

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

In this Issue:

- Halloween fun!
- What parents need to know about RSV
- Santa Claus is coming to town



Welcome to Sunnybrook

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

When you first come to the NICU to be with your baby or babies, you'll be given a welcome package. The intent of this package is to provide you with information that you

need, to help you feel connected with your baby, and to help you feel welcome and comfortable here at the hospital. The package has been developed in collaboration with NICU families.

No matter how much info we give you, your questions and comments are still very important

and always encouraged. Parents are not considered visitors in this NICU; you are highly valued team members and we welcome your presence and your participation.

We wish the best for you and your family.

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.

My Story

We have recently introduced, in our welcome materials, a poster called "My Story".

This project had a few sources of inspiration. The first was when a mother said, "I just found out our nurse loves 'Downton Abbey' too! I wish I'd known that weeks ago." The second was when we learned about a project that started in adult wards in the U.S. The

intent of that project was to help patients and staff learn non-medical things about each other, and to connect as people.

On your "My Story" poster, please share your family's likes and dislikes, hobbies, nicknames, and anything else you'd like us to know. Have fun with it, and take it as a memento when you go home.





Let's play dress-up!

One of our favourite holidays in the NICU is Halloween. We admire the creativity and ingenuity of families and staff who find wonderful ways to celebrate with babies.

This year, on Thursday, October 25, we'll have a craft and costume get-together in the Family Room at 1:30. We will have materials so that you can make or decorate NICU-friendly costumes for your babies.

Between 10 and 3 on October 31, if you would like a photo of your baby in his or her costume, we can drop by your room and take and print a photo for you. The camera and photo paper were donated to the unit by the Linden Fund. Thanks, Linden Fund!

We will also have treats and goodies in the Family Room throughout the day.

If you cannot be here but would still like your baby to be dressed up and have a photo taken, please send an email to kate.robson@sunnybrook.ca or mention it to your baby's nurse. We have a selection of costumes available including some very cute hats, princess outfits, tutus, and superhero capes. We can leave the costume with your baby as a memento of his or her first Halloween.

Of course, not everyone will want to participate and please do not hesitate to opt out; even if you aren't interested in the costumes we have other seasonal craft materials available, and of course you are always welcome to eat the treats!



What about a pumpkin hat for your little pumpkin?

Santa Claus is coming to town



Each year, we are honoured by a very special visitor to the NICU ... Santa! He has quite an entourage as well; there are always some elves in tow and even a walking, talking tree!

This year we've received notice that he'll be coming by on Sunday, December 16th. If you would like Santa to visit your baby and

take a photo, just let us know the week before and we will set it all up. Santa will arrive in the NICU about 1pm. He's wise in the ways of the NICU, and knows all about hand hygiene and infection control.

After he's done visiting with the babies, we'll be having a little party in the Family Room starting at about 3pm.

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.

The next class is October 21 at 1pm. Email Kate at kate.robson@sunnybrook.ca if you'd like to participate.



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

Get crafty!

Thanks to some very kind donors, we have lots of craft supplies on hand for those who like scrapbooking and creating special crafty mementoes. A hearty thank you to Pamela and Tammy! We very much appreciate your kindness and generosity!

We also have some craft packages

especially for siblings, so that they can draw pictures and create art to decorate their new baby's room.

If your interest lies more with journaling, we've also had a number of blank books donated by a graduate mom; thanks, Roslyn! If you'd like one, just ask Kate, the Parent Coordinator.

Crafting and journaling can help you deal with stress and can also help you mark important milestones. If you have any ideas about craft projects that you'd like to do, please let Kate know and we'll see if we can help.



RSV: What parents and families need to know

What is RSV?

RSV stands for respiratory syncytial virus. RSV is the cause of many colds, coughs and runny noses.

Its favourite time of year is the fall, winter and early spring. This cold virus is so common that most children have already had an RSV cold by the time they are two. We can keep getting colds caused by RSV all through our lives. RSV is spread by tiny drops of fluid that come from the runny nose, sneeze or cough of someone who has RSV. RSV can live on countertops and other hard objects for more than 6 hours and it can live on clothes and hands for up to 1 hour. You don't have to see the sick person to be in contact with "or catch" the RSV drops he or she may have left behind.

