

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

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Welcome to Sunnybrook!

A message for you from Graduate Families of the NICU at Sunnybrook and the Family Advisory Committee (FAC):

The beginning of the year is a time for making goals and plans. It's hard, though, when you're not sure from day to day or week to week where you'll be. Will you be in the hospital?

Will you be at home? What will that look like?

Though answers to these questions are different for everyone, one thing that can help is to talk to other NICU families. They, more than anyone else, know what you are going through. We have weekly gatherings to help you connect with other

parents who are in the same boat.

Also remember that healing takes time, care, and rest. Eat good food, take care of yourselves, and take anything unnecessary off your to-do list. Focus on yourself and your baby or babies.

We wish the best for you and your family.

Thanks to Liz West for the use of her beautiful photo.

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.

Introducing our new group for Dads

It's not easy to be a dad in the NICU. At a time when you'd rather be at home enjoying your new baby, you're stuck in a hospital. Your partner needs your help and support, if you have other kids you need to be strong for them, and you may have to manage work as well.

In one study, dads identified the feeling of not having control as being the most

challenging. They also said that it was tough not having many other men to talk to about their experiences. They spent all their time being strong for those around them, but never got the chance to express their own needs and worries.

That's why we are starting a group for dads. Two graduate dads, Sabir and Dave, will host. Both graduate and current dads are welcome.

All meetings will be in the Family Room at 7pm.

Tuesday, Jan 17

Thursday, Feb 9

Tuesday, Feb 21

Thursday, Mar 1

Tuesday, Mar 20

If you'd like to call in, we can set up a conference line. Email Kate, the Parent Coordinator, at kate.robson@sunnybrook.ca.

Celebrating Moments of Joy

While no one should deny that the NICU can be a stressful place, it can also be joyful. There are so many exciting milestones that people experience here. That was the idea behind our Milestone program, which gives babies special certificates for all their achievements.

But you can also celebrate your own personal moments of joy in your own way. One family asked a chaplain to help with a naming ceremony, and another asked a chaplain to bless their wedding rings as the parents put them on again when their baby was finally discharged from the hospital. They had their ceremony right by the elevators!

For dads who missed the chance to cut the

cord the first time round, you can ask your nurse if you can "cut the cords" when your baby no longer needs to be monitored.

NICU staff members have also helped organize Skype baby showers and family visits for relatives who are far away or who are too ill to come in.

We also have scrapbook supplies that you can use to craft your own acknowledgements of special days or moments. Talk to Kate, the Parent Coordinator, if you're interested.

To arrange a meeting with a chaplain for a blessing or naming ceremony, call 416-480-4421 or 416-480-4424 for the on-call chaplain.



A grad dad finally gets to cut the cord! Thanks, Andre, for letting us use this amazing photo.

Safe use of cell phones

We know that cell phones are an important tool for families; they help you manage your lives outside the hospital, you can often use them to take pictures of your lovely babies, and they help while away the time in the hospital. That's why their use is permitted in the unit.

However, it's also important to know that

they represent a real infection risk. Studies show that most phones are covered with dangerous bacteria.

So if you use your cell phone in your baby's room, please ALWAYS clean your hands before and after use. Clean the phone itself once a day using methods recommended by the manufacturer. Never use your phone while holding your

baby. Keep your phone in the curtained area as much as possible; if you bring it out to take photos, return it to the curtained area and then clean your hands. Taking these steps and being aware will help keep your baby safe.

POP QUIZ:

Which object is dirtiest?

- a) a toilet seat
- b) the sole of your shoe
- c) your cell phone

Yup – you guessed it. The answer is C!

Source: ABC News

So, how old is he?

How a grad dad answers a tough question

"He's so cute! How old is he?"

That has become a common question asked by people of all ages. Old men with their wives in the shopping mall veer across the corridors to ask and coo at my son. Cashiers in the grocery store look at Austin in his stroller and ask. How can such a heart warming, honest and innocent question create such confusion and pain?

Don't get me wrong, I take great pride in hearing how cute my boy is. Talking about his accomplishment and the landmarks he's reaching fill my heart and secretly makes me well up at times.

Well, if you're reading this, then you may be able to relate. You see, Austin was born a micro-preemie and was cared for by the NICU at Sunnybrook. My wife was rushed to hospital and Austin was born by emergency 'C' section at 25 wks 6 days. He weighed 770g. He was, and still is, small. He had a lot of hurdles to overcome in his first three months of life before he came home two days after his due date.

"So, how old is he?" It should be a quick and easy answer for most proud parents, but it's the part that confuses me and contributes to my turmoil. As a preemie he has his legal birthday, which is the day he was delivered, but he also has a corrected age, based on when his due date was.

I can understand the need for the corrected age, especially when I see Austin beside his cousin, who was born full term 20 days after Austin. While Austin is starting to pull himself up and testing the waters for some furniture surfing, his younger cousin is running up and down the halls, and looking for the best approach to scale to the top of any obstacles in the room. Furniture surfing is so old school for the younger cousin - been doing that for 3 months now.

