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Critical Congenital Heart Disease (CCHD) Technical Assistance Webinar

January 10, 2014

Presentations:

- Overview of Upcoming in Person CCHD meeting in February—Marci Sontag, PhD
- Virginia Educational Module—Sarah Manglicmot, BSN,RN
- Interactive Discussion—everyone on the call and led by Marci Sontag, PhD

Moderators:

- Thalia Wood, MPH, Specialist, NewSTEPS
- Marci Sontag, PhD, Associate Director, NewSTEPS

Please direct all comments/questions pertaining to this presentation to Thalia Wood at Thalia.wood@aphl.org or 240-485-2701.

Thalia Wood: Good morning. (Phone rings). Marci, are you able to do the presenter slides now, as well?

Marci Sontag: I have not been able to do the slides yet.

Thalia Wood: That's fine. It promoted you to co-presenter so ...

Marci Sontag: It says it's working, so we will let it work.

Thalia Wood: Okay.

Marci Sontag: This is Marci Sontag, and I'm sorry because we're not going to use all the lines because we really want this to be a very interactive call with a lot of participation, so we're going to put you on the honor system to mute your own lines, so either mute your line locally or you can use the commands, which ... Thalia, could you remind us what the commands are to mute our phones? Star six? Just to avoid the background noise, so ... Thalia, it looks like I am not being promoted. It looks like there's some responsiveness issues, so if I can't be a presenter, I can just go back to being a regular attendee.



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Thalia Wood: Okay, well, I went ahead and put the next slide, so if you want to talk about this slide, Marci.

Marci Sontag: Well, that's fabulous. I can't see the slide because it still says I'm being promoted.

Thalia Wood: Oh, okay. This is the one that ... the CCHD February meeting.

Marci Sontag: Excellent. Okay, thank you. As hopefully you have all heard by now, we are having a meeting in Silver Spring at the APHL offices for CCHD implementation. Really, the purpose of this meeting is to take what all of us are doing for CCHD implementation across all 50 states and, by the end of the meeting, hopefully be ready to move a step forward from wherever you are.

For those of us who are still at the very beginning stages and figuring out how do we implement these algorithms and how do we get approval in funding to do it in our states, to those of us who are really at the implementation stage and collecting data and figuring out what do we do for quality improvement and taking it to that next step, we'd like all of us to be able to move forward.

We have put together an agenda. We've talked to I think it's about eight states now who really are well on their way in CCHD implementation to help us present with some of the lessons learned that they have already accomplished. What have they accomplished? What are the challenges that they faced, and what are some of the solutions?

We have the agenda put together. We're going to run it by them, and then we'll be sharing the agenda with you publicly as who's speaking and what are the topics, but broadly the topics will be issues related to legislation mandates, how do we get things approved in our states, education, educating the nurses who are doing CCHD screening, educating the public. How do we go about those types of activities?

A big one we'll be spending a lot of time on is data collection and data interpretation. What are some of the successes of some of these states who are already well along their way? What have they done with HL7 messaging, with electronic birth certificates, with other methods of data collection? How are they collecting the data? What are the basic elements that we've needed to collect?



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Then moving into quality improvement, now that you have the data, what do you do with it? How do you partner with the Birth Defects Registry to make sure you've got all the babies that you need to be identifying? How are they collecting the data, et cetera, and then issues related to NICU? I'm missing something, Thalia. So really ...

Thalia Wood: Telemedicine.

Marci Sontag: Telemedicine. Thank you. That's the key one that I was not able to come up with. We will be approaching all of these issues both first from an experiential standpoint, letting the states who have already attacked these issues and really gone through them to share their experience, and then breaking out into small groups to say what are the barriers in your state for this particular issue, what do you think you're going to do, and really looking for solutions, so by the time you go home, you will have paperwork in hand to say, "I feel empowered to know what the next step is for my state," at whatever level you're at.

If you have not registered, please visit our NewSTEPS website and register. We are funding one person per state to attend this meeting, and then, in addition to that, we're welcoming other stakeholders, other people from states to attend the meeting and really join us. We'd love to have a really comprehensive meeting so, by the end of this, we're all ready to jump into this new year and tackle CCHDs, that we're all moving forward. Thalia, are there any other logistics that you would like to add to that?

