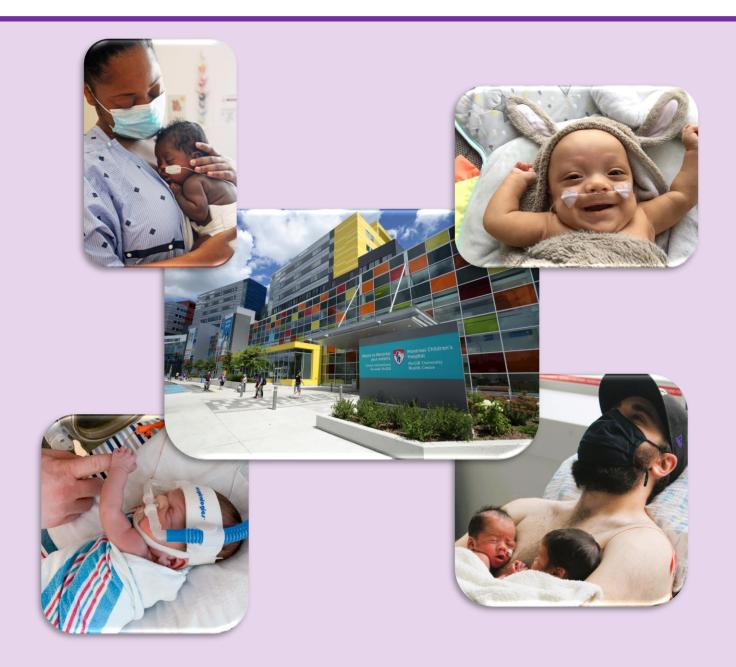
Welcome to the NICU

At the Montreal Children's Hospital



Chapter 1: Welcome to the NICU	3
 Visiting the NICU 	3
Who is taking care of my baby?	7
 Safety in the NICU 	9
 Words in the NICU 	10
Chapter 2: Parenting in the NICU	13
What can I do in the NICU?	13
 Stories from NICU Parents 	16
✤ Self-Care	16
Chapter 3: Breastfeeding in the NICU	18
"Liquid Gold"	18
Breastmilk: Getting Started	19
 All about Pumping 	20
 Pumping Videos 	21
 Frequently Asked Questions 	21
Chapter 4: Leaving the NICU	23
Where will my baby go after the NICU?	23
How can I get ready to go home?	24
 Life at Home 	26
Chapter 5: NICU Resources	28
 Hospital Services 	28
 Insurance and Benefits 	30
 Accommodations 	32
 Recommended Links 	33





CHAPTER 1 Welcome to the NICU

Dear parents,

Welcome to the NICU at the Montreal Children's Hospital. "NICU" stands for the Neonatal Intensive Care Unit. The NICU provides medical and surgical care to babies who are born early, have health problems or a difficult birth. The NICU Parent Handbook will guide you through your baby's NICU stay. We are also available to answer any questions. Our goal is to support you and your baby in the NICU.

You can visit our website for more information: <u>Neonatology (Neonatal Intensive Care</u> <u>Unit) | Montreal Children's Hospital (thechildren.com)</u>

Visiting the NICU

Getting to the NICU

- NICU front desk phone number: 514-412-4400 ext. 22389
- Directions to the hospital: <u>Getting to the hospital | Montreal Children's Hospital</u> (thechildren.com)
- Parking: <u>Getting to the hospital | Montreal Children's Hospital</u> (thechildren.com)

You can buy 7 day and 30 day passes at the Parking Desk on the ground floor (RC.1000) in the Larry and Cookie Rossy Promenade (walkway between the Montreal Children's Hospital and the Royal Victoria Hospital). Payment by Visa, Mastercard or Interac.

• The NICU is located in Bloc B (B like "baby") on the 6th floor.







Who can be present in the NICU?

Please note that the visiting policies may change at any time based on public health or infection control recommendations.

- Parents and legal guardians are welcome to stay with their baby at all times.
- Family members and friends are welcome **between 1pm** and **9pm**. It is your responsibility to meet them at the door and show how the unit functions.
- **Siblings can visit**. Please keep your child close to you. They can also have access to the JFK Park (more details in chapter 5 of this handbook).
- A maximum of 3 people (including the parents) are permitted to be at the bedside at the same time.
- 2 family members are permitted at the bedside without parental presence if you consent to it. Their names need to be given at the reception desk. The designated family members cannot welcome other visitors at the bedside and should stay the same throughout the hospitalization. All information concerning your baby is confidential and will only be given to you.

Babies are very vulnerable to infection, make sure you and your family members do not have a rash and are free of respiratory or gastrointestinal symptoms for at least 2 days before their visit.

When you arrive:

- Press the button outside the NICU door (B6S). A staff member will open the door.
- Hang up your coat and boots in the waiting room. Lockers are available. Please bring your own lock. In the winter, please bring a pair of indoor shoes to wear in the NICU.
- Remove all jewelry from your arms and hands, including your watch.
- Wash your hands with soap and water up to your elbows.
- Using a disinfectant wipes, clean your cellphone.
- Present yourself to the unit coordinator at the front desk. At your first visit, the unit coordinator will verify all your baby's information.
- Make sure to wash your hands each time you enter and each time you exit your baby's room.

