

CNFUN FALL NEWSLETTER

October 2020



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IMPORTANT DATES:



October 15, 2020:

Deadline for submitting data requests and study protocols

October 21, 2020:

Deadline for uploading data

Did you hear? 

CNFUN is now on Twitter!

Follow us at [@CNFUN_RCSN](https://twitter.com/CNFUN_RCSN)

#CNFUNresearch

APPLICATION FOR CNFUN DATA: UPCOMING DEADLINE

The deadline to submit your [application](#) for data request and study protocol is **October 15, 2020**. The same deadline applies to CNN, CPTBN, CNFUN, and CNTN data requests.

DATA FOR ANNUAL REPORT: UPCOMING DEADLINE

In preparation for the annual report 2020 and research proposals, we request that all sites upload their most recent CNFUN database information by **October 21, 2020**.

Thank you to all CNFUN sites who have already completed uploads of their most recent data!

NEW SUBSITE AGREEMENTS & FUND TRANSFERS

The new subsite agreements were emailed to all CNFUN site investigators as of June 2020. We are keen to process the agreements and fund transfers as quickly as possible and are happy to answer any questions you may have.

FAQ: I have received the draft agreement, what are the next steps?

A: The agreement should be reviewed with the legal contracts department at your site. Any legal negotiations and agreement questions can be directed to the CNFUN National Coordinator, Lindsay Richter (lrichter@bcchr.ca), and our contracts officer, Lianne Boon (Lianne.Boon@uilo.ubc.ca).

FAQ: If my site is not a Parent-EPIQ intervention site, is there a different version of the agreement?

A: No, the template is formatted in such a way that it can be used for both intervention sites as well as non-intervention sites. The agreement refers to the protocol for the description of the study activities that the sites will be performing. The protocol makes a distinction between the activities of the intervention sites vs. activities of the non-intervention sites. Therefore, the agreement is necessary to cover activity of Parent-EPIQ interventions and for all sites to get paid for work already done and the ongoing baseline CNFUN data collection and entry to the database.

COVID-19 UPDATE:



Since clinic visits may still have not returned to normal due to COVID-19, we understand that the typical assessments, clinical outcomes, and questionnaires needed for the CNFUN database may be difficult to complete at this time.

We have revised our guidelines for assessments completed and/or questions typically asked during the 18-months corrected age follow-up visits. **We are currently accepting data collected from 18 months up to 36 months corrected age for the CNFUN database.** Results from the Bayley Social-Emotional and Adaptive Behaviour questionnaire may still be used in lieu of an in-person Bayley.

MACARTHUR-BATES CDIs UPDATE:



The CNFUN Steering Committee has decided to eliminate collection of the MacArthur-Bates Communicative Development Inventories (CDIs). The **MacArthur-Bates CDIs will no longer be required.**

Looking for new opportunities to be more engaged in the network?

ANNUAL REPORT 2020: JOIN THE WORKING GROUP

The CNFUN 2020 annual report is coming soon. If you would like to join the working group to create the report, please let Dr. Anne Synnes (asynnes@cw.bc.ca) know by **October 21, 2020**.

ELECTIONS 2021: STEERING COMMITTEE MEMBER NOMINATIONS



We are excited to officially announce the upcoming elections for the Steering Committee. Get involved and consider nominating yourself or other CNFUN members! Nominations forms will be emailed to all members soon.

Elections will be held in late **January 2021**. This election is for the available Steering Committee positions (including nursing, psychology, and other allied healthcare professionals). Depending on site size, sites will be asked to designate either four or two voting members. Each voting member will be able to cast one ballot. More details to follow.

Parent-EPIQ Updates:**Aim 1 (Meaningful Outcomes), Part 1:**

Parents were asked at the 18-month visit how they would rate their child's level of neurodevelopmental impairment. Preliminary results were shared at the [CHILD-BRIGHT Virtual Symposium](#) in May. As of September, we have almost 600 responses recorded in the CNFUN database.

Aim 1, Part 2:

At BCWH and CHUSJ, parents were asked to complete surveys on how they perceive their child's challenges, strengths, and positive attributes. Recruitment for the quantitative survey wrapped up at the end of September. This fall, the clinical vignettes survey will be expanded to more parents in collaboration with the Canadian Premature Babies Foundation, Préma-Quebec, and the CHILD-BRIGHT network.

Aim 2 (Implement Parent-EPIQ):

Due to COVID-19, many interventions have been halted. Some intervention sites are planning to restart soon and complete another cycle in the next year.

RESEARCH HIGHLIGHTS:

New CNFUN Publications:

- Association between Transport Risk Index of Physiologic Stability in Extremely Premature Infants and Mortality or Neurodevelopmental Impairment at 18 to 24 Months**
Grass B, Ye XY, Kelly E, Synnes A, Lee S. *J Pediatr*. 2020 Sep;224:51-56.e5. [PMID: 32442448](#)
- Neurodevelopmental and Growth Outcomes of Extremely Preterm Infants with Necrotizing Enterocolitis or Spontaneous Intestinal Perforation**
Zozaya C, Shah J, Pierro A, Zani A, Synnes A, Lee S, Shah PS; Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network Investigators. *J Pediatr Surg*. 2020 May; S0022-3468(20)30326-2. [PMID: 32553453](#)

Congratulations to the CNFUN members who have had recently published papers!

CNFUN manuscripts in final draft or submitted:

- Roychoudhry S *et al.* Neurodevelopmental Outcomes of Preterm Infants Conceived by Assisted Reproductive Technology
- McRae L *et al.* Impact of Home Respiratory Support on Developmental Outcomes
- Synnes A *et al.* Family Integrated Care: Neurodevelopmental Outcomes at 18-21 Months Corrected Age
- Ghotra S *et al.* Parent-Reported Health Status of Preterm Children in the Canadian Neonatal Follow-Up Network Cohort
- DaSilva M *et al.* The Incidence of and Risks Factors for Inguinal Hernia in Preterm Infants
- Synnes A *et al.* Cerebral Palsy Rates After a Magnesium Sulphate Knowledge Translation Intervention
- Synnes A *et al.* Sociodemographic Characteristics of Children With and Without Neurodevelopmental Impairment in a Canadian Cohort of Very Preterm Children

**CONNECT**Twitter: [@CNFUN_RCSN](#)Website: www.cnfun.ca**CONTACT**

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