

Critical Congenital Heart Disease (CCHD) Resource Center

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APHL is collaborating with the Colorado School of Public Health to implement NewSTEPS.



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Who We Are

- NewSTEPs provides a resource center with information and technical assistance on CCHD for state programs
- The website and webinars are designed to help programs in areas such as implementation and education.



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Critical Congenital Heart Disease Work Group

- Monthly work group calls with selected group of experts
- Includes pediatric cardiologists, Federal partners, state CCHD program staff
- Determines topic and speakers for the bi-monthly Technical Assistance (TA) calls announced out to the CCHD and NewSTEPs listservs



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CCHD In-Person Meeting

- Six Health Resources and Services Administration grantees required to have in-person meeting
- Expanded to bring together 80 people including state public health professionals from 38 states, pediatric cardiologists, database vendors, and Federal partners for a two day meeting



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In-Person Discussion Topics

- Information gathered to utilize in the website resource center on:
 - Education
 - Quality control/quality improvement
 - Data interpretation and collection
 - Implementation, legislation, and approval
 - Neonatal Intensive Care protocols
 - Challenges in remote hospitals/home births/telemedicine



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CCHD Meeting: Legislation

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.



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CCHD Meeting: Data Collection

Challenges	Potential Solutions
Data Collection	
Resistance to reporting	Meet with hospitals, offer stipends, increase technical assistance, add pulse 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., Early Hearing Detection and Interventions known as EHDl), 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.



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CCHD Meeting: QI/QC

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 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.



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Neonatal Intensive Care (NICU)

Challenges	Potential Solutions
NICU	
Who gets screened?	<ul style="list-style-type: none"> • Perform pulse ox 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



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Home Births/Rural/Telemedicine

Challenges	Potential Solutions
Home Births/Rural/Telemedicine	
Screening resistance	Training in remote hospitals, awareness building, relationship building.
Unregulated/Unlicensed midwives	Identify champion for midwives who will work with them as 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.



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Education

Challenges	Potential Solutions
Education	
<p>Varied/multiple audiences</p>	<p>Partner with others to disseminate information Utilize materials already developed for specific audiences Take advantage of technology: e.g., listserves, webinars Tag onto other trainings when possible (e.g., Perinatal Nurse Managers, Perinatal Coordinators, etc.)</p>
<p>Lack of expertise within the state program</p>	<p>Recruit and partner with the experts in your state/territory (e.g., neonatologists, pediatric cardiologists, etc.)</p>
<p>Need for educational materials</p>	<p>Take advantage of existing materials: e.g., Children’s National Medical Center, Virginia’s on-line trainings, etc. Websites: State programs, NewSTEPS, CDC etc.</p>