Thalia Wood: No. I just want to remind people to register even if they're not being sponsored as one of the 50 people from each of the states to come in. We do want a registration so we can see who all is coming, so that's why there's a link on your screen right now for the registration that I can send out to people if you need it, as well.

Marci Sontag: Yeah. On that website, we also have some information about what local ... If you're not being funded through NewSTEPS, better local resources for the state, et cetera, and some more details about the specific times of our agenda. We decided to actually start the agenda ...

It starts on the Thursday morning of the 27th of February, and we're setting the agenda a little bit later than we might typically start meetings, as there are many people on the East Coast, New York, New Jersey, that



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area, and down in the D.C. area that can ... or Virginia area that can drive in and not have to pay for an extra day of hotels, so we're starting the meeting at about 9:30 on that Thursday morning, hopefully to allow for those of you who live close to be able to travel and maybe be a little more economical meeting for you.

As we are building that agenda, we want to get feedback from all of you on other experts in the area, other ways that we can help support you, so we're going to modify the agenda based on today's call, and we'll talk about that in just a minute.

Thalia Wood: Yeah. Thank you, Marci, and we would like to remind people that we have a deadline of February 1 for registration. I don't know why, Marci, you're still not being promoted, but if you want to, we can move ahead and ...

Marci Sontag: Oh, okay.

Thalia Wood: Yeah, so Sarah, are you on the line?

Sarah Manglicmot: Yeah, I'm here. This is Sarah.

Thalia Wood: Sarah, if you want to just talk about those, and I do have ... I did make a slide of your flyer called ... I could put that up here, as well, when you're ready for it.

Sarah Manglicmot: Okay, great. Yeah, that's one of the first things I'm going to talk about, so you can put that up whenever.

Thalia Wood: Okay, sure.

Sarah Manglicmot: I'm just going to quickly talk about the ... Virginia has a couple CCHD education resources that are available right now. The first one, I'd like to invite everyone to our 2014 CCHD webinar series. The first one is going to be on Tuesday, January 28 at 12PM, and it's a review of CCHD anatomy and physiology presented by Jan Balmer from the University of Virginia. Ms. Balmer is currently the Director of Continuing Medical Education at the University of Virginia School of Medicine, and prior to this position, she was a nurse clinician for the Division of Pediatric Cardiology at the UVA.



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This is a free webinar and provides one hour of nursing or medical continuing education credit. Future webinars in this series include parent education for CCHD screening and results in March, CCHD surveillance in Virginia in April, and talking to parents about a positive CCHD screening in May. There's more details and a link to registration on this flyer, and I can also send this flyer out onto the Listserv so that everybody has that. I can do that after the call here.

Male: Yes.

Sarah Manglicmot: The next resource we have is our CCHD interactive education module on our new website that we announced on the Listserv back in November. As a reminder, the website is www.newbornscreeningeducation.org, and it's for any clinicians who work with CCHD screening. It provides an hour of nursing or medical continuing education upon completion of a post-test.

The module covers an overview of CCHD and screening, including rationale, best practices for implementation, and interpretation of results. There is an interactive ... interactive scenarios such as answering a mom's worried questions, placing pulse-ox sensors on a baby, and interpreting case studies.

You do not have to complete the module all at once. You can sign in and out and use it as a review even after you submit the post-test. You do have to register for this course on the website, and currently our grant covers the \$39 cost for Virginia residents only, but there is a group pricing discount for any institutions outside of Virginia that want to use this as a professional-development activity, and I think Marci has some information about possible access for those attending the meeting in February.

Male: I'll work on the date last night first. How does that sound?

Marci Sontag: We are experiencing some conversations about state labs, so if you can please mute your phone, that would be fabulous.

Male: [Inaudible 00:09:46].

Marci Sontag: And I will use ... Thank you, Sarah.

Sarah Manglicmot: Sure.



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Marci Sontag: I'll use this time to talk about that access. We have been working with the Virginia folks on what does this website look like and how can we use it as a resource for other states who want to be able to use this. Many of us are trying to develop educational materials, and it really is helpful to be able to not re-create the wheel.