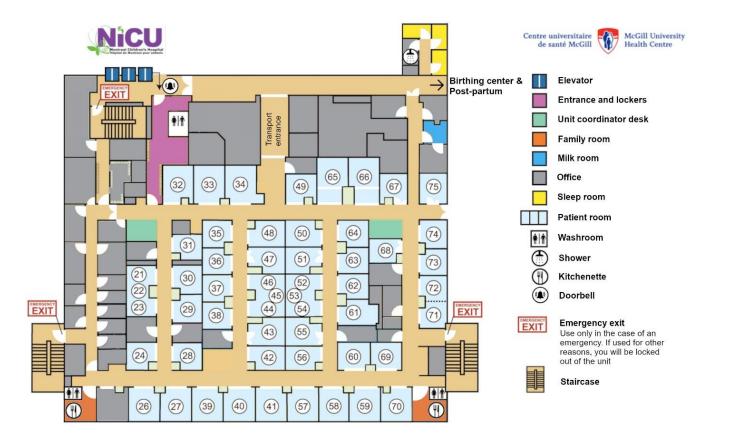




Inside the NICU

The NICU has 44 single patient rooms and 4 big rooms for twins or triplets. We invite you to take a virtual visit of the NICU: <u>Antenatal consult at MCH - NICU - YouTube</u>

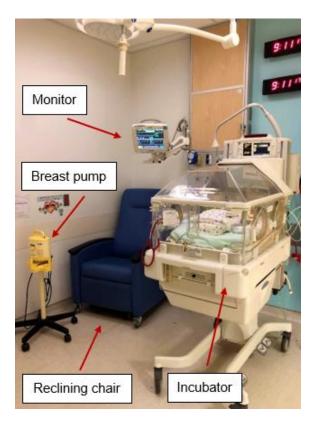
Here is a map of the NICU:





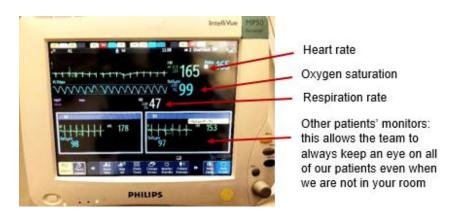


Here is what a typical room in the NICU looks like:



All babies are connected to a machine that monitors their heart rate (pulse), oxygen level (oxygen saturation) and breathing (respiration) rate. You will hear alarms that alert your nurse to check on your baby. An alarm does NOT always mean something is wrong with your baby. Please do not touch the monitors or alarms.

This is what the monitor looks like:







Family rooms and sleep rooms

The NICU has 2 family lounges. Each lounge has a coffee maker, a refrigerator, a microwave, a bathroom and a television. All food must be stored and eaten in the family lounge. No food is allowed in your baby's room. Drinks are allowed in your baby's room in a spill-proof cup. Please share the common space and keep it clean.

There are 3 sleeping rooms for parents and one shower near the NICU. Each sleeping room has a single bed. Availability of the sleeping rooms are assessed based on the needs of parents every day. Please tell your nurse if you think you need a sleeping room.



Below are some of the NICU staff you may meet during your baby's NICU stay:

A **neonatologist** is a doctor who specializes in newborns and will work with you to make medical decisions for your baby. There is always a neonatologist in the NICU.

A **nurse** will always be assigned to your baby. Your baby's nurse will change 2-3 times every 24 hours. Your baby's nurse may also be taking care of 1-2 other babies at the same time. The nurse monitors your baby, gives medications, helps to feed your baby, and helps to perform tests. The nurse will teach you how to participate in your baby's NICU care.

A **neonatal nurse practitioner (NNP)** is a nurse with specialized training in newborns and works with the neonatologist to provide medical care.

The Montreal Children's Hospital is affiliated with McGill University. **Trainees** in the NICU are both learners and caretakers of your baby. Trainees are always supervised. Examples of trainees:

- **Neonatal fellows** are doctors who have completed their pediatric training and are now receiving specialized training in newborns
- Pediatric residents are doctors who are receiving their pediatric training
- Medical students are training to become doctors





A **respiratory therapist (RT)** helps to manage any breathing problem your baby may have.

A **nutritionist** helps to manage your baby's growth. A nutritionist will make sure that you baby gets the right nutrients either through an IV (intravenous line) or through milk

A **pharmacist** helps to manage and prepare the medication for your baby. A pharmacist may also look at the mother's medications to know if there is an impact on your baby.

A **lactation consultant** helps families with breastfeeding. If your baby is not ready to feed at the breast, the lactation consultant can support you to pump your milk.

A **social worker** helps families cope with the stress of having a baby in the NICU. A social worker can also help you learn about financial support.

A **liaison nurse** follows your baby's progress and helps you and the team prepare and plan for discharge home or transfer to another unit or hospital.

An **occupational therapist** and **physical therapist** assess and promote your baby's motor skills. They may provide special exercises for your baby's development. An occupational therapist can also make sure that your baby can breastfeed or bottle-feed safely.

A **music therapist** uses music to support your baby's brain development and response to stress.

The **unit coordinator** helps to organize all of the activities in the NICU. The unit coordinator will greet you when you arrive in the NICU.





<u>Handwashing</u>

Handwashing is the most important way to keep your baby safe from infections. You can wash your hands with soap and water or use an alcohol-based rub for 20 seconds. There are 5 times you need to wash your hands:

- 1. When you arrive to the NICU
- 2. Before you enter your baby's room
- 3. Just before you touch your baby
- 4. After you touch your baby
- 5. When you leave your baby's room

You play an important role in keeping your baby safe from infections. Please ask, **"Have you cleaned your hands?"** to anyone that comes near your baby. We welcome the reminders!

