

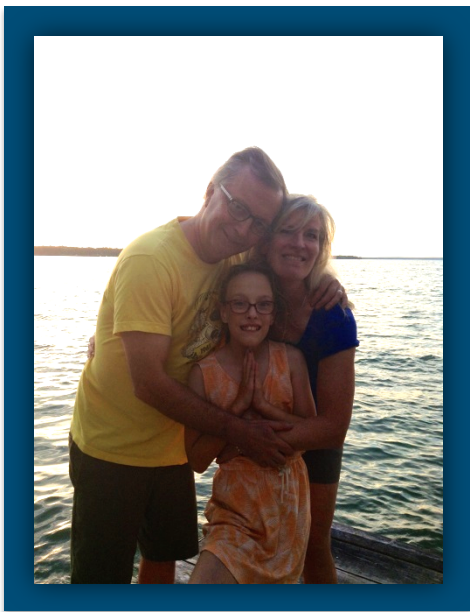


# CNFUN Newsletter

## Oct 2019

### This Issue is Dedicated to Parents

We appreciate our amazing parents!



Parents are the most important support for children including those in **CNFUN**.

**Parent-EPIQ** involves parents at all levels:

- Parents gave us the ideas
- Parents, like Rebecca Pearce, work alongside researchers
- Parents are providing the data to answer the question: Which outcomes matter?
- Parents like Diane and Brent in Vancouver, guide how to implement interventions to improve outcomes for preterm children.
- Parents like Katerina Staub, Kate Robson and Fabiana Bacchini have led the **Canadian Premature Babies Foundation**.

### New Logo for the Canadian Neonatal Follow-Up Network



Many thanks to the parent partners who suggested changing our logo and those who shared photos of their lovely children and contributed to the creation of this new logo. We invite you to take a moment to update the logo in slides and documents, if applicable (logo attached).

### The CNFUN 2019 Annual Report is coming soon

CNFUN has data on 6432 children born at < 29 weeks gestation from all across Canada and 5863 have linked neonatal data from the Canadian Neonatal Network. Look for site variations, annual changes in outcomes from 2009-2016 and gestational age specific outcomes.

### CHILD-BRIGHT Vancouver meeting 2019

“On September 22-23, the CHILD-BRIGHT gathered more than 50 of their network committee members and patient-partners in Vancouver for committee meetings, and to discuss our network's strategy for upcoming years.”

Breakout groups addressed the future regarding research, capacity building, knowledge translation, patient oriented research-citizen engagement and evaluation.

Implementing what we have learned from CHILD-BRIGHT including our research results, how to conduct patient oriented research and reaching out to new partners were some key points. Find more information in [https://www.child-bright.ca/vancouver\\_meetings\\_2019](https://www.child-bright.ca/vancouver_meetings_2019)

---

## Upcoming meeting and Conferences

### Evidence-based Practice for Improving Quality (EPIQ) conference 2020

CNFUN will sponsor one person from each of our member sites who are contributing data

**Save the date:** February 9-12th, 2020  
*Banff Centre, Banff, Alberta*

Please send the name and contact information from the site delegated to [carolina.segura@cw.bc.ca](mailto:carolina.segura@cw.bc.ca)

### PAS 2020

April 29-May 6, Philadelphia, PA  
<https://2020.pas-meeting.org/>

The CNFUN Steering Committee had reviewed the Data Request proposals for the abstracts that will be send to the conference

### CHILD-BRIGHT conference 2020

March 25 -27 Toronto, ON  
<https://www.child-bright.ca/events/2020/3/25/2020-child-bright-conference>

---

## Research Highlights

### Comparing Standardized and Parent-Reported Motor Outcomes of Extremely Preterm Infants.

Morgan-Feir M; Synnes A; Creighton D; Pillay T; Zwicker JG; Canadian Neonatal Follow-up Network. (CNFUN).

#### ABSTRACT

Extremely preterm infants are at increased risk of motor impairment. The Canadian Neonatal Follow-Up Network (CNFUN) afforded an opportunity to study the outcomes of extremely preterm children. The purpose of this study was to compare 18-month corrected age (CA) motor outcomes of extremely preterm infants with parent-reported functional outcomes at 3 years CA. CNFUN data of 1376 infants were used to conduct chi-square analyses to compare Bayley-III motor scores (composite, gross, and fine motor) at 18 months CA with parent-reported Ages and Stages Questionnaire motor scores (gross and fine motor) at 3 years CA. The correlation of motor scores at 18-months CA with parent-reported gross and fine motor scores at 3 years CA was also examined. We found that 1 in 5 infants scoring within or above the average range on the Bayley-III had parent-reported functional fine and gross motor difficulties at 3 years CA. Bayley-III scores were only moderately correlated with functional motor outcomes. Results of the study suggest that the Bayley-III at 18 months CA was able to detect the majority of infants with motor problems, but not all; therefore, ongoing follow-up of extremely preterm infants is required. The Bayley-III motor composite score has greater clinical utility compared to sub-scale scores.