I know Austin will beat all the other kids in the local cutest baby contest. Look at those brilliant blue eyes, and with those long eye lashes the judges will just love him. I know I do. I'm the proud father of this bundle of joy.

"So, how old is he?" What age category do I put him in? Do I enter him in the older category based on legal age? No one will believe me. He's so small compared to the other kids. Do I use his corrected age? He'd be the same size as his fellow babies. But the form wants his birthday too, and that contradicts things. I really don't feel up to getting into details.

"So, how old is he?" I pause and think before answering. Do I answer with a legal age of 15 months and watch the puzzled expressions strangers have as they wonder why their 8 month old is a giant compared to Austin? Or get the jokes of "must not be feeding him much, look how small he is".

How much of my story do I want to relive with these well meaning strangers? They have no idea what we've been through.

"So, how old is he?" Without thinking, I tell people that he's 12 months. That's his corrected age. That's where his benchmarks are. That's where his growth is charted by the pediatrician and the follow up clinic. That should be the easy answer. But I've found that often gets people asking, "Oh, so his birthday's in December is it?". Do I agree, tell a little white lie and move to the next topic or aisle in the store; or do I correct them to September and experience the looks of puzzlement when the math doesn't add up?

"So, how old is he now?" Again, I answer just over a year, and go with the corrected age because it's the easier to answer to give. Now it starts to come too easily as an answer. It rolls off the tongue, not just with strangers in the mall or the store clerk as we check out, but with some of the guys on the job site, or other friends I haven't seen in a while. Some people know of some of the struggles Austin, Mom and I have been through. They look confused, so I relive parts of our story, reopen some old wounds, and explain the dual age categories.

I have to keep checking my thoughts for another year. I'm supposed to use

a corrected age until Austin's second birthday. I want the next year to slow down so that I can cherish and enjoy, smile and laugh so hard I cry as Austin has each of his firsts. It can be hard enough finding out that he pulled himself up for the first time five minutes after I left for work. I know I'm going to miss some things; it's inevitable. I don't want to rush things, I don't want to miss a beat, but I can't wait until Austin's second birthday so we can drop this corrected age.

Brad is a proud graduate dad of the Sunnybrook NICU.

"I remain in touch with many of the mothers and consider their friendships very special. We formed a bond unique to parents who have had babies in the NICU. These friendships and the informal support they give will continue as we parent our preemies through any challenges they may face."
- Sandy, mom of 27 week twin girls

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 we invite special guests who can answer your questions about the NICU, and sometimes we parents sit and chat amongst ourselves.

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.

What can I do to boost my milk supply?

This is a question that most NICU mothers ask at one point or another. The key to a good milk supply is frequency of pumping. You don't need to pump for more than 15 or 20 minutes, but you do need to pump regularly.

Your goal is to pump 10 times in 24 hours, which does mean you'll

have to pump at least once at night.

Some moms report that particular foods help them produce milk, like oatmeal or dates. There's no harm in trying, but keeping your fluid levels up is probably a better bet. Herbal remedies are not recommended for moms of preterm babies because the

industry is not well regulated and so they're not considered safe.

Kangaroo care or skin-to-skin holding can make a significant difference in output, so always pump after a cuddle session.

You also will want to avoid certain cold or allergy medications and birth control pills which can dry up breast milk.

More than anything, it's important to remember that there are lactation consultants here to help you. If you have any questions at all about pumping or feeding your baby, ask them early and often. There are no dumb questions.

If you'd like to talk with a lactation consultant, let your nurse know. Happy pumping!

Valentine's Day

For those families who are with us on February 14, please drop by the Parent Lounge any time between 1:30 and 4. We'll be hosting a Valentine's Day party for NICU families and staff.

There will be a crafting session so you can create your own mementoes of the day. If you'd like a special

photo of your little Cupid, the Linden Fund just gave us a lovely camera and we'd be happy to do snapshots for you.

And of course we'll have sweet treats for all to enjoy. If you have any allergies or preferences please let Kate (the parent coordinator) know by February 9.



What you need to know about transfer & discharge

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.

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 or the Parent Coordinator. We understand your concerns and we are here to help you.

We need to hear from you!

We are always trying to improve our quality of care for babies and for families. Some of our most valuable changes have come about because of feedback from our families, and we are always grateful for our input.

We have set up a comments box in the Family Room where you can leave questions, comments or compliments. They are collected each week.

If you have an issue that needs to be addressed immediately, it's best to talk to a person directly. You can talk to your nurse, the charge nurse, the Patient Care Manager or the Parent Coordinator.

We would also love it if you would fill out the How's Your Baby survey found at www.howsyourbaby.com.

Our code is VON001. This survey is a very useful tool for us and helps us focus on areas that need improvement.

Feedback is the
breakfast of champions

*Ken Blanchard,
management expert*

"I use the Facebook group whenever I have a parenting question, even if it's not preemie related. I just like talking to other preemie parents because I know we're coming from the same place."

- Ellen, mom to 2 prems.

Online resources for preemie parents

There's a lot to know about being a preemie parent, and at times it can feel pretty overwhelming. That's why we're working hard at creating online resources for you so that you can find answers to your questions whenever you need them.