Top 10 NICU Safety Tips

- 1. Do not leave large items near your baby's bed. We need to have easy access to your baby in case of emergency. Every room has options for storage of small items. For larger items (example: bouncy chair), speak to your nurse before bringing it to the NICU.
- 2. Raise the bed rails, and close and latch the incubator doors and/or portholes when you step away from your baby. The brakes on your baby's bed should also always be on.
- **3.** Ask your nurse for a Sleep Belt if you think you might fall asleep while holding your baby. This prevents falls.
- 4. Do not leave any valuable items in your baby's room. You can bring a lock to use one of the lockers at the front of the NICU if needed.
- 5. Your baby's identification bracelet must remain on them at all times. Let your nurse know if the bracelet is too tight or missing.
- 6. Do not bring any devices that heat or cook (example: kettle). You will find appliances in the Family Rooms. Laptops, cellphones, and chargers are allowed in your baby's room.





- 7. Do not bring flowers or balloons to the NICU. Use these items at home to celebrate your baby's discharge!
- 8. Stay home if you are sick (example: fever, cough, runny nose). Talk to your nurse about video chatting with your baby using NeoConnect if you cannot visit.
- 9. Remove all jewelry below your elbow and place your cellphone in a plastic bag. This helps to prevent infection.
- 10. Wash your hands. Don't be afraid to remind others to do the same!

Most importantly, SPEAK UP if you see anything unsafe in the NICU!

Words in the NICU

You will hear many new words in the NICU. Below are some common NICU words. Please ask us if we use a term that you don't understand!

Apnea – When a baby has a pause in their breathing. This is NORMAL for babies that are born early but can be scary to see. The monitor will alarm when this happens. The nurse will come to check on your baby during or soon after it happens. It goes away as the baby grows, and we make sure that there are no apneas before a baby goes home.

Blood gas ("Gas") – A blood test that measures the levels of carbon dioxide, acid (pH), minerals ("electrolytes"), and red blood cells ("hemoglobin").

Bradycardia ("Brady") – When a baby has a temporary drop in their heart rate. This is NORMAL for babies that are born early but can be scary to see. The monitor will alarm when this happens. The nurse will come to check on your baby during or soon after it happens. It goes away as the baby grows, and we make sure that there are no "bradys" before a baby goes home.

CBC (Complete Blood Count) – A blood test that measures 3 types of blood cells: 1) red blood cells ("hemoglobin") which deliver oxygen to the body, 2) white blood cells which fight infection and 3) platelets which prevent bleeding.

Corrected age – Your baby's current age if they were born early. For example, if they were born at 32 weeks gestation (8 weeks early) + 4 weeks since birth = 36 weeks corrected age.





CPAP (Continuous Positive Airway Pressure) – a type of breathing support that gives your baby constant pressure to keep their lungs open. Nasal prongs are used to deliver the pressure.

Culture – A test to check for infection. A culture can be taken from blood, urine, spinal fluid, or any body part.

Desaturation ("Desat") – When the oxygen level drops. This is NORMAL for babies that are born early but can be scary to see. The monitor will alarm when this happens. The nurse will come to check on your baby during or soon after it happens. It goes away as the baby grows, and we make sure that there are no "desats" before a baby goes home.

EBM (Expressed Breast Milk) – Milk that a mother has pumped. EBM has 67 calories per 100 ml ("EBM 67"). We can add calories ("EBM 81") by using a liquid or powder called a fortifier.

Gavage – When a baby is fed through a tube. An NG (nasogastric) tube goes through the nose to the stomach and an OG (orogastric) tube goes through the mouth to the stomach.

Glucose – The level of sugar in the blood. It is measured with a blood test on your baby's heel. Hypoglycemia is when the glucose is low.

Isolette/Incubator – A special bed for your baby that provides heat and humidity.

Jaundice – The yellow color in a baby's skin. It is caused by the breakdown of blood cells (they release a chemical called "bilirubin") and may need special lights to treat ("phototherapy").

Murmur – An extra heart sound heard with a stethoscope. It can be normal or abnormal.

NPO – When a baby is not receiving any milk ("nothing by mouth").

PHM (Pasteurized Human Milk) – Breastmilk that has been donated by other mothers to the Quebec milk bank. The donor mothers are tested for infection, and their breastmilk is screened and pasteurized. It has some but not all of the same benefits as your own breastmilk. PHM has 67 calories per 100 ml ("PHM 67"). We can add calories ("PHM 81") by using a liquid or powder called a fortifier.





PICC (Peripherally Inserted Central Catheter) – An intravenous (IV) line that is put in the arm or leg and goes into a large vein near the heart. We use a PICC line if your baby needs an IV line for many days or weeks.

TFI (Total Fluid Intake) – This is how much liquid your baby receives in 24 hours. It is a combination of any fluid or medicine from an IV (intravenous) line and any milk.

TPN (Total Parental Nutrition) – IV (intravenous) fluid that gives your baby nutrition. It looks yellow in the IV line and can be given with fat ("lipids") which look white in the IV line.

Umbilical Catheter – An IV (intravenous) line that is placed in a blood vessel of the umbilical cord. A UAC (umbilical arterial catheter) is placed in the artery and can measure blood pressure and be used to do blood tests. A UVC (umbilical venous catheter) is placed in the vein and can be used to give your baby fluid and medicine.







