

# Predicting and Preparing for the Future of Babies Born Extremely Preterm:

## Parents Give Recommendations to Clinicians

Thivierge E, R Pearce, Luu TM, Jaworski, Synnes A, Bourque CJ, Janvier A

Research Centre, CHU Sainte-Justine, Montréal, Canada

### Introduction

- Parents of extremely preterm children face many challenges and uncertainties.
- The information and support provided by clinicians -both before and after birth- is invaluable although rarely evaluated.

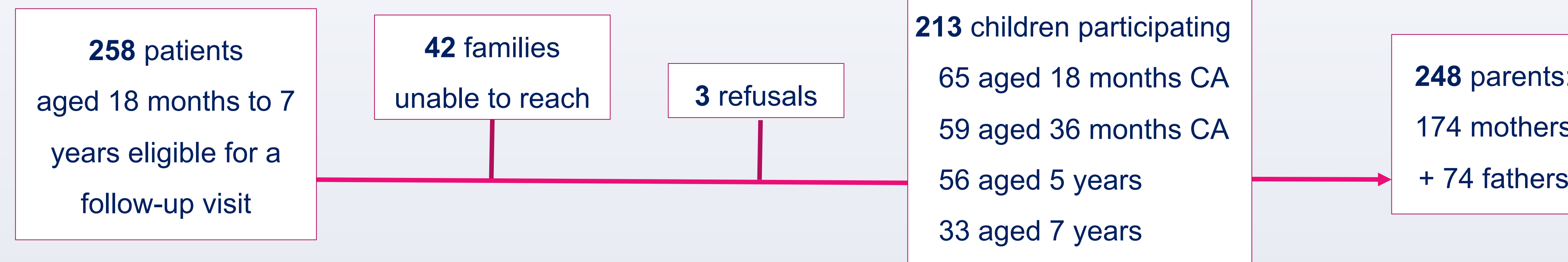
### Aim

To explore parental needs in terms of information around preterm birth.

### Methods

- **Design** : Cross-sectional survey
- **Population** : All parents of infants born <29 weeks' GA seen at the CHU Sainte-Justine NICU follow-up clinic from age 18 months to 7 years from July 2018-2019
- **Measure**: Parental questionnaire including open-ended questions
- **Analysis** : Descriptive content analysis and independent coding by 3 reviewers (medical professionals and parent).
- Mixed methods to assess the frequency of each theme in relation to clinical factors.

### Results



*Knowing what you know now, what do you wish doctors would have told you about prematurity before and/or after your child's birth?*

**45%**: satisfied with information received.

**22%** : wished discharge would be improved, to be better prepared for the future:

- What to expect: their child's outcomes (health, development and type of follow up)
- What to do: day-to-day life, how to care for their baby, resources for parental support

*"BPD does not help. We would have liked to know what leaving on oxygen meant that she should not go to daycare, the risk with infections, RSV shots, sleeping problems many preemies have. This could have been done weeks before we left the hospital"*

*"To be better prepared to what will happen after discharge: follow-up appointments, illness, feeding problems and other challenges related to prematurity."*

**19%**: wanted to know more about the life-trajectory of babies in the NICU

*"What are the different steps during the stay and how can we help as parents?."*

**16%**: prenatally wanted practical information on functional aspects of prematurity instead of diagnoses

*"While on bedrest, I would have liked to be more informed about the NICU to mentally prepare."*

**14%**: wished they had known more about resources for psychosocial support.

**14%**: wished for clinicians to be more optimistic and to give them hope:

*"Before birth, I would have liked to know that most micro preemies do well."*

*"Emphasize good news, while staying realistic about the negative aspects instead of the opposite."*

Many thanks to all families who participated in this study.

- Parents with education < high school vs ≥ high school are less likely to wish for more information about preterm birth prior to delivery (3% vs 17%, P=0.04)
- Mothers more likely than fathers to wish for more information about preterm birth prior to delivery (19% vs 6%, P=0.01) and about being a parent in the NICU (22% vs 8%, P=0.01)
- No difference in frequency of themes in relation to neurodevelopmental impairment.

### Discussion

High response rate, but only from parents who presented to follow up and whose child had survived. No comparison done with other NICU or complex care populations.

### Conclusion

Although half the parents are satisfied with information and support received, the other half recommends improvements, mainly to **make it positive and practical**.

Diagnoses did not help parents prepare for the future prenatally, in the NICU or at discharge, but **function and what parents could do (in a practical fashion)** did.