Before I go into that, I also wanted to mention that New Jersey has a fabulous website that they've also put together and interactive modules, and both Sarah and Jean from New Jersey will be talking about these, their modules, at the CCHD meeting at the end of February.

In preparation for the meeting in February, though, I know there are many people who are coming to this meeting who have varying levels of understanding of CCHD physiology, the heart defects themselves, and just an understanding of the screen, that there are many people who are new to this, in addition to those of you who are very much experienced, so we have worked with the folks in Virginia to be able to offer you free of charge one person to have access to this newborn screening website and modules through the state of Virginia.

As you register, within the days following registration, it'll ask you ... It'll probably take us about two weeks to get this all in place. We will send you out a code, or actually, I think you'll be directly contacted by Virginia to say your email has been given access to this. We really would encourage you, for those of you who are attending the meeting, if you have access to that code, please go in, go through this module, see what's there, see if something like this is useful, whether it's the Virginia modules or the New Jersey modules or others that are available, but how can we use what others are using out there for education and also to make sure that we're all at the same place as we enter this meeting in February.

We really want to start this with the understanding that we all have basic understanding of CCHD newborn screening, so we're not going to be giving a 101 on, you know, this is ... We're doing pulse oximetry. This is why we're doing this screening. This is the heart defects. We want to be able to assume that everyone has that basic knowledge.

These modules will be fantastic for that, so if you are the registrant that's paid for by your state or by NewSTEPS from your state, we will be sending you a link to be able to participate in this module. We'd like to thank



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Virginia really for helping to support this, producing this module, and then helping support this so we can all make sure we're well-educated and prepared to start the conversations in February.

Thalia Wood: Yes. Thank you, Marci, and thank you very much, Sarah, also. I think that answers the question that somebody typed in over the site about the ... This is different from the AAP module, and so to answer the question, one person from each state will have a link to use this, and otherwise there is a charge for this. Okay, are we ready to start the interactive part here, Marci? You might want to explain how this is going to work.

Marci Sontag: Are sure will. Sarah, did you have anything else you'd like to say about your modules or any of your educational tools before we move on?

Sarah Manglicmot: No, that was it. I am going to send out information. I know it was hard to kind of get the details of the flyer. I'm going to send out that flyer and a link to the website to everybody on the Listserv after the call.

Marci Sontag: That would be fabulous, and that's another place that ... Listening to these webinars is a fantastic way for you and your teams within your states to really understand anatomy and physiology and this is what we're dealing with, and to pass it on to any of the clinicians that you might be working with to help spread that knowledge throughout your program, so thank you, Sarah, in Virginia, for presenting that. Also, thank you to New Jersey, who I know will have something similar, and they will be presenting that at our meeting in February.

On to the interactive piece of our webinar. We realize some of the feedback we get from each of these conference calls each month is, "I wish there was more time for discussion. I have a question I wanted to ask. I wanted to ask about this," so for this webinar, we really are letting it be discussion-based led by you, and also recognizing that we only can call on the people to speak on our webinars that we know the work that they've done. We know many of you have done work that we might not be aware of, so we wanted to give this as a chance for you to demonstrate what you've done.

We had kind of an inspiration earlier in the week that's really based off of Choose Your Own Adventure books, if any of you have read those or read them to your children. In those books, the heroine and hero or heroine is presented with a choice. If you'd like the hero to go down into the dark



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cave, you turn to page 42, or if you'd like the hero to climb the big mountain, you go to page 54, and based on that, the story unfolds differently.

We have developed a Choose Your Own Adventure CCHD webinar, so we are going to choose the slides that we go to and how we determine this discussion based on your interactive feedback, and then really allow you time to discuss the issues, so on to the next slide. Thalia, I am not seeing the ability to vote here.

Thalia Wood: No. I'm going to ... This is just to give them an idea of what we're going to be asking, and I'm going to insert the poll now.

Marci Sontag: Okay, so the first question, we want to really be able to identify what would you like to talk about most. What's the thing that's bugging you the most right now or the thing that is the biggest challenge for you? Is it the babies that are born in outlying hospitals? Are we going to do telemedicine and get them followed up? And then NICU protocols and the data collection and surveillance. Maybe just the basics of implementation and legislation. Is it education, some of the issues that Sarah just talked about, or is it quality improvements? You've got screening going, and now what's the next step? For our first trial, we'd like you all to choose one of these, and that will take us to another set of questions that we will then use to start the conversations.

