Neonatal Outcomes in the Era of Periviability
The Journey of Ontario’s Tiniest Babies

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Disclosure

• I do not have an affiliation (financial or otherwise) with a pharmaceutical, medical device or communications organization.

• I do not intend to make therapeutic recommendations for medications that have not received regulatory approval (i.e. “off-label” use of medication).
Objectives

• At the end of this session, you will be able to:

1. Review behavioral phenotype of prematurity

2. Review etiology of phenotype

3. Discuss new CPS guidelines with resuscitation of periviable birth

4. Review benefit of databases to track preterm birth
Introduction

“Hope is not futile, and hope does not mean you don’t understand. It means that a good outcome is possible.”
Background

Canadian Premature Babies Foundation – Fondation pour Bébés Prématurés Canadiens

Figure 1: Rates of Preterm Birth in Canada, 2011/12\textsuperscript{10}
Background

• Age of viability decreasing
  – 22 x/7 weeks versus 23 weeks versus 24 weeks
  – (Rysavy MA, Lei L, Bell EF et al. Between-Hospital Variation in Treatment and Outcomes in Extremely Preterm Infants. NEJM 2015;327:1801-11)
Gray Zone

• **AAP-- Borderline viability: 22-24 weeks**

• **ACOG-- Periviable: 20 0/7 to 25 6/7 weeks**

• **CPS-- Extremely preterm birth: 22 0/7-25 6/7 weeks**
Neonatal Outcomes

- Outcomes of prematurity fairly stable 6-25%

- Impairment traditionally defined by the presence of
  - Cerebral palsy
  - Vision impairment
  - Hearing impairment
  - Cognitive impairment
Neonatal Outcomes

• 50-70% with challenges in school

• Challenges with:
  – Language comprehension and expression
    • (Verbal and nonverbal communication)
  – Learning
    • Spatial relationships
  – Impulse control, busy behaviour
  – Organizational abilities
  – Autism Spectrum Disorder (ASD)
  – Social immaturity
    • Emotional lability
  – Anxiety (separation anxiety)
  – Motor coordination

Prevalence and Associated Features of Autism Spectrum Disorder in Extremely Low Gestational Age Newborns at Age 10 Years

Neonatal Outcomes-Social

**Figure.** Frequency distribution showing proportion of children with each total SCQ score in the extremely preterm cohort (n = 183) and term-born classmates at 11 years of age (n = 137).

Behavioral Phenotype

• Describes a constellation of behavioral, cognitive, motor, and social difficulties observed in a population with a common biological disorder

• Premature survivors have a phenotype
  – Common biological disorder=alterations in brain development

• Back SA, Miller SP. Brain Injury in Premature Neonates: A Primary Cerebral Dysmaturation Disorder? Ann Neurol 2014;75;469-86.
Behavioral Phenotype of Prematurity
Etiology

Behavioral Phenotype of Prematurity

• **Dysmaturation:**
  – Gray matter architecture distorted
  – White matter connectivity altered
  – Cerebellum under-developed
  – Sensory system disorganization

• **Secondary cortical dysplasia**

  • Back SA, Miller SPM. Brain Injury in Premature Neonates: A Primary Cerebral Dysmaturation Disorder? Ann Neurol 2014;75:469-489
Etiology
Behavioral Phenotype of Prematurity

- Heightened parental stress potentiates:
  - Disrupted attachment
  - Diminished parental capacity
  - Depression
  - Goodness of Fit
  - Vulnerable child syndrome
“It sort of makes you stop and think, doesn’t it.”
Counselling and management for anticipated extremely preterm birth

Brigitte Lemire, Gregory Moore; Canadian Paediatric Society
Fetus and Newborn Committee
Posted: Mar 2 2017

<table>
<thead>
<tr>
<th>Table 4: Levels of care for the extremely preterm infant, based on risks for anticipated mortality or NDD</th>
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<td>Risk estimation for anticipated mortality or long-term NDD</td>
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<tr>
<td>Extremely high likelihood of mortality or severe NDD*</td>
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<td>Moderate-to-high likelihood of mortality or moderate-to-severe NDD</td>
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<td>Low likelihood of mortality or moderate-to-severe NDD</td>
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SCHOOLS, SKILLS, AND SYNAPSES
Heckman, James J
Economic Inquiry; Jul 2008; 46, 3; ProQuest
pg. 289
Caregivers attitudes for very premature infants: what if they knew?

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Figure 1: Percentage of respondents replying that they would always or generally resuscitate a preterm baby known to be a 24-week infant compared to an infant with outcomes described but no gestational age given.
Our child is not just a gestational age. A first-hand account of what parents want and need to know before premature birth

Katharina Staub (katharina.staub@cpbf-fbpc.org), Jason Baardsnes, Nina Hébert, Michael Hébert, Stephanie Newell, Rebecca Pearce
Canadian Premature Babies Foundation-Fondation pour Bébés Prématurés Canadiens, Shewood Park, AB, Canada

In our opinion, guidelines that are just based on gestational age make decision-making easier for physicians, not for parents (3,4). We hope that in the future, parents can collaborate in writing position statements about counselling before a premature birth. You are the medical experts of prematurity. We are the experts when it comes to the lives of our children and our families. For doctors, these discussions are routine. For us, these conversations change our lives forever.
• “We understand that clinicians need to examine outcomes and classify children: they can have serious, moderate, or mild disability or may be classified as ‘typical’. These categories were created by physicians. If we were asked to classify our children as disabled or not disabled, then doctors would have different categories.”

• “Why is hyperactivity a mild disability and cerebral palsy a major one?”
Opportunities for Data

• Continue to simplify outcomes
• Lack of emphasis on function, living well

• Databases existing in addition to BORN in North America:
  – Canadian Neonatal Network (CNN)
  – Canadian Neonatal Follow Up Network (CNFUN)
  – Vermont Oxford Network (VON)
  – National Institutes of Child Health and Human Development (NICHD)
  – Autism Treatment Network (ATN)
  – Kids Brain Health Network (Neuro DevNet)
  – Province of Ontario Neurodevelopmental Disorders (POND)
• Small Baby Care Bundle
  – Obstetrical care
  – Standardized delivery bundle of care
  – Standardized nursing practice

• Aim: to improve life outcomes for children with brain based developmental disabilities and their families
Conclusion

• Behavioral Phenotype of Prematurity associated with increased difficulty functionally

• Periviable birth = informed choice

• Data key to understanding and changing outcomes
Acknowledgements

- Rudaina Banihani, MD, Neo-Dev Paeds
- Maureen Luther, PT
- Patricia Maddalena, NP
- Rosanna Manarin, RN
- Lesley Barreira, Beh Ther
- Currently hiring, OT/PT

- Michael Luther, PhD, Psyc
- Connie Taras-Gold, SLP
- Marion Deland, manager
- Carol Grenade, admin
- Ruth Kim, admin
Questions…?