



Research priorities by parents of premies and clinicians who care for them (POP!)

Fresno CA

Beginning in January 2018, the Parent Clinician Advisory Boards (PCABs) of the California Preterm Birth Initiative (PTBi-CA) in San Francisco, Oakland, and Fresno convened to create priorities for postnatal researchers. The PCABs are made up of researchers, parents of premature infants, and front-line Neonatal Intensive Care Unit (NICU) clinicians from several disciplines (medicine, nursing, respiratory therapy, social work). Priority setting happened over 2-3 meetings at each site and consensus on the top priority topics was achieved at the 2018 all-site meeting. The Fresno-specific priority research topics, priority research questions, and full list of researchable questions, sorted by topic, are shown below.

We call for researchers, healthcare providers, and health systems to work together to answer these questions - and to share and implement best evidence-based practices – for the health of parents, babies and families everywhere.

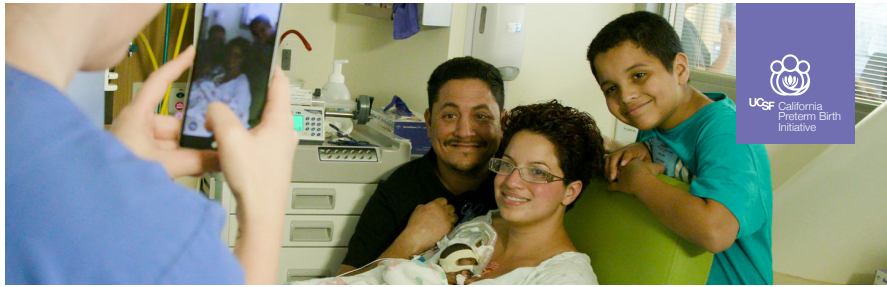
Top 8 Topics

1. Support in the NICU
2. Parent education in the NICU
3. Resources for parents after discharge
4. Parent follow-up from the NICU staff after discharge
5. Care of baby at home
6. Communication with parents
7. Pre- or post-natal care for moms
8. Developmental care and special needs

Top 10 Questions

1. How do we create environments that support parenting in the NICU?
2. How can we best identify the emotional, cultural, and spiritual needs of parents in the NICU and provide the right support?
3. What is the best way to individualize education that meets the family's changing learning needs during their NICU stay?
4. How can we best prepare parents to handle emergencies after discharge?

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5. How can we provide a resource network for NICU parents that can be accessed and utilized in different counties?
6. What is the best way for the NICU staff to follow up and help parents with their transition to home, and provide better assistance for care issues (e.g. feeding difficulties) after they have been discharged home?
7. How do we create a model of communication between parents and staff that allows parents to report problems or concerns with care and get follow-up?
8. How can we improve pre-natal education on risk factors for preterm labor for all mothers?
9. How can we help mom's better identify the signs & symptoms of preterm labor and clinicians be more responsive to pre-term labor concerns?
10. What is the best way to help parents understand the developmental needs of their baby after going home and identify when they need additional help?

Researchable questions by topic - Fresno parents of preterm babies and NICU clinicians

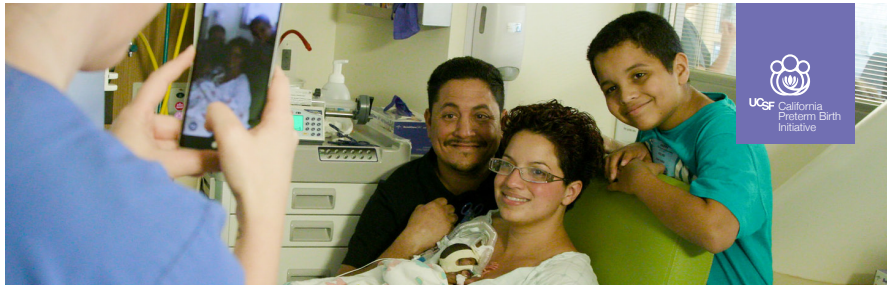
Parent support in the NICU

- What is the best way for a nurse to support a parent?
- How do we provide more interpreting services?
- How do we become more culturally sensitive?
- How do we recognize when a parent is overwhelmed?
- How do we as medical personnel allow you to parent while your baby is in the NICU?
- How do we educate our clinicians about resources outside of the NICU to support parents?
- How do we standardize social work assessment and assistance when the parents don't live in the same county?

Parent education in the NICU

- How do we make education more specific to a family's needs?
- How can we (clinicians) change our workflow to accommodate parent education when they come in at off times?
- How should we best educate parents to know what to expect in the care of their baby in the first weeks or month after discharge?
- How much education should we give parents at one time?
- How often should parents do CPR before they go home with their baby? How close to going home?
- How do we better prepare parents for emergencies?
- How do we provide education that supports the parent's learning needs?
- How do we standardize teaching parent-infant holding techniques?
- How do we caution parents about public exposure of their babies?

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- How do we continue to emphasize infection prevention?

Resources for parents after the going home

- How can we connect parents with resources? When is a good time to connect them to resources? Before going home? After going home?
- How can we connect parents with resources across different counties?
- How can we improve EMS services care of preemies?
- How do we direct parents toward parent support groups?
- If there isn't a support group, how do parents start one? (Premature Warriors Support Group)
- How do we facilitate the creation of support groups?
- How do we consolidate resources?

Follow-up from the NICU staff after discharge

- How frequently should NICU staff call parents to address their questions after they go home with their baby (s)?
- What is the best way for NICU staff to follow up with parents and provide additional resources after they go home? Online? Phone call?
- How do we provide better assistance after discharge for care issues (such as feeding problems)?
- How can we provide home visits to assist parents?
- How do we use social media (e.g. NICU hospital Facebook page) to follow up with parents?

Care of baby at home

- For bottle feeding, how do we help parents know which nipples in the stores compare to the nipples used in the NICU? How will they know which ones to buy?
- How do we facilitate 24-hour on-call assistance to answer questions?

Communication (providers, staff and parents)

- How do we improve our handoff process, between disciplines and shifts?
- How do we create a shared model of communication between disciplines?
- How can we improve the process for parents to report problems or communicating issues with care?
- How do we improve transfer of information to the pediatrician?
- How do we include parents in multi-discipline rounds? How do we communicate a multi-discipline plan of care to parents?

Prenatal or postnatal care for moms

- How do we improve pre-natal diabetes education?
- How do we ensure pre-natal GBS education for parents?
- Why aren't all moms educated about pre-term birth by their doctor's? Why do they wait until we are in pre-term labor?

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Developmental care and special needs

- How do we help parents understand developmental care?
- How do we ensure consistent quality of care among clinicians and shifts?
- When is a premature baby, considered a special needs baby? How can we best educate parents about special needs and how do they get extra help after going home?
- What does developmentally delayed mean?

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