

A newsletter for
Sunnybrook NICU
families and their friends

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Welcome to Sunnybrook!

Fall Poem

The winds will blow
their own freshness
into you,
and the storms
their energy,
while cares will drop
away from you
like the leaves of
Autumn.

- John Muir

Even if you've been out
of school for a while,
do you still feel that

back-to-school energy?
We do, and we have so
much going on this
season at Sunnybrook.
You're invited to all of
it!

There are many
holidays we'll be
marking together, and
we have our regular
gatherings every
Thursday for parents
and family members.
And of course you will
have your own
personal milestones

and achievements to
acknowledge.

We urge you to take
the time to celebrate;
the NICU can be a
stressful place but we
hope you also
experience many
moments of joy here.

We wish the best for you and your family.

from Graduate Families of
the NICU at Sunnybrook and
the Family Advisory
Committee (FAC)

Halloween in the NICU

Every year parents and staff members work together to create some amazing costumes for the littlest of trick-or-treaters. We have had tiny Harry Potters, many ladybugs with spotted bibs, and quite a few cats and dogs (courtesy of knitted headbands with strategically-placed ears). We have also seen some cleverly disguised incubators!

If you would like to celebrate Halloween, talk to your nurse or to the Parent Coordinator about what is possible and what will conform to our infection control policies.

We will also have a Halloween party on Monday, October 31, in the family room from 2-4. We won't make you do tricks but there will be more than a few treats.



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.

Thank you to Liz West for
the use of her photo.



The way we were

One year in the new unit!

It's hard to believe that one year ago, our staff and families were working hard to bring babies from the old location at Women's College Hospital to our shiny new home up at Sunnybrook. It's been an exciting year full of happy discoveries – like that there's a Druxy's in the Odette Centre! And a Toronto Public Library in the Veteran's Wing!

The happiest discovery, though, is that families like the

privacy and quiet of the new single-room design.

To celebrate our first anniversary in our new space, we're holding an open house on September 9 from 5-8. Please join us in the Family Lounge for treats and talk.

We will also be hosting an hour of discussion with our department heads from 6-7. The intent is for parents and families to share feedback with us about what we're doing and to

ask questions. When families share feedback with NICU staff, we all learn and we all benefit.

If you can't be there in person, feel free to share comments or questions with Kate, the parent coordinator who can make sure they're addressed. Her email is kate.robson@sunnybrook.ca.

Welcome to the Follow Up Clinic

Who is on the clinic team?

A physician, Dr. Church, who specializes in both Neonatology and Developmental Behavioral Pediatrics; a nurse practitioner, Patricia Maddalena, whose area of expertise is transition to home, helping parents adjust to life at home, infant and toddler behavior and development, and feeding; a physiotherapist, Maureen Luther, who focuses on normalizing a child's motor development as well as feeding challenges; an occupational therapist, Denise Hohn, who focuses on behaviour, preparing for school, and social emotional development; and Laura Cooper, occupational

therapist, who specializes in school transition as well as motor based challenges.

What does the team do?

The focus of the team is to work with families to optimize a child's development following challenges such as preterm birth and/or hospitalization in the neonatal period.

What happens at the first visit?

The family is introduced to the team. Usually, a baby is seen by several team members in one visit and often, for the infants, that team consists of Dr. Church, Patricia Maddalena, and Maureen Luther. A

full review of the medical course since transfer and/or discharge is completed and the baby weighed and measured.

Maureen, with consent from parents, will do a brief video assessment which evaluates how the infant is moving. This assessment is a valuable tool as it provides information on the function of the brain.

What happens after the visit?

Even if babies are doing exactly as one would expect for their age, expect homework! The clinic at Sunnybrook is unique in that it evaluates and provides intervention at every visit. So parents always leave with homework!

That homework is critical because many small moments of exercise can add up to important skills being acquired!

How long do families come to Follow Up?

The clinic continues to offer visits through 6 years, with the goal that all of these small homework assignments following each visit result in a happy, successful 6 year old child!

If you have more questions about Follow Up, please ask your nurse or the Parent Coordinator.

Upcoming Events and Holidays



Cadets bring wreaths to the Sunnybrook cenotaph

Open House:

Celebrate our first year in the new unit with us on September 9, from 5-8 in the Family Room. (Page 2 for more info.)

Thanksgiving: We will come together on October 7th to celebrate Canadian Thanksgiving. Look on the parent board the week before Thanksgiving for more details.

Halloween: On Monday, October 31st from 2-4 we'll share Halloween treats in the

Family Room (see page 1 of newsletter for more info).

Remembrance Day:

Each year Sunnybrook honours veterans with a special service on November 11; memorial wreaths are placed at the Cenotaph on Bayview Avenue.

Winter Holidays:

Throughout the season we'll mark many religious and secular holidays: Eid al-Adha, the Islamic New Year, Hanukkah, Christmas, Kwanzaa, and the coming of 2012. Santa

will also pay us a visit on December 11. Details about celebrations will be posted on the parent boards in the parent corridors. If there is a special day you would like us to celebrate, let us know!

