

From Emergency to Everyday:

Lessons Learned from State Newborn Screening Program Reflections on a Year of COVID-19

April 2021

The Newborn Screening Family Education Program hosted a webinar series convening key newborn screening (NBS) stakeholders including providers, NBS program representatives, parents, and advocates, to learn how state newborn screening laboratories supported families during the COVID-19 pandemic. This resource reflects the perspectives of webinar attendees and shares strategies to support families through future health emergencies.

Stakeholders Identified These Needs:

- Adequate staffing
- Forum to discuss challenges and successes
- Increased funding
- Patient/provider education
- Food aids and psychological support services
- Funding to hire extra staff
- Resources to prevent or reduce burnout

Realities of Newborn Screening Programs During Emergencies

- **Increased Home Births:** Stress on midwives who are not necessarily familiar with NBS
- **Parental Concern:** Parents increasingly left the hospital before 24 hours due to fear of exposure leading to need for early collections, often requiring a repeat screen; delays in confirmatory or repeat testing due to parental hesitancy
- **Staffing:** Hospital and clinic staff also infected with COVID-19; staff being redeployed to address shortages and performing jobs they have not done before including NBS, leading to unreliable samples
- **Logistics:** Stress on couriers who pick up NBS samples and COVID-19 samples

COMMUNICATING WITH FAMILIES

Attendees shared the ways that they think families are most comfortable receiving newborn screening information.



42% of respondents

believe that families prefer a phone call or text message



34% of respondents

believe that families prefer an in-person healthcare visit

Suggestions to Better Communicate with Families

- Use email and text by Primary Care Providers (PCPs) to communicate with families and NBS labs during health emergencies, natural disasters, and other disruptive events
- Incorporate parents into communication stream with PCPs to provide easily accessible information

BEST PRACTICES IN SUPPORTING FAMILIES



SLOW

- Minimize interruptions in the newborn screening process including barriers in courier services and outpatient service centers



START

- Leverage and build on workflow and communications systems already in place
- Adapt to identify solutions to courier and outpatient center changes
- Identify family needs including heightened concerns for taking new babies into public



CONTINUE

- Explore best communication strategies with families and primary care clinics
- Develop tools to provide additional support for families going through NBS during a health emergency

[Watch the full webinar on Expecting Health's YouTube Channel](#)