CHAPTER 2 -Parenting in the NICU

You are the most important person in your baby's life. You are the most vital member of your baby's team in the NICU. We encourage you to participate in your child's care as much as possible.

What can I do in the NICU?

Medical Rounds

Every day, the NICU team visits each baby's room to discuss their health and treatment plan. These meetings are called Rounds. Rounds take place every day from **9:30 am to 12:00 pm** but may occur a bit earlier or finish later on the weekend. You are an important member of your baby's NICU team, so we hope you can join us during Rounds for your baby. Please share your input and ask questions. If you cannot attend Rounds, a NICU team member can update you when you are available in person or by phone.

Baby Care

There is a lot you can do to take care of your baby in the NICU. Your nurse can teach you how to keep your baby comfortable, clean your baby, change your baby's diapers and feed your baby. You can learn other skills, like giving medicine, when you feel ready. We also invite you to decorate your baby's room with small toys and pictures of your family.

You might find these videos about baby care in the NICU helpful:

- Soothing methods: <u>V Leaflet 6 Soothing methods YouTube</u>
- Diaper change: <u>V Leaflet 4 Diaper change YouTube</u>
- Swaddling: <u>V Leaflet 5 Swaddling YouTube</u>





Feeding

Learning when your baby is ready to breast feed or bottle feed is an important step to going home. Your baby might be a candidate for our Family Driven Feeding (FDF) program.

You might find this video about feeding helpful:

• Learning to feed your baby: Learning to Feed Your Baby (youtube.com)

Skin-to-Skin ("Kangaroo") Care

Skin-to-skin care or Kangaroo Care is when you hold your baby on your chest. Skin-toskin care helps your baby sleep better, breathe better, gain weight and fight off Infection. Skin-to-skin care can help you connect with your baby, cope with the "baby blues" and make more breastmilk. It is best to do skin-to-skin for several hours each day so that your baby can get comfortable (use the bathroom before!). Your baby loves your natural smell so please avoid perfume. If your baby is not ready for skin-to-skin care, there are other types of touch that are great for your baby, like hand-hugging. Talk with your nurse about what type of touch is best for your baby.

You might find these videos about skin-to-skin care and touch helpful:

- Skin-to-skin ("Kangaroo") Care: <u>V02 Kangaroo care 20211220 1 YouTube</u> and <u>Lactation Kangaroo care - YouTube</u>
- Touch: <u>V Leaflet 3 Touch YouTube</u>
- Holding: <u>V Leaflet 7 Handling YouTube</u>

Brain Development

Learning and brain development begin even before your baby is born and continue in the NICU. Talking, singing and reading to your baby help your baby to develop language and other healthy skills. Every baby in the NICU gets a free book in their preferred language through our "Books for Babies" program. Ask your nurse for a book if you don't see one in your baby's room. You can also bring your own books from home!





You might find these links about language helpful:

• Language passport:

language passport pamphlet eng.pdf (thechildren.com)

- Talk to me video:
 - English : <u>Talk to Me English YouTube</u>
 - Français: Parle Moi YouTube
 - Arabic عربي : <u>Talk to Me Arabic (vimeo.com)</u>
 - Farsi فارسى: <u>Talk to Me Farsi (vimeo.com)</u>
 - Hebrew אָברִית: <u>Talk To Me Hebrew (vimeo.com)</u>
 - Chinese Mandarin 普通话: Talk to Me Mandarin (vimeo.com)
 - Romanian Română : Talk to Me Romanian (vimeo.com)
 - Spanish Español : Talk to Me Spanish (vimeo.com)
 - Bulgarian български : <u>Talk to Me- Bulgarian (vimeo.com)</u>
 - Tamil தமிழ் : <u>Talk to Me Tamil (vimeo.com)</u>

NeoConnect (voice recorders & video chats)

We know that you can't always be with your baby, and that's ok! NeoConnect offers two ways to connect with your baby even when you're away. You can record yourself talking, reading or singing and your baby will listen when you're away. Ask your nurse for a voice recorder. You can also do a video call with your baby through WhatsApp. Ask your nurse how to set up a time to see your baby on a video call.

You might find these links about NeoConnect helpful:

- Voice recorder instructions: <u>NeoCardio Lab NeoConnect Program / Programme</u> <u>NéoConnect</u>
- How to download WhatsApp: <u>NeoCardio Lab NeoConnect Program /</u> <u>Programme NéoConnect</u>







Stories from NICU Parents

Hearing stories from other NICU parents is a great way to learn how to parent in the NICU. Here are stories from some of our former NICU parents:

- The Story of Florence, Elise and Antoine (French): <u>L'histoire de Florence, Elise et</u> <u>Antoine / The Story of Florence, Elise and Antoine - YouTube</u>
- The story of Massimo, Priyanka and Anthony (English): <u>The story of Massimo,</u> <u>Priyanka and Anthony - Premature birth at 24 weeks - YouTube</u>
- The story of Teo, Ode and Marko (English): <u>The story of Teo, Ode and Marko -</u> <u>Congenital Diaphragmatic Hernia - YouTube</u>
- The story of Noah, Alina and Armen (English): <u>The story of Alina, Armen and</u> <u>Noah – YouTube</u>
- The story of Emmanuel, Sandra and Thierry (English): <u>The story of Emmanuel</u>, <u>Sandra and Thierry - Congenital heart defect / Transposition of great vessels –</u> <u>YouTube</u>

Self-Care

You cannot take care of your baby until you take care of yourself. Having a baby in the NICU is one of the most stressful times in a parent's life. There will be some good days, but there will also be hard days. There is no "right" way to feel, and there is no "right" way to parent in the NICU. We are here to support whatever is best for you and your baby.