CCHD Landing Page

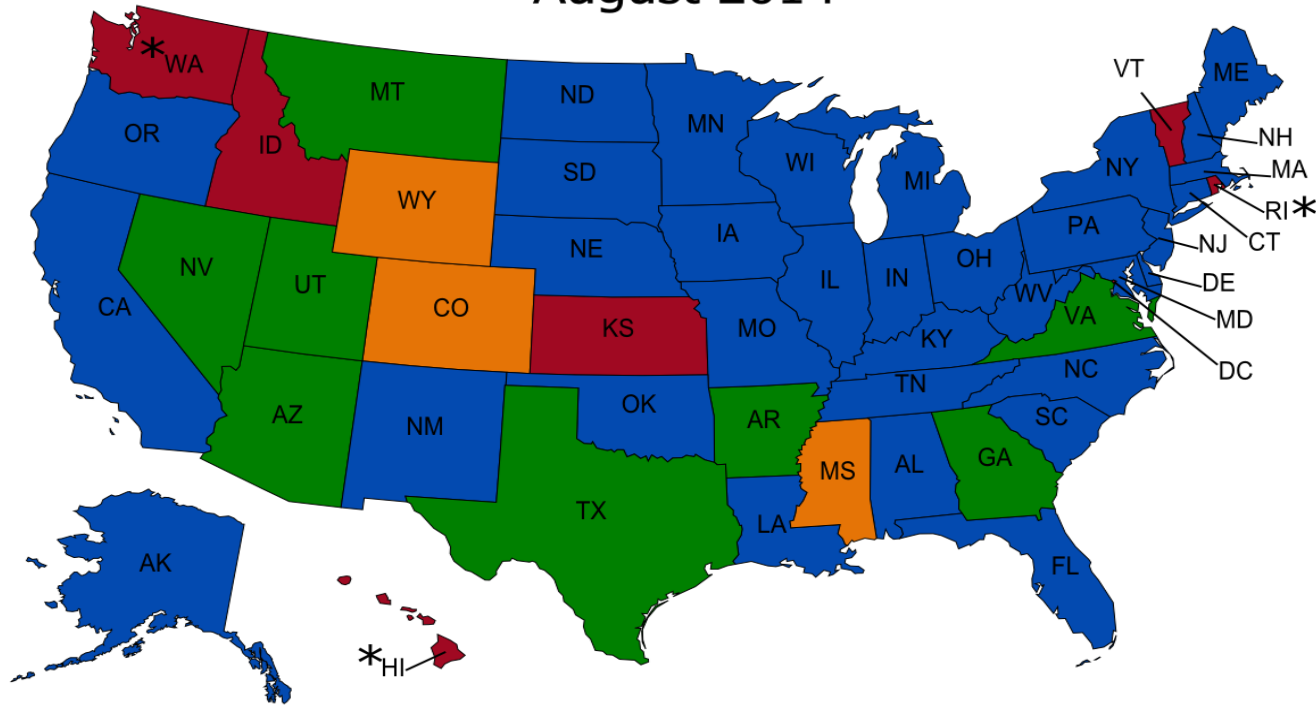
- Go to <https://www.newsteps.org/cchd>
- This is found under Disease Specific Activities on the home page
- Contains many links to more information so look for the purple hyperlinks
- Please send us any additional materials or information you feel is pertinent



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CCHD Screening Status August 2014



Screening Status

- Universally required by law or rule and fully implemented
- Required by law or rule but not yet fully implemented
- Being considered via legislation/statute/rule change but not yet approved
- Supported as standard of care without a law

*Universally offered

Critical Congenital Heart Disease (CCHD) Technical Assistance (TA) Webinar

NewSTEPS hosts monthly CCHD TA webinars to address the needs of stakeholders in the states and in screening programs with topics including education, data collection, telehealth, and more. Links to the previous webinars and topics can be found [here](#).

If you would like to be added to the CCHD Listserv to receive announcements about the calls please contact [Lisa Vasquez](#) [✉](#).

The monthly webinars take place on the second Friday of each month at 1 pm ET. The call in number is 866-740-1260 with a code of 4852701. Webinar links will be provided via the listserv.

If you have ideas or suggestion for future calls, please contact [Thalia Wood](#) [✉](#).



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Legislative Updates

The latest updates on CCHD newborn screening bills for each state are developed by the [Newborn Coalition](#).

Data collection is a critical component of CCHD newborn screening and should be considered in initial legislative efforts. Examples of Legislative language to support public health data collection for CCHD screening can be found linked [here](#).

The [Network for Public Health Law](#) provides insightful legal assistance, helpful resources and opportunities to build connections for local, tribal, state and federal officials; public health practitioners; attorneys; policy-makers; and advocates.



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Educational Resources

Newborn screening for CCHD touches many aspects of the community. NewSTEPs has compiled educational resources from the community that can be used to support screening efforts in other states and regions. These can be found linked [here](#).

News and Events

Please check back frequently as we will be adding additional news and events. We have compiled a list of [pertinent publications](#) which serve as resources for the NBS community.



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Data Collection

The collection of data from pulse oximetry screening will help to ensure all babies are screened and receive appropriate follow-up following an abnormal screen. Evaluation of the programs and the algorithm also requires data collection at the public health level. Suggested data elements and tools used for data collection have been developed by many programs. Best Practices are also provided from states that have developed an effective data collection process to provide insight into their methods.