Thalia Wood: You have to fill all three votes right now, and then I'll show the results here in just about 20 seconds.

Marci Sontag: I feel like we should have some Jeopardy music, Thalia.

Thalia Wood: Yeah, there you go. That would be good. Okay, I'm going to show the results.

Marci Sontag: Okay.

Thalia Wood: Okay. It looks like data collection is the first big issue.

Marci Sontag: Data collection continues to be the biggest challenge. All right. More votes are still coming in, but data collection is the first thing we will talk about, so thank you, all. Now we have some followup questions to that, so I'll let Thalia ... give her a minute to find those slides. This is the next chance to really drive how this conversation will go, so as we're waiting



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for Thalia, be thinking about what are the challenges that we're facing and what are the biggest challenges of data collection and surveillance.

Thalia Wood: When I'm going to the poll for this slide, you can have multiple choices. You can answer more than one.

Marci Sontag: Okay, so look at these, and I think, as we go to this poll, some of these might have to have been shortened, so I'm going to read through these first, and then we'll go to the poll. Oh, I guess ... This is fine. So the biggest challenge is getting buy-in from the nursing staff to do the data entry and develop a data-entry system, is identifying the right system. How do you get the data entry into your public health system?

Development, how do you develop the IT system? You know what you want to do, but you need to develop it. The public health authority. You don't have the authority to collect the data from the hospitals. What do we do about that? How about interpreting the data? Once you have the data, what do you do with it? Money, actually that financial standpoint of how do we pay for all of this? We just don't have any funds to do any data collection, so we're feeling strapped. Or is there another issue that's the most challenging for you?

Thalia Wood: Okay, I'm going to skip to the results since we got cut off here for a minute, so there we go. Marci, do you want to lead the discussion on this?

Marci Sontag: I absolutely will. This is fascinating. We really appreciate these surveys. This is really helping to inform us. Public health authority is one of the biggest challenges. Oh, look at this. We have a very dynamic survey today, don't we? We'll let these settle out a little bit, and we can actually use this to head down two paths since we're ... It looks like we have two answers that are right there with the most interest, but first, I'd like to talk about that public health authority. For one of you who selected that, would you be willing to share what is your challenge? What's the challenges you're facing, and for those of you that may have overcome some of these challenges, please be ready to respond, as well ... Well, just go ahead.

Kathy: This is Kathy Moline from Virginia.

Marci Sontag: Hi, Kathy.



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- Kathy: I chose public health authority in the fact that we are, at the present time, not legislated, and we are able to put it and have just started documenting it on our electronic birth records, which will then allow us to look at a failed screening through our Birth Defects Prevention Program and our birth defects surveillance, but it is a voluntary part of our birth certificate.
- You heard from Sarah Manglicmot before, and she's done a fabulous job of convincing people to please fill this in, so we'll soon be getting data to say whether we can do it. At the present time, it is not part of our newborn screening panel. Our birth defects surveillance system says that we get it on diagnosis, not on screening, so we have to be able to look at how do we have that authority to really do it. Thank you.
- Marci Sontag: Can I ask a follow-up question, Kathy? How are you able to add it to the electronic birth certificate? I know in my state, we can't add things unless there's some sort of mandate.
- Kathy: In the state of Virginia, the state registrar under code has the ability to add things that are of public importance or that needs to be looked at, everyone agrees needs to be looked at, and so it was able to go on her authority to be added to the electronic birth record. It is under the part, though, that is voluntary and is not mandated by law, so it's under worksheet number two, I believe it's called, Sarah, that allows them to put in voluntary things that can add information and data to help support programs such as ours. Does that answer the question, Marci?
- Marci Sontag: It does. Thank you. So that then ... I'm just going to feed you your next potential challenge is getting that buy-in from the nursing staff to fill that in, but that's ...
- Kathy: Right, and we can't wait because they have seven days to get the birth certificate registered, so we are very excited to look through our birth defects because we can actually see the birth certificate information, so to be able to see whether they're filling it in or not.
- Sarah Manglicmot had many calls making sure that they were doing it correctly, so I think she's done a great job in encouraging them to really understand the importance of them. There were hospital registrars giving us this data and making the connection between the information that the



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registrar puts into the hospital and the actual being able to increase and improve and enhance the services given to this child, to this infant.

