



## WORKGROUP REPORT

**Liaison Name:** Amy Gaviglio and Lisa Hom

**Name of Workgroup:** CCHD Technical Assistance Workgroup

**Meeting Date:** December 1-2, 2016

### **Summary of Workgroup Activities:**

The CCHD TA Workgroup continues to host TA webinars aimed at a host of issues and topics regarding implementation and sustainability of CCHD screening. Topics in 2016 have included:

- Data Collection
- CCHD presentations from NBS and Genetics Symposium
- Out-of-Hospital Births (including an international perspective)
- Lessons Learned from EHDI and the NewSTEPS data repository

Webinars are now hosted every other month and the format is more discussion-based rather than lecture-based.

We have also recently convened a workgroup to develop CCHD-related data and case definitions and are working on a White Paper focused on Best Practices for CCHD Screening from a public health program perspective.

The workgroup will be implementing a survey of states to examine what screening practices are amongst NICUs as this is known to differ substantially within and amongst states.

Michigan and Minnesota are currently working on a cost-analysis model to determine how much it costs programs to perform individual-level data collection and follow-up for CCHD.



## **Successes:**

- Nearly all babies eligible for pulse oximetry screening in the US are being screened
- Development of best practices paper

## **Challenges:**

- Data collection still remains an issue – both in terms of resources (staff and infrastructure) as well as what to collect (e.g., data definitions, what data do we need from Echos, etc.). Determining line between need to have from a program perspective and nice to have from an analysis/clinical perspective
- Screen algorithm likely still needs refinement, inclusive of well-baby, NICU, and high-altitude populations
- Still determining effectiveness of screen, which is likely variable from state to state and region to region within a state

## **Salient Questions/Points/Strategic Direction Related Topics for Discussion:**

- NBS program role still uncertain – there continues to be more questions than answers.
- Health equity and disparities evident here as in other areas – need more of a focus on this topic in general.
- How can we better engage and align with Birth Defects Registries
- Implementation/Mandate in and of itself has resulted in decline in death rate from CCHD (soon to be published data from Scott Grosse) – is data collection also necessary, and if so, to what extent?
- Where does NBS fit into the bigger picture of CCHD detection and efforts being done in other arenas (e.g., prenatal and clinical detection rates). We are going to start seeing other conditions where NBS supplements other ways of detection or other public health efforts (e.g., CMV) and how much effort do programs put into these efforts where they are not the “only” detection or preventative measure.