CNFUN
Canadian Neonatal Follow-Up Network
Réseau Canadien de Suivi Néonatal
RCSN

CNFUN Newsletter
February, 2019

In this newsletter:
- CNFUN network updates
- Parent-EPIQ project updates
- Upcoming meeting and conferences
- Research highlights

2019 CNFUN Steering Committee

We wish to welcome the new Steering Committee members and thank the members who accompanied us in the past for their great work and dedication.

CNFUN Updates

Steering Committee elections

In January 2019 the CNFUN held the elections for the Steering Committee.

Congratulations to the 2019 Steering Committee members

- Anne Synnes (BC) – Director
- Dr. Thuy Mai Luu (Montreal) – Quebec Representative / francophone
- Dr. Jehier Afifi (Halifax) – Atlantic Representative
- Jill Zwicker PhD (BC) – Occupational therapist representative
- Lynn Whitty (ON) – Nurse Representative
- Ruth Grunau PhD (BC) – Psychology representative
- Dianne Moddemann (MB) – Western Representative
- Dr. Rudaina Banihani (ON) – Ontario Representative
- Kevin Coughlin (ON) – Ontario Representative

CNFUN launched the Parent-EPIQ project on April 2018

Parent-EPIQ is one of 13 projects funded as part of the CHILD-BRIGHT (Child Health Initiatives Limiting Disability- Brain Research Improving Growth and Health Trajectories) CIHR SPOR initiative for chronic disabilities. (PI: A Majnemer, S Miller, D Goldowitz)

Parent-EPIQ has 3 aims:
- To define outcomes that are meaningful to parents of very preterm children (< 29 wks GA) at CNFUN visits at 18-21 mos CA.
- To implement Parent EPIQ interventions to improve cognitive and language abilities in a preterm population at 12 intervention sites.
- Evaluate whether CNFUN measured outcomes across Canada are improving using annual benchmarked reports for Parent-EPIQ intervention and non-intervention sites.

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CNFUN Updates

CNFUN site members 2019

CNFUN sites active members		Membership status
VGH/GVS	Victoria General Hospital	Confirmed
BCWH	BC Women Hospital	Confirmed
ACH/FMC	Alberta Children's Hospital, Foothills Medical Center	Confirmed
EDM	Royal Alexandra, Glenrose Rehabilitation Hospital	Confirmed
HSCC	Winnipeg Health Sciences Centre Children's Hospital	Confirmed
SBGH	St.Boniface General Hospital	Confirmed
WRH	Windsor Regional Hospital	Confirmed
LHSC	London Health Sciences Centre	Confirmed
MSH	Mount Sinai Hospital	Confirmed
SUNY	Sunnybrook Health Sciences Centre	Confirmed
JGH	Jewish General Hospital	Confirmed
MCH	McGill University Health Centre	Confirmed
HSJ	Centre Hospitalier Universitaire Sainte-Justine	Confirmed
CHUS	Centre Hospitalier Universitaire de Sherbrooke	Confirmed
CHUQ	Centre Hospitalier Universitaire de Quebec (Laval Site)	Confirmed
IWK	IWK Health Centre	Confirmed
	Membership in progress	
HMR	Hôpital Maisonneuve-Rosemont	Pending
HHSC	Hamilton Health Sciences Centre, McMaster Children's Hospital	Pending
KGH	Kingston General Hospital	Pending
	Membership not current	
RQHR	Regina General Hospital	Not current
RUH	Royal University Hospital	Not current
CHEO	Children's Hospital of Eastern Ontario	Not current
HSC	Hospital for Sick Children	Not current
SEHC	Moncton Hospital	Not current
SJRH	Saint John Regional Hospital	Not current
ECH	Dr. Everett Chalmers Hospital	Not current
JCHC	Charles Janeway Children's Health and Rehabilitation Cent	Not current

CNFUN Updates

Annual Report

In Dec 2018 the CNFUN released the first Annual Report which has been circulated to site investigators. Thank you to the MiCare coordinating site, annual report working group and to all the site investigators and teams at all of the Canadian Neonatal/Perinatal Follow-Up Programs who made this possible. The annual report will be made available on the CNFUN website once it has been updated.

