



Introduction

The Canadian Neonatal Follow-Up Network (CNFUN) is a collaboration between Neonatal and Perinatal Follow-Up Programs in Canada and their multidisciplinary team members. It was developed in liaison with the Canadian Neonatal Network (CNN) to facilitate collaboration in research, integrated data collection, knowledge translation and to improve the quality of care and long term outcomes of children seen in their programs. Funding to establish the CNFUN database was obtained through a 2008 CIHR Team grant in Maternal-Infant Care (MiCare).

CNFUN's Mission & Goals

CNFUN's mission is ***to be a network of health care professionals dedicated to improving the care of newborns and children at high risk of adverse outcome as a result of conditions requiring intensive medical care.***

Specific CNFUN goals include:

- Establish a network of Canadian health care professionals involved in neonatal / perinatal follow-up programs
- Develop a common standardised set of assessments to be done at standardised ages and common definitions to create the CNFUN data set.
- Develop a national electronic database of the CNFUN dataset and link it to neonatal and perinatal datasets (e.g., CNN, CPN, CAPSNet, etc).
- Use the CNFUN database to improve health care and it's provision by providing accurate up to date information for decision making, identifying best practices and facilitating the acquisition of long term outcomes data in neonatal, perinatal and early intervention research.
- Be advocates for our population of children by ensuring that the best evidence is translated into practice.

Administrative Structure

A Steering Committee will oversee CNFUN activities and make policy decisions. Site representatives from participating institutions provide representation, input and liaison for participating institutions. The Steering Committee will be appointed for the first 3-5 years and will be elected thereafter. It will be composed of:

- The director of the network;
- A member who is a member of the Quebec consortium;
- 4 members representing different geographic regions of Canada; and
- Members representing allied health care professions.

The Network Coordinating Centre will provide administrative support to CNFUN, its committees and institutional and individual members.

Membership

Membership is open to all health care professionals with an interest in neonatal/ perinatal follow-up. There are two types of membership – institutional and individual.

Institutional Membership is open to all institutions which have a neonatal or perinatal follow-up program.

- **Application:** to be submitted to the Chair of the Steering Committee
- **Membership fee:** none
- **Obligations:** membership requires commitment by the institution to collect and contribute the data to the CNFUN data set. Institutional members agree that their data may be used at the discretion of the network, within guidelines agreed upon between network members.
- **Benefits:** The database will be maintained and error checked by CNFUN and the institution's own data will be available for its own use. The institution will have open access to the national CNFUN database through the liaison member. Research projects using network data will need to be approved by the Steering Committee.
- **Representation:** The institution will appoint a liaison representative who will represent the institution for policy decisions of the Network and who will vote for election of members of the Steering Committee.
- **Renewal and Termination:** Institutional membership is on-going until terminated by the institution, by written notice to the Chair of the Steering Committee. Membership may also be terminated by the Steering Committee if an institution fails to maintain data contribution to the CNFUN database.

Individual membership: is open to all health care professionals with an interest in neonatal / perinatal follow-up.

- **Application:** should be submitted to the chair of the Steering Committee and should be endorsed by an existing member.
- **Membership fee:** none
- **Obligations:** members agree to abide by the rules governing research conduct and use of the data.
- **Benefits:** Members may use network infrastructure for research collaboration. Research projects using network data must be approved by the Steering Committee.
- **Renewal and termination:** Individual membership will need to be renewed every three years.

Relationship to the MiCare project

The CIHR Team in Maternal Infant Care (PI: Dr. Shoo Lee) was awarded funding by CIHR in 2008. MiCare is providing funding to establish the CNFUN database under Project 1. The goal of Project 1 is to create the CNFUN database and link it to the existing databases for the Canadian Neonatal Network (CNN), Canadian Perinatal Network (CPN) and the Canadian Perinatal Surgical Network (CAPSNet) to form one, integrated MiCare database.

The MiCare database will therefore link population-based sociodemographic, clinical practice, outcomes and resource use data for high risk pregnancies and infants throughout the entire period from pregnancy to childbirth, infancy and developmental follow-up. This unique database will enable study on how the interactions between determinants, mechanisms and processes of care affect pregnancy and infant outcomes over both the short and long-term.

The Overall MiCare research program is designed to improve outcomes and reduce costs through a better understanding of how different practices and risks affect long-term outcomes of preterm infants, and how improved methods of knowledge translation can enhance quality of care.

A member of the CNFUN steering committee will represent CNFUN on the MiCare Steering Committee. The CNFUN director will represent CNFUN on the MiCare Network Directors Committee.