Sunnybrook Services: Baby Snaps

Sunnybrook has recently launched a program called Baby Snaps, dedicated to capturing the best possible portrait of your new baby or babies. Their aim is to create the best portrait with the minimum of interruptions. They use minimal extra lighting to create beautiful images.

The photographers have been educated about NICU infection control protocols and you can make an appointment for a Baby Snaps photographer to meet you and your

baby in your baby's room. Please discuss appropriate times with your baby's nurse before booking.

The portrait session is free and your baby's portrait will be available online, that same day, for you to share with family and friends. Your baby's images will be hosted for 2 months on www.babysnaps.ca.

There is a charge for any packages ordered, which you can do directly with the photographer or online. Photos will be



delivered to your home within 10 days.

If you would like to set up an appointment, please call ext. 3837 to book a time. Leave your name, room number and the best time for you and your baby, and the photographer will come to your room.

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.

Publications and online resources

We have a number of publications and resources available for NICU families.

When you arrive in the NICU, you will be given our new "Welcome to the NICU" booklet, developed in collaboration with our families. In addition to our quarterly Parent to Parent newsletter, we

also have pamphlets that share helpful tips with your family and friends, and handouts from Pharmacy and Social Work. A graduate mom designed a lovely sibling handbook to help kids learn about having a little brother or sister in the NICU. If you'd like a copy of any of these, please ask the Parent Coordinator.

Our new website is available in early September and will include all of this information, as well as a new blog and a list of our new educational videos. You can also see those videos on the SunnybrookMedia YouTube channel.

If you're on Facebook, there is a parent-run

group called Sunnybrook NICU Families. It's private so if you'd like to join send a request and the group admin, a grad dad, will add you. Parents share stories, post photos, and exchange parenting tips and tricks. The Family Advisory Committee also posts updates and activities on this group.

Get to know the Sunnybrook Foundation

Many families ask how they can give back to the unit, and we are very grateful for this! We do think it's good for you to focus on your needs and your baby while you're with us in the hospital. After discharge, and after taking time to enjoy life at home with your family, if you are interested in helping

other NICU families, you can do so through the Sunnybrook Foundation.

They have interesting programs like Gifts of Giving where you can give very targeted gifts related to hospital programs, E-Cards, and Champions of Care where you can honour Sunnybrook staffers who made a difference

for you with a donation in her/his name.

They will also help you arrange charitable events like dinner parties or sporting events; for help or to learn more you can email events@sunnybrook.ca.

Of course, you can always show support for the unit in other ways. Many families volunteer

to join the Family Advisory Committee, some donate their outgrown items to the unit or to NICU families in need, and many share their stories and photos with us.

We are deeply grateful to all of our graduate families who find so many creative and loving ways to show support.

Santa says, "Save the date!"

Did you know that every year Santa makes a special visit to our NICU? He's very organized this year and has asked us to save Sunday, December 11 for him.

If you would like him to visit you and your baby or babies in your room, just ask your nurse. More information about his visit will be posted on the Parent Boards the week before.

Santa doesn't come on his own; he has elves and even a special tree along for the ride. We'll have a party for him and his posse in the Family Room after he's finished meeting with all the families and babies.

You may think that Santa and his team look a little familiar but we assure you that's a complete coincidence.



Our tree delights some graduates

Getting to "Over the Rainbow"

A graduate mom's experience with post-partum depression

It can happen to you. Even after you think you've been through it all - the ups & downs, the long hours waiting, the times when you hold your breath praying for good news - it can still happen when you finally get home. Post-partum depression.

Everyone will tell you how lucky you are to have your tiny baby home. You're in the clear at last; no more monitors beeping, no more security doors, hand sanitizer, or glass between you and your little one.

You're in charge now and you don't have to ask permission to hold your baby or call in for reports when you can't be in the NICU with him.

But being in charge also means being alone. In the middle of the night when everyone's asleep except you, there is so much time to think. It all comes flooding back: the trauma, frustration and fear. It's not unlike PTSD.

So take a deep breath when you can. Listen to the soft breathing of your new miracle. Because that's exactly what he is, a miracle. You've both been through an ordeal. You need time to adjust to being alone together

and to relax into an actual normal life. Talk about how you feel. Tell your partner, your mother, your sister or your best friend. And then make an appointment & tell your doctor.

If you're thinking "he's so perfect and such an angel, so why do I feel so bad?" then you probably need some help. Regrets, second-guessing yourself, and a feeling of being overwhelmed are normal to new mothers, but if you're exhausted and wondering if there's something wrong, maybe there really is.

It took me more than 6 weeks after I brought my son home to admit I was in over my head. My tiny baby had been in the NICU for 102 days. Before that, I had been airlifted and had an emergency c section to deliver twins at 25 weeks. My boy's twin brother died early on and I truly thought I wouldn't recover from that shock. I kept going only because I still had my little peanut in the incubator who needed me.