Currently the CNFUN and local databases have being reviewed a revise report will be available in June 2019.

The Parent-EPIQ Project

Updates:

Progress to Date AIM 1- Step 1

Ethics approval (as part of the MiCare project or CNFUN) has been obtained at several sites and data collection is in progress as part of the CNFUN database

Progress to Date AIM 1- Step 2

Quantitative study: Vancouver/TorontoOnline survey developed based on qualitative work by Jaworski et al (J Pediatrics 2018), which identified positive aspects and challenges/concerns related to preterm children. Parents (n=200) will now be asked if they agree with previous findings. Ethics approved and data collection started in Vancouver.

Progress to Date AIM 1- Step 2

Qualitative study: Montreal
Parents (n=100/250 recruited) are asked open-ended questions about (1) what two things they would like to improve about their child, (2) the impact of preterm birth on their life, (3) what they would've liked doctors to tell them in the NICU, (4) what they would have done differently knowing what they know today.

Vignettes: Vancouver
11 vignettes describing single or multiple impairments using CNFUN definitions will be presented to parents who will rate level of severity. Survey to be conducted online after the 18-21-month CA visit.
Ethics approval has been obtained. Data collection will start March 1st , 2019.

Upcoming meeting and Conferences

EPIQ conference

Intervention and Non Intervention sites meeting
February 10, 15:00 – 17:30, 2019
Toronto

EPIQ conference

Steering Committee Meeting
February 10, 12:00 – 12:55, 2019
Toronto

Research Highlights

Title: Parent Reported Health Status of Preterm Survivors in a Multicentric Canadian Cohort

Authors: Satvinder Ghotra, David Feeny, Ronald Barr, Anne Synnes, Junmin Yang, Saroj Saigal, Michael Vincer, Jehier Afifi, Prakesh S Shah, Shoo Lee, Canadian Neonatal Follow-Up Network

Description of Study

Background:

With improved survival of very preterm newborns, there is an increasing emphasis on the long-term health of survivors. Patient reported outcome (PRO) measures are important outcome indicators, which provide a patient or proxy perspective on an individual's health and well-being. In addition, PRO tools often provide a multi-dimensional and comprehensive assessment of the health across multiple domains i.e., physical, mental and social, consistent with the World Health Organization definition of health.

Objectives: To report the parent perspective on health status of preterm survivors at 3 years corrected age (CA) in the Canadian Neonatal Follow-Up Network.

Methods: Infants born at <29 weeks' gestation between 2009 and 2011, who were followed in a Canadian neonatal follow-up clinic until 3 years of CA were enrolled. Parental perspective on outcomes across 12 health attributes was captured using the Health Status Classification System for Pre-School Children (HSCS-PS) questionnaire. Parents categorized severity of concerns for each health attribute from level 1 (no concern) up to level 6. A single health status summary score was computed as the sum of level code of 8 HSCS-PS attributes, with higher score indicating worse health status.

Results: Health status information was available in 811 (60%) of 1351 eligible preterm survivors. Most affected attributes of health status were speech (52.1%) and self-care (41.4%). At 3 years, 78% had a parent-reported health concern; these were mild in more than half of the population. Severe health concerns were reported in only 7% of the sample. Health status mean summary scores were 10.5, 10 and 9.6 in 23-24, 25-26, and 27-28 weeks gestational age groups, respectively ($p<0.01$). The differences were most pronounced in attributes of vision, mobility, self-care and thinking and problem solving.

Conclusions: Although most parents identified an area of concern for their children at 3 years of age, severe health concerns were expressed by only a small percentage of parents. Findings on the parent perspective on long-term outcomes from this multicentric cohort of preterm survivors provide important information for parental counselling and health care delivery.