At sunnybrook.ca/nicu you will find all kinds of useful info, as well as links to our educational video series and our new blog, *Inside the Sunnybrook NICU*. This blog is a collaboration between parents and staff, so if you'd like to contribute we'd love to have you participate.

There is also a Facebook group run by a graduate NICU dad; it's not an official Sunnybrook group but it's a great way to connect with other families. It's called "The Sunnybrook NICU Families" group; you need to send a request to join.

NICU Orientation: have you been told

1. What kind of touch is best for your baby?
 2. How to produce and store breast milk for your baby?
 3. Where the Family Room is?
 4. Where the water/ice machines are?
 5. Who to talk to if you have a question?
 6. What rounds are and how to participate?
 7. How to get breast pump kits delivered to your baby's room?
 8. About our Welcome to the NICU booklet?
 9. Where the pump room is?
 10. About our transfer and discharge policies?
 11. How to get your baby's OHIP card?
 12. About our milestone certificates program?
- If you have any questions about anything on this list, ask your nurse or the Parent Coordinator. Do you think there are more items we should add to our Orientation list? Let us know!



Sometimes we have to step back and let go of the old dreams in order to begin dreaming the new ones.

Save the Date: 2012 Premie Picnic is June 24!

Every year, graduate families and staff members gather together to celebrate our wonderful children. For families, it's a chance to see other parents and staff members again. For staff, it's a chance to see what these little bundles look like years

later. And for the kids? Well, it's a chance to have a picnic, make new friends, enjoy yourself and get your face painted.

This year's picnic will be from 12 to 4 pm on Sunday, June 24, in McLean House Park which is close by

Sunnybrook. For updates, visit the Sunnybrook NICU Families group on Facebook. We provide food and fun stuff to do; we ask you to bring picnic blankets or lawn chairs if you like to sit. Hope to see you there!



Face painting, treats, AND bouncy castles? Yup! It's quite a picnic

When Santa came to the NICU



Each year, Santa makes time to visit his newest and smallest friends in the NICU. Any family who is interested gets a visit, and we end the day with a big party for families and friends in the Family Room.

This year, Santa had a lot of help making things happen, and so we have many thanks to give. Thank you to the elves and the tree for helping Santa. Thank you parent volunteers for bringing the delicious food and arranging for donations. Thank you Doug for your lovely photographs. Thank you

Crayola and Scholastic for your generosity in providing gifts. Thank you Andrea and the crew from the Toronto Toy Tea for all the baby and sibling gifts. Thank you to Mandy at pinkstix.com for the beautiful gifts for our moms.

And last but not least, thanks to Santa for making this day so amazing! The gift you give our families is the best one of all.

What is the Family Advisory Committee?

Part of how Sunnybrook shows its commitment to Patient and Family Centred Care is by involving parents and families in ongoing education, development and programming. Graduates of our NICU are invited to participate in our Family Advisory Committee.

At our FAC meetings, we might discuss involving graduate parents in new employee

orientations, plan events like the Premie Picnic, design new materials for NICU families like the NICU milestones project or the Sibling Handbook (created by a graduate parent), or give feedback to staff about research or other new initiatives. It's a wonderful way to stay involved with Sunnybrook after discharge and we welcome your involvement. Meetings are usually the 2nd Thursday of the

month from 6-8 in the Family Lounge. Join the Sunnybrook NICU Families group on Facebook and keep in the loop about meeting times and major activities.

Your touch is magic



Talk to a nurse about what kind of touch is best for your baby.

Thanks to all the graduate parents who shared photos with us!

Your Touch is Magic

You may have noticed some posters in the NICU with some photos of some adorable babies and some pretty nice-looking parents too.

These posters are meant to encourage parental touch, since research shows your touch is very positive for your baby.

There are different touching techniques you can use; your nurse can explain what kind of touch is best for your baby.

Generally speaking, babies prefer steady touches rather than light, stroking touches.

You can hand-hug, do skin-to-skin holding

(aka kangaroo care – more on that below), or modified skin-to-skin holding.

Thanks to all our graduate families who shared your beautiful photos with us; we appreciate your help in spreading the word about the magic of touch.

Kangaroo Care ... did you know?

1. Moms and dads can both do skin-to-skin holding, also known as kangaroo care.
2. You don't need to worry about baby getting cold. A mother's body changes in temperature depending on what baby needs.
3. Kangaroo Care gives babies a better quality of sleep, which in turn fosters growth.
4. Plan it so you can hold for long periods of time (1 hour+). Getting your baby in and out of bed isn't restful for her/him. Talk with your nurse about the best time of day for holding.
5. Studies show holding babies skin-to-skin protects them from infections.
6. In 2003, the World Health Organization put kangaroo care on its list of endorsed practices.
7. Other studies show kangaroo care may help the brain develop and shorten the overall length of hospital stay.



Happy mom, happy baby!
Thanks to grad mom Michelle for sharing this lovely photo.

What is Family Centred Care?

Sunnybrook NICU

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

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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>.