Who is at highest risk for getting very sick with RSV?

Some RSV colds are very mild but babies can become quite sick with RSV. Some babies develop deep lung infections from RSV such as pneumonia or bronchiolitis. Those at most risk for becoming very ill with RSV are:

- Premature babies born before 33 weeks gestation and born either during the RSV

season or, still under six month of age in November (the start of the current RSV season).

- Infants with certain types of congenital heart conditions.
- Babies less than 2 with chronic lung conditions that have recently been on oxygen or, have needed other medications to help them breathe.

- Babies less than 2 years old with Down Syndrome .

- Certain premature infants born between 33 weeks gestation and 35 completed weeks gestation (and born either during the RSV season or, still under six month of age in November, the start of the current RSV season) **when specific risk factors are present** (baby's doctor can explain these and will score the baby for risk level using a "risk scoring tool".

- Other specific medical conditions. Speak to your baby's doctor if you have concerns.

What can be done to prevent an RSV cold or infection?

There is no medication or vaccination to prevent your baby from getting RSV. The best way to protect your infant from RSV is to prevent them from coming in contact with the virus in the first place. Wash your hands with soap and water or

by using an alcohol based hand sanitizer before you touch your baby or your baby's things. Ask others to do the same and wash little sibling's hands too.

It is also important to keep your baby away from anyone who is not feeling well. Adults or children with any of the following should not go near the baby or the baby's things: coughs, runny nose, sore throat, fever, upset stomach, or diarrhea as they could spread RSV or another illness to the baby.

It is sometimes hard to tell relatives not to visit at these times but remind them the baby will not be this little and vulnerable for long and everyone would feel terrible if the baby caught a cold.

Particularly during the baby's first winter, keep him or her away from groups of people such as at malls, family gatherings, play groups or daycares as the baby could easily come into contact with RSV or another illness.

Medicine for high risk babies during the RSV season

Even though there is no medicine that can stop a baby from catching RSV, there is a medicine that can be given to help

high risk babies fight RSV if they get an RSV cold. This medicine called Synagis (palivizumab) also helps prevent RSV from becoming a deep chest infection like pneumonia or bronchiolitis. The medicine works by giving the baby passive antibodies to fight RSV. If your baby is high risk and needs this medicine, it will be given to your baby every twenty-eight days during the baby's first RSV season. A nurse or doctor gives the baby the medicine by injection (needle) in the hospital, at the doctor's office or, at an RSV clinic.

If you have any RSV questions or concerns

you may contact Marguerite Dennis RN, the NICU RSV Coordinator, by email at marguerite.dennis@sunnybrook.ca.

NICU World and Home World: What are the differences?

When parents first enter into the NICU for the first time, most of us can't imagine that we'll ever get used to it. It seems like such a strange environment ... it's "NICU World", full of beeps, machines, numbers and lots and lots of people.

With time, though, it does become familiar ... and then by that point we are either transferred to another hospital or discharged home. Just as we've learned all the ways of this new world, we're sent to another. And Home World looks quite a bit different from the NICU.

So are all the lessons we learn in this strange NICU World wasted? What can we leave behind? What can we take with us?

With the help of some graduate NICU parents who have spent time in both NICU World and Home World, we've come

up with some helpful lists.

We will leave behind in NICU World ...

- reliance on monitors and other things that beep. We probably won't need these in Home World. We'll get by just fine with our own knowledge of our baby and our 5 senses. We'll know when something's wrong and we won't hesitate to ask for help.
- hospital schedules. In Home World babies don't have to do everything on a 3 hour schedule, and they certainly won't need their temperature taken before every feeding! We'll recognize that as our baby grows his or her rhythms will change too.
- daily weights. We'll have to give up our fascination with those numbers! Instead, we'll pay attention to our

baby's cues and to numbers of wet and soiled diapers.

We'll take with us ...