Some parents blame themselves for their baby's NICU stay. Please remember that this is not your fault. There is nothing you did or didn't do to cause your baby to be in the NICU. Some challenges are outside of our control. Many parents find it helpful to talk through these feelings, and we are available to listen at any time.

We have a psychologist available to meet with any parent. **Please let your NICU team know if you would like to meet with a psychologist.**





Here is what other parents have found helpful:

- Learn about the typical NICU stay for babies like your baby so you know what to expect
- Give yourself time to adjust to the NICU. Take it one day at a time.
- Take time for yourself. Do not spend every moment in the NICU. Eat, rest and spend time doing the things you enjoy. This is a marathon, not a sprint!
- Ask for help. Loved ones can help with food, shopping, or cleaning.
- Ask the NICU staff any questions you may have.
- Talk with someone about how you're feeling. This can be a spouse, family member, friend or NICU staff.
- Get involved in your baby's care even if it is a bit scary. Your nurse will guide you every step of the way.





CHAPTER 3 -----Breastfeeding in the NICU

We understand that feeding can bring up a lot of emotions for parents. We want to make sure you have all of the information about breastfeeding to help you make an informed decision with your baby's NICU team.

"Liquid Gold"

Your breastmilk is the optimal food for your baby. It is made to meet your baby's specific needs.

Benefits of breastfeeding for babies in the NICU:

- Fewer infections
- Better digestion
- Helps with brain development
- Helps your baby go home sooner

Benefits of breastfeeding for the mother:

- Increases bonding to your baby
- Better coping during this stressful time
- Less risk of breast cancer

Depending on your baby's needs, there are 3 ways your baby may feed your breastmilk:

- At the breast
- Through a feeding tube
- With a bottle

The BEST way to make LOTS of BREASTMILK is to start hand expressing frequently as soon as the baby is born.





Golden Rules

- 1. Start hand expressing early. Ideally, within 1-2 hours after birth. Express for 10-20 minutes every 3 hours. Start as soon as you can. It's never too late!
- Every drop counts. Do not throw away any breast milk. Drops are normal. 2. Collect them in a syringe and have someone bring them to your baby. Even if there are no drops, continue to stimulate regularly.
- Express 8 times each day. First, start with hand expression then add in a breast 3. pump.

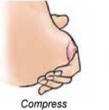
Manual Expression

- To get milk to flow, start by massaging your breast gently for 1-2 minutes.
- Make a "C" with your thumb and index finger.
- Place your thumb and your index finger on either side of the nipple, 2 to 5 cm • away.
- Press your fingers into your breast by pushing back into your ribs.
- Bring your thumb and index finger together. You do not need to press hard.
- Repeat the motion several times, repeating the same rhythmic movements.
 - Do not slide your fingers along your breast.
 - Maintain firm pressure on your breast without stretching the nipple.
 - Work your way around the breast with your fingers until it is emptied.

Collect drops into a medicine cup. Once all of the drops are in a cup, you can then suck them into a syringe to store.



Press (back towards your chest)











Pumping Routine

- 1. Wash your hands before pumping
- 2. Pump 8 times per day, including at least once overnight (between 00:00 and 05:00) to establish good milk production
- 3. Before your milk comes in, pump each breast for 15 minutes. (You can pump both breasts at the same time or one at a time). Once your milk is in, pump until breasts are "emptied" (until very low milk flow).
- 4. Breast milk must be put in syringes or bottles provided by the hospital.
- 5. Put a sticker with your baby's name on each bottle. Write the date and the time the milk was pumped. Ask for stickers at the front desk of the NICU
- 6. If you are sick (cold, flu, gastroenteritis, COVID-19) your baby still needs your milk. It will provide antibodies, which protect against infection.

<u>Cleaning your pump kit</u>

Clean after each use. Take your kit apart in the bowl or basin given. Wash each piece with hot soapy water (no soaking). Do not wash tubing. Do not leave the tubing on or in the pump when you leave the NICU.

Disinfect your kit once a day. Boil in water for 5-10 minutes or place in the dishwasher or use a pump sterilizing bag in the microwave. A microwave for pump kit disinfection is available in the NICU.

Transportation and Storage of breastmilk

- Fresh or refrigerated breast milk must be put in the refrigerator outside the milk lab in the NICU. Place it in the bin with your baby's name.
- When you bring milk from home, use an insulated lunch bag or cooler with an ice pack.
- At home, put your milk in your refrigerator. If your milk is at home for more than 24 hours, please freeze.
- Frozen milk must stay frozen on your way to the hospital and must be placed in the milk lab freezers when you arrive. Our freezer space is limited so please plan to store some frozen milk at home.
- Breast milk can be kept for 6-12 months in a freezer.





- Hand expression of breastmilk: Manual expression of breastmilk YouTube
- Using the beast pump: <u>Using the breast pump YouTube</u>
- Increasing your breastmilk supply: <u>Maximizing breastmilk production YouTube</u>
- Milk storage and pump kit cleaning: <u>Milk storage and pump kit cleaning -</u> <u>YouTube</u>

Frequently Asked Questions

Do I need to express my milk?