---

## Research Highlights

### Preterm children with suspected cerebral palsy at 19 months corrected age in the Canadian neonatal follow-up network.

Synnes A; Gillone J; Majnemer, Lodha A; Creighton D; Moddemann D; Shah PS; Canadian Neonatal Follow-up Network. (CNFUN).

The CNFUN database collects information on cerebral palsy (CP). The clinicians on the database working group decided to include suspected CP as well as no CP and definite CP for children where not all features of CP are present. In this paper we describe the frequency of suspected CP, the neonatal, 18 month and 3 year characteristics of children with suspected CP as compared to those with and without CP.

**STUDY DESIGN AND METHODS:** We used the CNFUN cohort of births <29 weeks' gestation with linked Canadian Neonatal Network and CNFUN 18-24 mo evaluations and 3-year questionnaires (Ages and Stages-3 and Health Status Classification System-Preschool). CP, no CP and suspected CP groups, classified at the 18 month visit were compared using chi square and ANOVA.

**RESULTS:** Of 3086 survivors, 2280 had complete 18-month corrected age (CA) and 1261 had 3-year CA data. Suspected CP (3.6%), CP (6.4%) and no CP (90%) groups differed ( $p < 0.05$ ) in birth weight, gestational age, complications of prematurity and NICU length of stay. Children with suspected CP had Bayley-III motor, cognitive and language composite scores at 18 months midway between CP and no CP, had the lowest sensory impairment rates and highest hospital readmission rates. At 3 years, gross motor, fine motor, problem-solving, communication and social skill abilities differed: abnormal outcomes were intermediate for children with suspected CP ( $p < 0.01$ ).

**CONCLUSIONS:** CP incidence varied from 6.4% to 10% with exclusion or inclusion of children with suspected CP. Children with suspected CP have characteristics mostly midway between those with and without CP and developmental concerns persist to 3 years and require surveillance beyond 19 months.

**SIGNIFICANCE and COMMENTS:** CP should not be a primary outcome at 18-24 months, especially for RCTs. Children with suspected CP have functional concerns at 3 years and need to be followed clinically beyond 18 months. We need to address how we should categorize children with suspected CP in our analyses. They are currently included with the no impairment group

## Latest publications

Lodha A, Entz R, Synnes A, Creighton D, Yusuf K, Lapointe A, Yang J, Shah PS; investigators of the Canadian Neonatal Network (CNN) and the Canadian Neonatal Follow-up Network (CNFUN). [Early caffeine administration and neurodevelopmental outcomes in preterm infants](#). Pediatrics. 2019 Jan;143(1).

Fischer N, Soraisham A, Shah PS, Synnes A, Rabi Y, Singhal N, Ting JY, Creighton D, Dewey D, Ballantyne M, Lodha A; Canadian Neonatal Network™ (CNN); Canadian Neonatal Follow-up Network (CNFUN); Investigators .

[Extensive cardiopulmonary resuscitation of preterm neonates at birth and mortality and developmental outcomes](#). Resuscitation. 2019 Feb;135:57-65.

Ediger K, Hasan SU, Synnes A, Shah J, Creighton D, Isayama T, Shah PS, Lodha A; Canadian Neonatal Network; Canadian Neonatal Follow-Up Network.

[Maternal smoking and neurodevelopmental outcomes in infants <29 weeks gestation: a multicenter cohort study](#). J Perinatol. 2019 Apr 17. doi: 10.1038/s41372-019-0356-3. [Epub ahead of print]

Shafey A, Bashir RA, Shah PS, Synnes A, Kelly E , Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Outcomes and resource usage of infants born at  $\leq 25$  weeks gestation in Canada. Accepted to Paediatrics & Child Health. Feb 7, 2019.

Synnes A, Gillone J, Majnemer A, Lodha A, Creighton D, Moddemann D, Shah PS; Canadian and Neonatal Network; Canadian and Neonatal Follow-up Network.

[Preterm children with suspected cerebral palsy at 19 months corrected age in the Canadian neonatal follow-up network](#). Early Hum Dev. 2019 Sep;136:7-13.

Morgan-Feir M, Abbott A, Synnes A, Creighton D, Pillay T, Zwicker JG, on behalf of the Canadian Neonatal Follow-Up Network.

[Comparing Standardized and Parent-Reported Motor Outcomes of Extremely Preterm Infants](#). Children (Basel). 2019 Aug 1;6(8). pii: E90. doi: 10.3390/children6080090.

Albaghli F, Church P, Ballantyne M, Girardi A, Synnes A. Neonatal Follow-up Programs in Canada: A National Survey. Accepted to Paediatrics & Child Health Oct 9, 2019.