A list of recommended minimum data elements to be collected within the CCHD screening system has been developed by a workgroup of experts working in CCHD in February of 2012. They are presented in Table 2 of the publication linked [here](#).¹⁶

NewSTEPS will be collecting outcome data on CCHD newborn screening, including quality indicators and basic information about the cases diagnosed with CCHD. Specific data to be collected can be found in the [NewSTEPS data repository](#).

Point of Care Newborn Screening Tests share similarities that could inform the implementation of other point of care tests.



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Stay Connected with NewSTEPS

NewSTEPS Listserv

A NewSTEPS listserv has been created for NBS stakeholders. This listserv acts as a forum for peer exchange of information, relevant to NBS. We encourage you to post information and questions on topics such as NBS laboratory practice, quality improvement, education and training, program evaluation and policy.

To join this valuable listserv and start receiving messages, please send an email as described below:

To: lyris@lists.aphl.org

Subject: (leave blank)

Body:

join aphi-newsteps firstname_lastname

Your affiliation/signature line

Health Information Technology Listserv

The Newborn Screening Health Information Technology (HIT) listserv acts as a forum of peer exchange of information relevant to newborn screening HIT activities. We encourage you to post information and questions on topics such as electronic exchange of data policies and

Join the Listserv

The NewSTEPS listserv acts as a forum for peer exchange of information, relevant to newborn screening and NewSTEPS activities. [How to join...](#)

News and Events

AUGUST 3, 2014

Rhode Island Health Department expands infant screening to include rare immune deficiency

The Rhode Island Health Department recently issued a statement noting that all newborns will be...

JUNE 25, 2014

APHL Awarded Multi-Million Dollar Cooperative Agreement for NewSTEPS

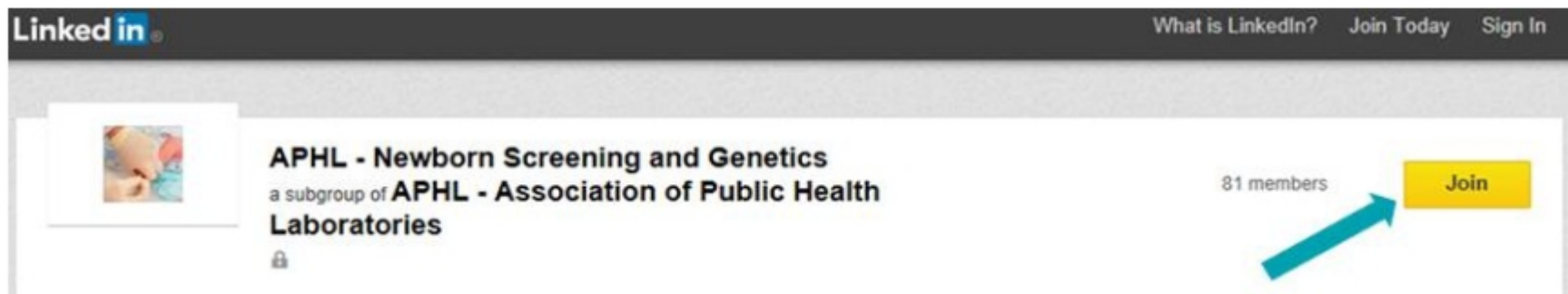
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For information how to join this listserv please click [here](#).

Join Us on LinkedIn

The Newborn Screening and Genetics Program at APHL has joined [LinkedIn](#). To further connect our newborn screening (nbs) community and support the growing network of NBS professionals we encourage you to connect and interact with one another on the APHL-NBS LinkedIn group page. Once you navigate to the link above, click the yellow "Join" button and you will be approved by APHL to join the group. Please contact Yadi Belay (Yadashe.belay@aphl.org) if you have any questions regarding LinkedIn.



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Next Steps for CCHD

- Case Definitions—working with Centers for Disease Control and Prevention on case definitions for the seven most common CCHDs picked up by pulse oximetry
- Working with Birth Defects Registries to help identify infants who were missed and to ensure a complete reporting system



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Conclusion

- NewSTEPS is the resource for:
 - Technical assistance
 - Webinars
 - Data collection
 - Bringing people and resources together



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