- the knowledge that we are the best medicine for our baby. Our touch, our smell, the taste of our milk, our love, the sound of our voice. These will always be important for our children.
- good hand hygiene and infection control habits. We may find that others in Home World think we're being too uptight. WRONG! For the first year after baby comes home, we'll follow the same hand hygiene rules as we did in the hospital, and we'll tell our friends and family not to visit if they're sick. After that, if all goes well, we'll relax ... a little.
- the willingness to ask questions and work with a team. Just as our questions and comments were vital to

the wellbeing of our baby in the NICU, they still are once we've gone home. We've learned that it's important to speak up and we won't forget that lesson.

- the friendships we've made with other NICU families and staff. They more than anyone else understand what it's like. We will treasure these friendships for the rest of our lives.

Pizza Night

Twice a month two graduate NICU dads come in to host a pizza night for current NICU families.

Sabir and Dave encourage all family members to attend. They'd also specifically like to invite NICU dads to come out. The NICU can be a pretty female place at times, and dads need an opportunity

to connect as well. Don't be shy!

Pizza nights 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.

See you there!



Doesn't this look good? It could be yours ...



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: the first year at home, car seat safety, and what parents need to know about research



Study: Kangaroo Care positively impacts brain development

A new study from Université Laval shows that preemies who had frequent skin-to-skin contact (also known as kangaroo care) with their parents have better brain functioning in adolescence.

The study looked at three groups: full-term infants, preemies who were mostly in incubators, and preemies who regularly experienced kangaroo care with their parents. They assessed brain functions of these children when they reached the age of 15. They found that at the age of 15 all brain functions of the kangaroo-care group were comparable to those of the full-term infant group.

What does this mean for you? We've known for a long time that kangaroo care is good medicine for babies and parents. Here is more evidence to support the practice. We encourage you to hold your babies whenever you can. Talking to your nurse or to the rounds team early in the day about kangaroo care will help make it happen. Giving the team information about when you'll be arriving and when/if you need to leave is also helpful.

There may be times when your baby isn't able to come out for a cuddle; ask your nurse about hand-hugging or modified kangaroo care in these situations.

Also remember that the sound of a parent's voice is very soothing to babies. In fact, pretty much everything about you is good medicine for your baby.



Our Parent Coordinator holding her baby – who's now 7!

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 often using methods recommended by the manufacturer, or if possible keep it in a plastic bag. 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

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.

You may also be contacted after discharge or transfer for survey purposes. It's never too late to send us feedback; sometimes families get back in touch after a year or more with really helpful comments. We are always grateful.

"What good mothers and fathers instinctively feel like doing for their babies is usually best after all."

Dr. Benjamin Spock

Wear Purple for World Prematurity Day, November 17

November 17 is World Prematurity Day, when we try to focus the world's attention on the issue of premature birth.

We will be hosting activities in the hospital from November 15 to 17, and will also be having an Open House celebration on the 17th at 4pm in the Family Room. We invite you and your family to participate with us.

You can help mark the day by wearing purple, by joining the World Prematurity Day group on Facebook, by updating your Facebook status so that others know about World Prematurity Day, and by sharing your story on the World Prematurity Day Facebook page.



Thanks to the March of Dimes for the use of this photo

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.

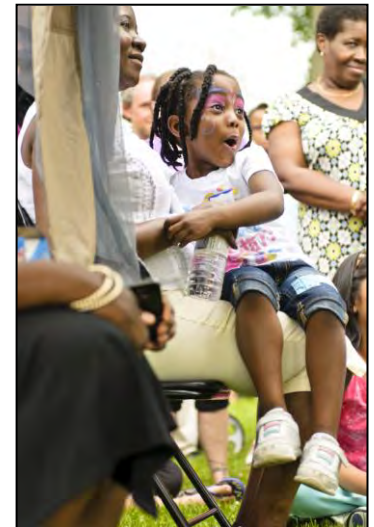
Our next picnic will be on Sunday, June 23, from 12-4. It's at McLean House Park just north of the hospital, behind the Estates of Sunnybrook.

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
Parent Coordinator:
Kate Robson

Kate.Robson@sunnybrook.ca

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>.