ONTARIO NEONATAL FOLLOW-UP PROGRAM

ONTARIO'S NEONATAL FOLLOW-UP SYSTEM

There are currently 25 Neonatal Follow-Up Programs (NFUPs) across Ontario. In 2012/2013, 14,000 high-risk infants visited a clinic and 3,000 new patients were enrolled.

The Provincial Council for Maternal and Child Health (PCMCH) convened a group of neonatal follow-up providers to strengthen and optimize the system of follow-up for the province.

To facilitate a coordinated system of care for high-risk infants, collaboration is required between the NFUP clinics, community providers, family doctors and paediatricians, public health units and other relevant care providers.

About The Neonatal Follow-Up Program

The Ontario Neonatal Follow-Up Program (NFUP) provides assessment, monitoring, identification, and early intervention for high risk infants who meet neonatal follow-up criteria (see Appendix A for full criteria). The NFUP's role is essential within the system of care in Ontario to address the needs of these infants and children who have, or may develop a physical, developmental and/or behavioural disability.

What We Do

Specific services offered by the NFUP vary by each program. Please contact your local program to find out what services are available in your area. Generally, the NFUP serves several purposes, including:

- Monitoring infants who have a greater chance for challenges in physical, motor, cognitive, social, language and learning development.
- Examining care and establishing best care guidelines for emerging populations such as congenital cardiac conditions and neonatal encephalopathy.
- Providing anticipatory guidance, teaching parents about their child and his/her developmental pattern, and fostering parental resilience.
- Providing informed monitoring of children with a greater chance high prevalence, low severity developmental challenges to facilitate early identification of conditions that occur as children enter school.
- Provide expertise for families, and where available, provide local expertise for communities and schools to foster earlier identification and facilitate earlier remediation and accommodations thereby minimizing disability and cost to the system.

Why It's Important

Some infants who were cared for in a NICU are referred to the NFUP. Alternatively, others who meet specific criteria can also be referred to the clinic by a family doctor or paediatrician if there are concerns about development. The NFUP's role is to work collaboratively with you to focus on the child's development and collaborate with you. It is important that families attend their follow-up appointments to ensure early identification and intervention of any developmental issues a child might have.

Please talk about the importance of the NFUP with families you work with and refer them to their local program if they have any questions or concerns.

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Frequently Asked Questions

Q: What are the criteria for follow-up?

A: Babies should be followed closely by their primary care provider and referred on if there are concerns. Please see **Appendix A** for full criteria for referring a baby to the NFUP.

Q: What services are provided by the NFUP?

A: The services offered vary by each NFUP clinic and are dependent on the qualifications of staff available and needs of the child. There is a common focus, however, on the developmental needs or 'touchpoints' identified for each age. All programs screen for developmental delays and other domains of development, make referrals to treatment centres and make referrals to community programming, therapy or early intervention. The NFUP clinic do not provide direct therapy and children should be referred on if they require that service.

Q: How often do families have to attend appointments at the NFUP?

A: Visit schedules can vary by each NFUP clinic. The recommended visit schedule for most children is 6 weeks, 4, 8, 12, 18 and 36 months of age (corrected).

Q: Are NICUs responsible for setting up a family's first neonatal follow-up appointment?

A: Generally, the discharging NICU is responsible for assuring a first appointment has been made. However, a referral can be made by another provider if a baby is missed.

Q: Are there resources available for families and parents?

A: Yes. Please visit http://www.pcmch.on.ca/nnfu-resources-parents-families/, for a list of resources to educate families about the NFUP and potential ways to support their child. As well, click **HERE** to download an information package with resources for parents.

Q: Are there alternatives to having a family travel long distances to attend a clinic visit

A: Yes. We want to work with families to assure that the visits are productive and feasible. Sharing care with sites closer to home is an option and can be explored.

Q: What about children who were initially missed in follow-up…can they be re-referred?

A: Yes. The goal is to have children seen. Those who missed appointments can still be re-enrolled.

Q: How do I contact a NFUP clinic to make a referral?

A: Please access the directory of the Ontario NFUP to find the clinic in your area.

Contact Us

For more information about the Ontario Neonatal Follow Program or to find a clinic in your area, visit

www.pcmch.on.ca

Appendix A: Criteria for Referral to Neonatal Follow-Up Program

Level of Care	Follow-Up Criteria
Level IIc (Regional): Low-moderate risk of neuro-developmental impairment	• GA >30+0 to 33+6wks • BW <3rd percentile or Head Circ <3rd percentile • Hyperbilirubinemia exchange transfusion level – Severe > 425 µmol/L or exchange transfusion • Symptomatic Hypoglycemia <2.2mmol/l over 6 hours, requiring intensive care monitoring and treatment. • Intrauterine death of one twin (if surviving twin is <36+6wks GA) • Maternal drug use/Neonatal Abstinence Syndrome (NAS) requiring pharmacological treatment • Meningitis, not requiring Level III care • Multiples ≥ 3, >30wks GA • Perinatal acidosis (pH<7 plus or Apgar <5 @ 10mins) • Sarnat Level 1/Mild neonatal encephalopathy or Level 2 encepholapathy that does not require Level III NICU • Periventricular leukomalacia >30wks GA, up to and including term • Seizures – Any neonatal seizure • Twin-to-twin transfusion syndrome – requiring laser ablation, born between 30+0 to 36+6 wks GA • Moderate/late pre-term infant failing to establish full oral feed at term equivalent
Level IIIa (Tertiary): Moderate-High risk of neuro-developmental impairment	• GA <30 wks gestation • BW < 1250g • Bronchopulmonary dysplasia– oxygen dependence / respiratory support at 36 wks corrected GA • Hypoxic ischemic encephalopathy Sarnat Level 2 or 3/Moderate or severe encephalopathy • Therapeutic hypothermia • Intraventricular hemorrhage ≥ Grade III • Meningitis – Fungal or Bacterial (excluding staph epidermis) requiring Level 3 support • Necrotizing enterocolitis requiring surgery or penrose drain • Neonatal stroke • Periventricular leukomalacia <30 wks • Twin-to-twin transfusion syndrome – requiring laser ablation, born at <30 wks GA • Viral encephalitis requiring Level III NICU care • Other: Based on site specific capacity
Level IIIb/ Children's Hospital (Quaternary): Moderate-High risk of neuro-developmental	• Congenital diaphragmatic hernia • Omphalocele • Cyanotic congenital heart disease requiring pump or extracorporeal membrane oxygenation within the neonatal period • Extracorporeal membrane oxygenation • Children with medical complexity ≥ 3 subspecialists involved