Yes! Babies in the NICU will not be able to breastfeed right away. If you express drops of breastmilk starting 1-2 hours after birth, you will have better milk supply in the long term. If you do not express breastmilk early, your body will not know that it needs to make milk.

Do I have access to a breast pump at the hospital?

Yes. You can ask your postpartum nurse to bring you a breast pump to your room after giving birth. Remember to ask for help with expressing milk with your hands as soon as possible. There is also always a pump in your baby's NICU room. A NICU nurse will give you a kit for hand expression and to use with a pump.

Do I need a breast pump at home?

Yes. You need to pump 8 times every 24 hours so you will need a pump at home. An electric breast pump is better than a manual pump.

You can purchase or rent a pump at stores that sell breastfeeding supplies (e.g. Walmart, Melon and Clémentine) or buy online. There are organizations that can help you (e.g. Entre Maman et Papa, Préma-Québec). Do not buy a used pump (think of it like a toothbrush!).

The cost to rent is usually ~\$90 per month. A refundable credit card deposit is usually required. The cost to buy a pump is usually \$200-300 for a single pump (pump one breast at a time) or \$350-450 for a double pump (pump both breasts at the same time).





Are there reasons why someone should not breastfeed?

Breastfeeding contraindications are rare. Even if you are sick, your baby still needs your milk, and your milk helps to prevent infection. It is safe to breastfeed while taking most medicines because only a small amount ends up in your breastmilk. If you have questions about any medicine, breastfeeding consultants and pharmacists are here to help.

If I had breast surgery (reduction or augmentation), will I still be able to make milk?

You can still make milk by following the same recommendations. Your maximum milk supply will mostly depend on where the cut was made, the breast mass removed (for reductions), and the time between your surgery and now. Breastfeeding consultants will work with you to get your best milk supply.

Will I be able to meet with a breastfeeding consultant?

Yes! Just ask your nurse to contact us, and we will be happy to help.

What if I can't or choose not to breastfeed? What if I don't have enough breastmilk?

We are here to support you and your baby in the NICU. You and your baby's NICU team will decide what milk or combination of milk is best for your baby. We have different kinds of formula in the NICU to meet your baby's nutritional needs. Some babies in the NICU also qualify for Pasteurized Human Milk (PHM) which is breastmilk that has been donated by other mothers in Quebec. The donor mothers are tested for infection, and their breastmilk is screened and pasteurized. Talk to your NICU team to learn more.





CHAPTER 4 Leaving the NICU

Leaving the NICU ("discharge") can be both an exciting and scary time. Your baby is "graduating", but it is also a big transition. We want you to have time to prepare for this big step. It is never too early to ask your baby's NICU team:

- "How long do you think my baby will be in the NICU (days, weeks, months)?"
- "Where will my baby go when they leave the NICU at the Montreal Children's Hospital?"

Where will my baby go after the NICU?

Most babies go to one of the following places when they leave Montreal Children's NICU:

<u>Home</u>

Babies are ready to go home when:

- They can breathe by themselves and don't need their breathing or heart rate to be monitored.
- They can drink milk by the breast, bottle or a feeding tube and are gaining weight. If your baby is going home with a feeding a tube, you will need to learn how to use the feeding tube.
- They can stay warm in a regular crib.
- Any medical problem they had in the NICU is gone or can be managed at home

Sometimes babies are not ready to go home, but they don't need the high level of intensive care at the Montreal Children's Hospital NICU. If this is the case, your baby will be transferred to either the Pediatric Medicine Ward at the Montreal Children's Hospital or a NICU/Nursery at a hospital near your home.





Pediatric Medicine Ward at the Montreal Children's Hospital

Your baby will have their own room with a bathroom, a window and a couch for parents to sleep. Babies who go to the Pediatric Medicine Ward:

- Are 35 weeks corrected gestational age or older
- Weigh 2kg or more
- Don't need any help to breathe or need only oxygen through small nasal prongs ("low flow")
- Continue to need daily care by a Pediatrician or other healthcare providers at the Montreal Children's Hospital

NICU/Nursery at Another Hospital

Each hospital is a little different. If you have a hospital preference, please let your baby's NICU team know. In general, babies who go to a NICU/Nursery at another hospital:

- Don't need any help to breathe
- Continue to need daily care by a doctor and nurse

How can I get ready to go home?

It's never too early to prepare for life at home with your baby. This is true even if your baby is going to the Pediatric Ward or another hospital before going home. Below are the main items that are important to get ready before going home:

Medication

- Know what medicine your baby will need to take at home
- Learn how to prepare and give your baby the medicine. Your baby's nurse can teach you.
- Find a pharmacy close to your home.
- Get the prescription filled before going home. The NICU can fax the prescription to your pharmacy if you provide us with the fax number.





<u>Milk</u>

- Know what type of milk your baby will feed at home.
- Learn how to prepare your baby's milk if your baby is not exclusively breastfeeding. The nutritionist or nurse can teach you.
- Get any formula you need before going home. If your baby requires a special formula, you may need a prescription. Talk to your baby's NICU team.
- Take home the breast milk that you stored in the NICU.
- If your baby is going home with a feeding tube, learn how to use the feeding tube. Your baby's nurse can teach you.