So when I got home in time for Christmas, I should have been relieved and Overjoyed, right? Instead, like a shell shocked soldier who

returns home after witnessing war, I was numb. I felt nothing at first; then I was simply exhausted and overcome with regret.

At first, I figured this was just how all new mothers feel, especially those who have a complicated delivery. But as the days wore on, I realized I was feeling worse instead of better; I had no hope and felt no joy. Finally I admitted to myself that I thought I needed help.

After talking to family and friends I was encouraged to go to my doctor. I was so nervous and ashamed that I cried in her office. She prescribed an antidepressant and booked me to see a social worker. I was embarrassed and afraid of what people would think of me, but at the same time I thought that if Tony Soprano can see a therapist, so can I!

It was hard to talk to a stranger about my ordeal at first, and it certainly brought back painful memories that I didn't want to deal with. Once I started talking though, it got easier and I've been able to put some feelings and nightmares to rest. I was also encouraged to write. Keeping a

journal throughout my NICU days had helped clear my head, so my therapist suggested I continue, especially during those long hours in the middle of the night when I couldn't sleep.

Putting my thoughts down on paper stops them from circling around in my head. The antidepressant, meetings with the social worker, writing, and finally being able to get out and visit with my sweet baby have all combined to help me become healthier.

So now after 9 months of having my healthy and happy superstar home, I feel much more like a normal person. I haven't found my way back to exactly where I was, but it's a start. It's been a long, hard road, and the trip isn't over yet, but there is life after the NICU and there is Somewhere Over the Rainbow.

Written by graduate mom Carly Reynolds. Thank you, Carly!



Austin turned 1 on Sept. 1st. He is healthy & happy. He & his mom & dad are enjoying being a family together at home and will always be grateful to the staff at Sunnybrook.

Post-Partum Depression Resources

If you need help, there is a lot of support available to you. If you're still at Sunnybrook, talk to one of our social workers. Post-discharge, your family doctor or OB can give you a referral to an appropriate service.

Here are some resources we'd like you to know about.

Women's Mental Health Program, Sunnybrook Health Sciences Centre, Toronto
Physician referral required. Please contact your OB or family doctor to initiate a referral to this program.

www.sunnybrook.ca

Reproductive Life Stages Program, Women's College Hospital, Toronto
Services include: assessment, symptom management, individual and group therapy. Physician referral required.
416-323-6400 ext. 5635

www.womenscollegehospital.ca

Women's Health Centre, St. Joseph's Health Centre, Toronto
Provides information to clients with perinatal mood disorders. Offers support group, individual counselling

and referrals to other professionals. Self-referral.

416-530-6850
www.stjoe.on.ca

East Toronto Postpartum Adjustment Program
Offers education and group support. Free childcare and snacks are provided for group sessions. Self-referral.

416-469-7608

Maternal Infant Program and Perinatal Psychiatry at Mount Sinai Hospital, Toronto
Physician referral required. Referrals for pregnant women and up to one year postpartum.

Assessment and follow-up needed
Contact Will Smid at 416-586-4800, ext. 8325

www.mountsinai.on.ca

Credit Valley Hospital Women's Reproductive Mental Health Program, Mississauga
Accepts physician referrals for residents of Oakville, Milton, and Halton Hills.

905-813-2200
www.cvh.on.ca

Toronto Public Health, Healthy Babies Healthy Children Program
416-338-7600

York Region Public Health, Health Connections
1-800-361-5653

Peel Region Public Health, Healthy Babies Healthy Children
905-799-7700

Peel Postpartum Family Support Line
905-459-8441

Durham Region, Health Connection Line
905-666-6241; 1-800-841-2729

Halton Region Health Department
905-825-6000; Toll free: 1-866-4HALTON (1-866-442-5866)

Our Sisters' Place Mood Disorders Association of Ontario
36 Eglinton Avenue West, Suite 602, Toronto, ON
Telephone: 416.486.7432 Toll-free: 1.866.363.MOOD (6663)

For general information about community resources, call 211 or visit www.211ontario.ca.

If you are in crisis, remember you can always go to your local hospital's ER.



Preemie Picnic, June 24, 2012: Save the date!

Whether you spend 5 months or 5 minutes in our NICU, you and your family have a standing invitation to our yearly Preemie Picnic.

Our next picnic will be on Sunday, June 24, 2012, from 12-4. It's held at McLean House Park which is just north of the hospital. It's part of the Estates of Sunnybrook.

Planning for the 2012 picnic is in the early stages, but based on what has been popular in previous years we can tell you that we hope to have bouncy castles, a fire truck and a kid's entertainer. There will be kid-friendly food, bubbles, and many friendly faces.

Here are some photos from this year's picnic; you can see more on the Sunnybrook NICU Families Facebook page. Many thanks to our wonderful Sunnybrook photographer Doug Nicholson for the fantastic shots!



What is Patient & Family Centred Care?

Sunnybrook NICU
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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 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>.