worry. It is of course fine for you to take a break from the hospital, but staying away because of your fears or discomfort will actually make those fears worse. If you're struggling with your feelings and you think your feelings are preventing you from being present in the hospital, talk with your social worker.

The most important thing to remember is that taking care of yourself IS taking care of your baby. Babies need healthy, happy parents. So make a pledge to yourself and your baby that you'll set aside a bit of time every day to take care of yourself, so that you can be the best possible parent to your child.

Caring for myself is not self-indulgence.

It is self-preservation.

- Audre Lorde

Transfer & discharge: what parents need to know

One question that is on every parent's mind is "When can we go home?" Of course, the answer is always different from person to person and from family to family. Here are some things to keep in mind when trying to imagine what the next few weeks and months may look like.

For most of our families, the first step toward home is **transfer to another hospital**. Level II hospitals care for babies who do not need full neonatal intensive care but still need support as they grow. Babies are transferred to be closer to your family home, when they don't need our level of care any more, and when a bed is available at the Level II hospital.

Transfer can feel stressful, but try to think of it as a positive step on the road to home. There is a bulletin board in the

parent corridor with maps and information about Level II hospitals, also sometimes known as "special care nurseries."

Discharge is when babies go home with their families. Some babies go home a few weeks after their due date, some go home right around their due date, and some go home a little bit before. Generally speaking, babies born very early (before 28 weeks) tend to stay past their due date.

Babies are ready to go home when their breathing is stable (no spells for a week), they are feeding well from breast or bottle, they are gaining weight reliably, and they have no pressing clinical issues that need monitoring by our hospital.

Our discharge coordinator will meet with you before you go home to discuss with you all that is involved. We can help you find a pediatrician and will set up your first follow up appointments. We will also give you a copy of your discharge letter; read it carefully and talk to us about any questions you have.

If you're feeling stressed about transfer or discharge, talk to your nurse, the Discharge Coordinator or the Parent Coordinator. We understand your concerns and we are here to help you.

"I was really angry when the team said my baby was ready for transfer. He was great but I didn't feel ready to go! Then when we were leaving I saw a mom being wheeled in, and I realized that us leaving meant a new baby would have the space he needed. Someone had made space for us, and now we were making space for someone else."

"It took a few days at the new hospital to feel comfortable, but by the time we went home we loved the nurses there too and felt very good about the experience."

- Jen, a mom of a 27 week boy.

What is EMPOWER?

EMPOWER is a new study that is being done to determine when it is best for mothers with low milk supply to start taking Domperidone.

Domperidone is a medication that promotes milk-making

in new mothers by increasing prolactin.

You might be eligible for this study if:

1. Your baby is less than 30 weeks gestation at birth
2. You are pumping regularly (8 times a day or more)

3. You are less than 21 days postpartum
4. You are struggling with a low supply

Ask your nurse for more information, or speak with a lactation consultant.

You can also email empower@sunnybrook.ca.

Even if you're not eligible for this particular study, if milk supply is a concern ask to speak to a lactation consultant right away. There are many techniques you can use to boost supply and the best time to start is now!

Milk & Cookies, every Monday

When: Every Monday from 1-2

Where: in the Family Lounge

What: You are invited to an informal family information session 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. If you have questions, ask to speak to our Lactation Consultant.

Upcoming topics include: your baby's five senses, sunscreen use with babies, understanding head ultrasounds, and car seat safety.



The importance of journaling

Journals can be an important tool for NICU parents – even for those of us who've never been interested in journaling before. Not only can we keep track of individual milestones and experiences, but they can also be safe places for expressing hope, fear, or anything else we're feeling.

Research shows that there are many benefits to journaling. People who keep diaries or journals are less likely to be depressed, and people

who journal through a medical experience emerge with a better understanding of the details of that experience.

Are you wondering what you'll write about? Some parents end each day with a list of hopes for the days to come. Some keep track of weight and other important statistics. Others write poetry or stories for their baby. Some do journal scrapbooks and paste in photos or news articles. Some ask nurses or other

team members to write notes for their baby to read some time in the future. There is no right way or wrong way to keep a journal; it's whatever works best for you.

A graduate parent recently donated some blank journals to share with current NICU parents. The donor said, "I found my journal to be the best and cheapest kind of therapy. Better for me than my other favourite thing, which was donuts. I wrote in it every day, and now I

have the whole story there to share with my sons when they're big enough."

If you would like a blank journal, please talk to Kate, the Parent Coordinator. My extension is 87815 and my email is kate.robson@sunnybrook.ca

A note for parents:

If your baby is almost ready for transfer or discharge, please start taking frozen breast milk home.

The Dairy Queen has limited freezer space.

