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

**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.**

**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.

**Results**

- 258 patients aged 18 months to 7 years eligible for a follow-up visit
- 42 families unable to reach
- 3 refusals
- 213 children participating:
  - 65 aged 18 months CA
  - 59 aged 36 months CA
  - 56 aged 5 years
  - 33 aged 7 years
- 248 parents:
  - 174 mothers
  - 74 fathers

**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

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

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

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

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

- **“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.”**

- **“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.”**

**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.

Many thanks to all families who participated in this study.