Family Doctor/Pediatrician

- Every baby should have a primary care provider before leaving the NICU. This is usually a family doctor, a pediatrician or a midwife. The doctors in the NICU don't provide primary care after your baby leaves the NICU.
- You are responsible for finding a primary care provider for your baby. We can provide you with a list of doctors in your area and a consult form. Ask your baby's NICU team for the list and consult.
- You can also find a family doctor at <u>Québec Family Doctor Finder</u> <u>Gouvernement du Québec (quebec.ca)</u>
- You will be given a summary of your baby's stay in the NICU. Give a copy of this document to your baby's primary care provider.

Follow-Up Appointments

- Make sure we have the right phone number(s) to reach you for any follow-up appointments your baby needs. Talk to the unit coordinator at the front desk.
- A CLSC nurse will see every baby that leaves Montreal Children's Hospital within one week. They will check your baby's weight and make sure your baby is doing well at home. The CLSC will call you to schedule an appointment. You will need to sign a CLSC referral consent form.
- Know what other follow-up appointments your baby needs. Sometimes you will know the time and date of these appointments before you leave the NICU. Other times, you will be called at home with the appointment date and time.





Car Seat

- If you are taking your baby home in a car, you must have a valid, non-expired car seat (you can use a stroller or carrier if you are taking public transportation) Bring your car seat to the NICU before going home. Your baby's nurse will help you make sure your baby is safe in the car seat.
- Read your car seat manual and install your car seat in your car safely before you go home.
- For more information about choosing and installing the car seat in your car, please visit <u>Choosing the right seat at the right time - SAAQ (gouv.qc.ca)</u>

Life at Home

Bringing your baby home after the NICU is a big milestone! It will look different for every baby and family. Here are a few key items to remember:

Safe Sleep

Depending on why your baby is in the NICU, your baby might need to sleep on their side or tummy in the NICU. We might use blanket rolls or pillows to keep your baby in a good position. This will change when they go home. At home, **the safest way for your baby to sleep is on their back in their own crib with only a sleep sack or light swaddle.**

Your baby will practice sleeping on their back before going home. Your baby will only go home when they are ready to sleep on their back.

Very few babies who are in the NICU need a breathing monitor at home (example: babies who go home with oxygen). **Please do NOT buy a breathing monitor for home.** There is NO evidence that home monitors decreases the risk of Sudden Infant Death Syndrome (SIDS). Monitors that you buy can give you a false sense of reassurance or make you worry for no reason. There are better ways to protect your baby from SIDS:

- Always put your baby to sleep on their back in their own crib
- Keep pillows, blankets and stuffed animals out of the crib
- Sleep in the same room as your baby
- Do not smoke
- Breastfeed





<u>Crying</u>

Sometimes babies cry because they are hungry, cold, tired, have a dirty diaper or in pain. Many times, babies keep crying even when you have tried everything to calm them down. This is normal. Remember, crying won't hurt your baby, but it can be hard to listen to.

When you can no longer stand to listen to your baby cry:

- Lay your baby down gently in their crib
- Step away and leave the room
- Call someone (partner, friend)
- Check on your baby every 15 minutes
- WAIT until you have calmed down to pick your baby up again

Never shake a baby. You can cause brain damage or even kill your baby.

If you are feeling angry or overwhelmed, there is a free, confidential parents' helpline: 1-800-361-5085

When to See or Call a Doctor?

The doctors in the NICU cannot give you advice or care for your baby after your baby leaves the NICU.

If you have a concern about your baby's health after they leave the NICU, you should call your baby's primary care provider (family doctor/pediatrician) or **speak to an Info-Santé nurse, just dial 8-1-1**

Common reasons to take your baby to the doctor or Emergency Room right away:

- Rectal temperature 38.0°C (100.4°F) or higher, and your baby is less than 3 months old (3 months corrected age if born early)
- Hard to wake up or much sleepier than usual
- Vomiting a lot
- Has trouble breathing or breathing very fast
- Is pale or has abnormal color
- Has other symptoms that are worrying you





CHAPTER 5 NICU Resources

Hospital Services

<u>Hospital Wi-Fi</u>

Network name: CUSM-MUHC-PUBLIC

- Username: public
- Password: wifi

Food & Amenities

- **Cafeteria:** Basement level (S1) in Block C (Royal Victoria Hospital)
- **Depanneur (Convenience store):** Basement level (S1) in Block A of the Montreal Children's Hospital
- **Restaurants and shops:** Ground floor (RC) in the Larry and Cookie Rossy promenade that connects the Montreal Children's Hospital to the Royal Victoria Hospital and basement level (S1) in Block A of the Montreal Children's Hospital
- **ATMs:** Basement level (S1) in Block A of the Montreal Children's Hospital and basement level (S1) and ground floor (RC) in Block C (Royal Victoria Hospital).

Child Life Services

- Child Life specialists work to improve the quality of life for patients and their families. They can also help brothers and sisters cope when a baby is in the NICU.
- Child Life specialists hold activities in the NICU, but they can also meet with you and your baby individually. Ask your baby's NICU team if you would like to meet with a Child Life specialist





Just for Kids Sibling Park

- Just for Kids Sibling Park is a drop-in daycare for siblings at the Montreal Children's Hospital. Priority is given to neonatal and pediatric intensive care unit siblings.
- Location:
 - Child Life Activity Centre BS1.2702 (near the giant teddy bear)
 - Hospital phone number: 514-412-4400
 - Room extension: 62309
- Schedule (subject to change, always refer to their poster on the unit)
 - Regular hours
 - Friday: 4 p.m. 7 p.m.
 - Saturday and Sunday: 12 p.m. 6 p.m.
 - Summer hours (June 25th Labor Day):
 - every day from 12 p.m. 6 p.m.
- For more details, please refer to this document: JFK Brothers and Sisters Park Program Description (Eng Fr)

Spiritual Care Services

- The Spiritual Care team is available to meet with families from all faith traditions. Ask your baby's NICU team if you would like to meet with a Spiritual Care professional
- The multi-faith chapel (room A 02.0045) is always open to everyone.

