



## Research Priorities by Parents of Premies and Clinicians Who Care for Them (POP!)

*Community Report – San Francisco, Oakland, Fresno*

### Background

Almost 1 in 10 babies in the United States (US) are born too early (before 37 completed weeks of pregnancy). Babies born premature often need many weeks of neonatal intensive care unit (NICU) hospitalization and may have lifelong health and development problems. Priorities for prematurity research have traditionally been determined by career and physician researchers, without input from families or NICU healthcare providers. From January to February 2018, the Parent Clinician Advisory Boards (PCABs) of the California Preterm Birth Initiative in San Francisco, Oakland, and Fresno convened to create priorities for preterm birth researchers. The PCABs are made up of researchers, parents of premature infants, and front-line NICU clinicians. Priority setting happened over 2-3 meetings at each site. Together these sites created individual priority topic and question lists, a list of 227 researchable questions, and two geography-wide priority research topics.

### Priority Focus Areas for Prematurity Research

The following two major themes were prioritized by consensus and summarize parents' and clinicians' research questions

#### Preterm Infant Development

Questions about preterm infant development; decreasing parent-infant separation and increasing bonding; improving parent and nurse knowledge about developmental care; preparing parents to care for infants with developmental delay; whether nursing certification in developmental care impacts infant outcomes; how to best identify and communicate when a baby has, or is at risk of, developmental delay; the connection between prematurity and sensory and executive disorders like autism and attention deficit disorder; how early intervention improves outcomes; impact of comorbid conditions by body system on development; and the impact of NICU environment on development.

#### Transition and follow-up support after discharge

Questions about how to best support families after discharge; how to prevent complications and readmissions after discharge; what long-term help is available for the child and family and what are the gaps between what is available and what is needed; if there are models of care that would best support parents after discharge such as support groups; which touch points after discharge are needed to decrease parent anxiety and improve infant outcomes; what are the best approach to providing resources to parents and which resources are best; how and if NICU staff should follow-up with families after discharge; would home visits to families after discharge improve outcomes, are there ways to

improve developmental follow-up and surveillance for developmental delay, how to decrease parental stress at follow-up visits; can follow-up visits be more efficient and how can social media be effectively utilized to follow-up and support parents?

# PCAB Top Priority Topics for Future Research

San Francisco, Oakland, Fresno (combined)

## Development

- Development and developmental outcomes/Sensory processing (SF)
- Developmental care for the preterm infant (O)
- Developmental care and special needs (CRMC)
- NICU environment (O)

## Transition and follow-up support after discharge

- Family care after discharge (O)
- Resources for parents after discharge (CRMC)
- Follow-up from the NICU staff after discharge (CRMC)
- Care of baby at home (CRMC)
- Developmental follow-up clinics and practices (SF)
- Family transition from birth hospital to NICU (O)

## Communication

- Best practices for communication between families and clinicians (O)
- Communication with parents (CRMC)
- Communication/consistency around care practices (SF)

## Parent Role

- Hospital/NICU practices and policies for family integrated care and psychosocial/emotional support in the NICU (O)
- Early parent involvement and education in the discharge process (O)
- Parent-infant bonding/skin-to-skin care (kangaroo care) (SF)
- Parent and family experience/social support (SF)
- Parent support in the NICU (CRMC)
- Parent education in the NICU (CRMC)

## Neonatal conditions

- Reflux (SF)
- Respiratory disease (SF)
- Nutrition (SF)
- Pain (SF)
- Prematurity and birth defects (SF)

## Transition and follow-up support after discharge

- Implementing novel strategies to prevent preterm birth (O)
- Pre- or postnatal care for mom (CRMC)

## How to Use These Priorities

PTBi-CA uses the research priority topics and questions generated by the PCAB to inform the research priorities of the initiative. The PTBi-CA postnatal research aim is focused on improving preterm baby and family outcomes by improving parent integration into their babies care in the NICU.

We call on **healthcare providers and health systems** to use the best available evidence to improve services related to the priority topics and questions, to educate patients/clients on what is known about these and to practice respectful care and shared decision-making in all patient/client interactions.

We call on **research funders and researchers** to join us in tackling the unanswered questions about prematurity that matter most to families who have experienced a preterm birth and the clinicians who care for them – and to partner with women, families and communities most affected by the preterm birth epidemic when doing this research.

## JOIN US!

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