

CCHD Meeting Summary

Solution Oriented Themes	
Be proactive, not reactive	<ul style="list-style-type: none"> • Engage partners and legislators early and often. • Participate early, prior to legislation being passed. • Perform pilots in tandem with lengthy rulemaking process. • Be cautious- ensure legislation is thorough and not limiting, restrictive or short-sighted.
Share model practices between systems	<ul style="list-style-type: none"> • Early and Ongoing collaboration with stakeholders • Bundle activities- what worked for Hearing may work in Congenital Heart Defect (CHD) screening
Pursue diverse funding streams	<ul style="list-style-type: none"> • State and federal advocacy • Local/community grants • Mission specific funding (i.e., technology grants)
Get on the radar	<ul style="list-style-type: none"> • Partners with hospitals before rules are passed • Pursue conversations early
Appeal to advocates/partners	<ul style="list-style-type: none"> • Identify collaborators. • Work with stakeholders (March of Dimes, Heart Assn., Hospital Assn, etc.) • Promote voluntary screening activities in hospitals



NewSTEPS

A Program of the Association of Public Health Laboratories™

CCHD Meeting: Day 1 Summary

Challenges	Potential Solutions
Legislation	
Funding	Integrate parent advocates in legislative activities Non-traditional approaches (e.g., cigarette taxes)
Lack of Public Health authority	Early and ongoing collaboration with stakeholders
Reluctance of hospitals to report to states	Centralized reporting system
Lack of dedicated staff to build infrastructure	Capitalize on existing contracts
Discordant messaging	Collaborate with stakeholders, including early engagement of midwives and other groups
Sustainability	Integrate third party insurers and other partners early to conduct sustainability planning.



NewSTEPS

A Program of the Association of Public Health Laboratories™

Challenges	Potential Solutions
Data Collection	
Resistance to reporting	Meet with hospitals, offer stipends, increase technical assistance, add oximetry data to reporting rules.
Identifying data to collect	Integrate HL7 messaging, link NBS data to birth defects surveillance system.
False negatives	Collaborate with tertiary care centers, birth defects registries.
Funding for surveillance	Link to existing systems (i.e., EHDI), prioritize and don't duplicate data elements, include costs in fee increases.
Lack of uniform terminology	Plan ahead when establishing reporting fields; utilize existing standards.
Telemedicine	
Screening resistance	Training in remote hospitals, awareness building, relationship building.
Unregulated/Unlicensed midwives	Identify champion for midwives who will work with them and well as champions for training within the realm of home births. Offer small community service oriented grants for equipment.
Large geographic areas with no access to cardiologists and NICUs	Promote education when considering training vs. transport solutions. Work with pediatric cardiologists outside of the state to help facilitate transports.



NewSTEPS

A Program of the Association of Public Health Laboratories™

CCHD Meeting: Day 2 Summary

Challenges	Potential Solutions
QI/QC	
Assessing hospital performance	Hospital score cards; compare these to national standards; Collaborate through perinatal collaboratives; Encourage hospitals to perform real time checks routinely
Out of states transfers	Memorandums of Understanding (MOU) with other states
False negatives	Collaborate with tertiary care centers, birth defects registries, death registries
Unique Point of Care Screening	Identify engagement partners, partner hospitals together
Variation between states	Centralized data system to capture diagnosis, pulse ox value, time, zip code (to determine altitude).
Disparate terminology	Create definitions; Create a collaborative to tackle this; lessons learned from EHDI
Getting hospitals to report electronically	Provide options (i.e., spreadsheets to enter data weekly); Articulate benefits of reporting.

CCHD Meeting: Day 2 Summary

Challenges	Potential Solutions
NICU	
Who gets screened?	<ul style="list-style-type: none"> • Perform pulse oximetry at discharge or transfer and conduct follow up accordingly. • NICUs are population based and one protocol does not fit all.
What is purpose of NICU screening?	Need more data to determine this: to catch babies early before they crash?
Protocols	<ul style="list-style-type: none"> • Algorithms and protocols should not be too specific since NICUs are not homogenous. • Collaborate to conduct research/examine data to support protocols. • Existing genetic regional collaboratives with states who are required by legislative mandate to collect data could participate.
Identify resources for data	Example: Vermont Oxford Neonatal Network



NewSTEPS

A Program of the Association of Public Health Laboratories™