Family Resource Centre

- This is a health library just for parents with librarians that can guide you to the right resources about children's medical conditions and help you learn more about support groups.
- Located in Block A on the ground floor (RC) and online at: <u>National Bank Family</u> <u>Resource Centre | Montreal Children's Hospital (thechildren.com)</u>





Ombudsman (Complaints and Quality Commissioner)

- The hospital Ombudsman helps patients and families by investigating and helping to resolve complaints.
- We invite you to discuss any concern with the NICU team, but if the issue cannot be resolved, parents are welcome to contact the Ombudsman.
- To reach the Ombudsman:
 - Phone number: 514-412-4400 ext 22223
 - Email: ombudsman@muhc.mcgill.ca
 - MUHC complaint form: <u>https://muhc.ca/sites/default/files/docs/MUHC_Complaint_Form.pdf</u>

Insurance and Benefits

If you have questions about the information below, please ask to speak to a social

Declaration of Birth

- You will need to register your baby's birth to apply for insurance and benefits.
- You have 30 days to complete the Declaration of Birth Forms on paper or online. If your baby was born at the Royal Victoria Hospital, you should have received a paper copy. The online forms can be found here: <u>Electronic Declaration of Birth</u> (gouv.qc.ca)

Quebec Parental Insurance Plan (QPIP)

- QPIP pays benefits to anyone taking maternity, paternity or adoption leave. Your baby does not have to be in the NICU to qualify for QPIP. You must have received work income to qualify.
- For more information and to apply, visit <u>Québec Parental Insurance Plan</u> (gouv.qc.ca) or call 1-888-610-7727





Family Caregiver Benefits for Children

- You are eligible for these benefits while your baby is in the hospital if you would be eligible for regular employment insurance (EI)
- You will be paid 55% of your usual income for a maximum of 35 weeks.
- You cannot receive QPIP and Family Caregiver Benefits at the same time. You can pause QPIP when you receive Family Caregiver Benefits and re-start QPIP when your baby is discharged.
- A medical certificate will need to be signed by your baby's doctor.
- For more information and to apply, visit <u>Caregiving benefits and leave -</u> <u>Canada.ca</u>

Supplement for handicapped children (Regie des Rentes du Québec-Provincial)

- All babies born at 29 weeks' gestation or less qualify for this supplement. This does not mean that your baby is "handicapped."
- Some other permanent medical conditions qualify for this supplement. Talk to your baby's doctor or social worker to see if you are eligible.
- Your baby's doctor will need to fill out part of the forms.
- For more information and to apply, visit: <u>Retraite Québec Supplement for</u> <u>Handicapped Children (gouv.qc.ca)</u>

Private Insurance

• Don't forget to register your baby if you have private insurance.





Espresso Hotel

- Lodging, meals and transportation for families of the Cree Nation of Eeyou Istchee
- Located at 1005 Guy St, Montreal, QC H3H 2K4
- For information and to determine your eligibility, ask to speak to a social worker, call 514-989-1393 ext. 73270 or visit Lodging and meals | Cree Health

Ronald McDonald House

- A temporary home away from home for families who live more than 55 km from Montreal
- Located at 5800 Hudson Road, Montreal, QC H3S 2G5
- For information and to determine your eligibility, ask to speak to a social worker, call 514-731-2871 or visit <u>Ronald McDonald House of Montreal Home</u> (manoirmontreal.qc.ca)

<u>Ullivik</u>

- Lodging, meals and transportation for families from Nunavik
- Located at 695 Av. Orly, Dorval, QC H9P 1G1
- For information and to determine your eligibility, ask to speak to a social worker or call 514-932-9047

Kat Demes Pavilion

- Free housing for parents of sick children facing long stays at the Children's, only a few minutes from the hospital, featuring private rooms and common areas.
- Located at 5004 Blvd. De Maisonneuve Ouest, Westmount, QC H3Z 3B9.
- For information and to determine your eligibility, ask to speak to a social worker





Recommended Links

• Canadian Premature Babies Foundation: Parent led organization providing education, support and advocacy for premature babies and their families in Canada

https://www.cpbf-fbpc.org/

- Caring for Kids: Information for parents about children's health from the Canadian Paediatric Society https://caringforkids.cps.ca/
- Fondation En Coeur: Information and support for children born with heart disease and their families in Quebec (in French only) <u>https://en-coeur.org/</u>
- From Tiny Tot to Toddler: A guide for parents from Quebec National Institute of Public Health.

https://www.inspq.qc.ca/en/tiny-tot/consult-the-guide

• **Préma-Québec**: Provides psychological and financial support to parents of premature babies in Quebec

http://www.premaquebec.ca/en





From Tiny Tot **B**





Pour les parents d'enfants prématurés





<u>Acknowledgements</u> We would like to thank Ms. Adriana Di Marco, a former NICU mother, for reviewing the handbook.

Montreal Children's Hospital July 2024