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

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $500,000 with 0 percentage financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.