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# Impact of COVID-19 on Newborn Screening Systems in the United States

Jelili Ojodu, MPH

Director, Newborn Screening and Genetics

Association of Public Health Laboratories

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# Newborn Screening

- Essential public health service
- State-based, unique programs
- Multiple stakeholder engagement
- Multi-faceted system
- Continuity of Operations

# Newborn Screening COVID-19 Challenges and Response Webinar

**WHO:** Open to the public, geared toward dried blood spot, hearing and screening newborn screening stakeholders nationally

**WHAT:** Listening session with a panel of NBS experts

**WHERE:** Online, National Webinar, Open Registration

**WHEN:** May 21, 2020 at 2:00 pm ET

**WHY:** To discuss challenges, barriers and solutions to NBS during the COVID-19 pandemic in the US

**HOW:** Jointly led by the APHL and the National Center for Hearing Assessment and Management (NCHAM) and supported by the Maternal and Child Health Bureau (MCHB) of HRSA



Recorded and transcribed webinar available online at [www.newsteps.org/webinars-events](http://www.newsteps.org/webinars-events)

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# Dried Blood Spot (DBS) Screening during COVID-19: Challenges



## Staff/Closures

- NBS coordinators too busy processing paperwork to receive presumptive calls from state NBS programs
- Specialty care center staff deployed to hospitals downstate, specifically to ICUs and EDs
- Hospitals closing outpatient clinics



## Families

- Parents hesitant to return to hospital for repeat screening
- Families not allowed onto floors



## Early Discharge

- Neonatologists told to discharge babies at 12-24 hours, leading specimens to be collected earlier than normal
- Reference range and lab/computer testing set up to only manage specimens collected after 24 hours



## Quality Assurance

- Couriers not allowed on nursery floors and drivers hesitant to enter hospitals to pick up specimens
- Equipment needed to be maintained despite staff working remotely

# Dried Blood Spot (DBS) Screening during COVID-19: Solutions



## Staff/Closures

- Developed protocol for handling forms from babies with COVID-positive moms
- Moved staff to different buildings/separate work areas and eventually went remote
- Cross-trained staff to ensure coverage
- Instituted mandatory masks and temp checks and managed work based on needs



## Families

- Educate parents on importance of NBS when baby is older by sending home brochures
- Sent educational disorder packets to primary care providers in the event the family did not visit the specialty care center



## Early Discharge

- Sent out a FAQ and online video to entire health commerce system that included how primary care providers can ask for repeat specimens
- Instituted Saturday testing & night hours
- Updated language of reports to include risk assessment
- Updated language for babies on TPN based on profile and referred suboptimal specimens



## Quality Assurance

- Worked with UPS to change their pick-up locations to ensure no specimen was left at a hospital
- Set up remote connection to instruments and data analysis
- Set up electronic tracking sheets for remote staffers entering specimens
- Contacted vendors to ensure sufficient supply of reagents and plastics

# Potential Next Steps

- 1
- Make Continuity of Operations Planning (COOP) more inclusive of issues outside of laboratory testing, i.e. include the potential for staff shortages and future work-from-home orders
  - Make COOP more comprehensive for Critical Congenital Heart Disease (CCHD) screening and hearing screening

- 2
- Early Detection and Hearing Intervention (EDHI) programs that have seen success with screening at one month of age, diagnosis by three month of age and referral by six month of age should consider reducing these targets to screening before one month of age, diagnosis before two months of age and referral before three months of age

- 3
- Provide information and support to midwives and doulas experiencing increased inquiries and to families considering home birth
  - Ensure that disease advocacy groups are included in discussions on long-term solutions to COVID-19 issues to reduce duplication in efforts and put the right information into the hands of families that need it

- 4
- In the event of a second shut down, ensure that parents are aware of resources geared towards attending follow-up screenings
  - Create more flexibility in how families receive information about how to communicate with their deaf or hard-of-hearing baby

- 5
- In order to combat fatigue brought on by virtual support, begin to brainstorm innovative ways of reaching families
  - Support workforce of family leaders so that they become engaged in the system
  - Return to risk communication principles

# In addition to COVID-19, the Newborn Screening system continues to:

- ✓ Add disorders to their screening panels and modify existing algorithms
- ✓ Maintain quality practices
- ✓ Engage in continuous quality improvement (CQI) projects
- ✓ Uphold accreditations/certifications
- ✓ Perform collection, screening, analysis, reporting and follow-up in a timely fashion
- ✓ Address instrument failures, calibration needs, power outages, staff shortages, etc.
- ✓ Save babies!

## To the Newborn Screening Community from APHL:

Thank you for all that you're doing. You are saving the lives of newborns every day and you continue to do so throughout this difficult and unprecedented time. Your efforts and your sacrifices are helping numerous families, and for that we are deeply grateful.

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