The contact number is 416-480-6100 x87948

The weight wait

For a preemie, learning to eat and keep it down isn't always easy. Thanks to grad mom Stef for sharing her story about her daughter's experience. Her story was first posted on nicublog.sunnybrook.ca.

In March of 2008 my daughter Elsa was born at 24 weeks gestation. Apart from the typical preemie woes (ventilated for 7 weeks, PDA ligation, ROP requiring surgery), she also struggled with feeding. You families know the drill - creep up slowly to full feeds, then setbacks put the babes back to TPN, creep back up, start breast feeding, setbacks mean re-intubation...

After 4 months in the NICU, our only issue holding Elsa back from coming home was oral feeding. Elsa was an expert fake breast-feeder. She SEEMED to be breastfeeding, but when we did our post feeding weigh-in we would discover that she was FAKING! Sometimes she would actually 'lose' weight after nursing. We persevered with nipple shields and eventually stopped doing pre and post weights - not because things improved, but because it was causing unneeded extra stress.

We introduced bottles, but Elsa continued to struggle with strength and stamina. We tried every trick in the book - stripping her down, different positions, special chin holds - you name it, but she still either fell asleep or vomited. Elsa was diagnosed and treated for reflux and eventually, about 1.5 months after her due date, she was eating and gaining enough weight to come home!

Things didn't improve all that much once we were home. We continued to alternate between breast feeding and bottles of my pumped milk fortified with formula for extra calories. Rob and I discovered that singing while feeding Elsa helped. It seemed to keep her calm, focused and awake and helped us relax as we hoped for more millilitres to go (and stay) down her hatch.

Because then there was the vomiting... There seemed to be nothing worse than when after all that effort to get a bottle in, she proceeded to expel her entire feed. All our hard work literally down the drain.

Fortunately solid foods were much easier. She continued to slowly gain weight and stay on

her curve, but it felt as though we worked for every measly ounce gained. Everything Elsa ate was slathered in butter. We dipped almost everything in something - hummus, avocado, sour cream ... Her feeding and weight gain was all consuming.

Elsa just turned 4 years old and although she is still small, she eats really well now. She likes a wide variety of foods and will try anything. Salmon sushi is one of her favourite foods!

I'm glad those days of recording every ml she consumed are long gone. I still stress about what she eats, but now I know she's eating well, she's healthy and happy. I hope that she provides a little bit of hope for those of who judge it a good or bad day based on how much your baby ate and how little of it you had to clean up.



Elsa enjoying some corn on the cob

During summer, enjoy the weekly Sunnybrook **BBQ and Hot Dog Cart** (weather permitting). The weekly Summer BBQ takes place in the Blythwood Patio (HG 15/17) every Thursday from 11am to 2pm. The Hot Dog Cart is now open outside H-wing Monday to Friday (excluding Thursdays), from 11am to 2pm.

Talk and treats, every Thursday

Sometimes the best people to talk to during a difficult time are people who are in the same boat. Our graduate families tell us they found the support of other NICU families invaluable while they were in the hospital.

And so every Thursday from 1:30 to 3:30 we host a family get-together in the family room. Sometimes graduate families drop by to share their stories and tips,

sometimes we do scrapbooking or other crafts, and sometimes we parents sit and chat amongst ourselves. We celebrate holidays together ... we're currently planning some Olympics activities and something special for Labour Day weekend.

You are always welcome and please let your family members know they're welcome to drop by too (if

they're healthy). One session we had 5 moms, 3 dads, one uncle and one grandma! We ate lots of cookies that day.



The next Preemie Picnic: JUNE 23, 2013

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

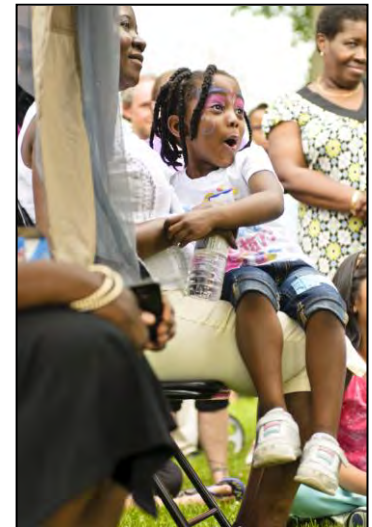
It's a wonderful event, where families and staff come together to ooh and ahhh over these amazing kids.

Thanks to all who helped this year: Kraft Canada, Scholastic, Sunnybrook Foundation, Toronto Fire Department, Pizza Pizza, the

Toronto Firefighters Association, Monkeywear.com, Doug Nicholson, our NICU Physicians, the Linden Fund, ToroLUG, and Ray Anderson for his spectacular magic act!



Precious handprints



Loving the magician!

What is Family Centred Care?

Sunnybrook NICU

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

Newsletter Editor and
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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>.