Sarah Manglicmot: Can I just add one thing. This is Sarah. I'm from Virginia, as well. I had trainings where I invited both the nurse managers and the birth registrars for the hospitals because the birth registrars are actually putting in the data, but they really need to work with the nurses to know where to get the information from the charts, so I've really been working with both the clinician and administrative side to get them trained. We actually had a really good turnout for people coming to these voluntary trainings, and I've had a lot of people asking questions, which leads me to believe that they are doing it and planning on continuing doing it.

Marci Sontag: That's fabulous. Thank you, Virginia.

Debbie: This is Debbie Freedenberg in Texas, and we have slightly different issues under public health authority. We do have a law that authorizes us for CCHD screening. However, we have not implemented yet because we're awaiting our rules before we can implement the program, but our issue is our law did not come with any additional funding, and our law refers to confirmed cases reported, so we're trying to figure out ways where we might be able to figure out who's actually been screened and who hasn't or percentages, and at this point in time, we don't have the ability to really track the screens.

Similar to what Virginia said, it's confirmed cases, and at Birth Defects, we'll have some of that information, but again, it's not going to be real-time. It will be at least a year later that that information will become available from Birth Defects Registries, so as I said, it's a slightly different twist to it in that we have the authority, but the law, as it was passed, just states confirmed cases be reported.

Marci Sontag: And that's a ... as where those of us who have not passed laws yet, I think that's important for us to remember that laws or other statutes that will require screening is to have that language in there. Anna Marie has done a nice job of reminding us of that, to make sure we have the right [inaudible 00:24:33] so we can get the [inaudible 00:24:34] we need.

Jean: Yeah. Hi, this is Jean from New Jersey to describe our data collection process currently and then what we would hope to move to. Currently, we're asking the hospitals ... It is sort of on a volunteer basis, although we



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have 100% buy-in for quarterly aggregate data, so we have a template that is sent out, and it asks questions such as how many births in your center? How many babies were screened, and if they weren't screened, why were they not screened? Were they not medically appropriate at the time or they transferred out, et cetera?

We do have 100% cooperation for quarterly aggregate data, and then the little twist that we have ... I hear the conversation with only confirmed cases or diagnoses being reported to the Birth Defects Registry. We added failed pulse ox as a diagnosis to our Birth Defects Registry, so we're able to track all failed cases that are reported to the BDR, and then we are able to tease out ... We have a list of several questions aimed at teasing out was the baby's condition picked up due to the pulse-ox screening or from something else. That's what we're working on now with the quarterly data and then the actual CCHDs that are reported and other defects that are reported to the Birth Defects Registry with the addition of failed pulse-ox screening as a diagnosis.

Our electronic records system currently does not enable us to get individual-level data from the EDC. However, we anticipate rolling out a new system in which we have specific questions related to CCHD screening, so we anticipate in the near future, if not this year, sometime in the near future that we will have this new vital-information platform, and at that point, we will have robust data, individual-level data.

Troi:

This is Troi Cunningham with Kentucky. We have a ... it sounds like a unique system in that it's called the KY Child System. On the hospital end, and this is mandated, all hospitals in Kentucky are on this system. There's a tab for them to enter the birth-certificate information. There's a tab for the newborn-screening blood spot. We have all that with bar codes to be identified, that information. There is a tab for the hearing screen, and there's also a tab for the CCHD screen.

What we have on that CCHD screen is exactly developed from that algorithm, the AAP algorithm, and so it asks detailed information on all of those elements. That is all fed into vital statistics and to the KY Child System, which then feeds into us. We get a real-time, a daily report that shows us which infants have been born four days of age or older, but have not received a CCHD screen. Then we fax that list to each hospital for them to follow up and let us know why the child did not receive the screen.



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Also, on the KY Child Screen, it has an area for them to put in why a screen was not performed, if the baby was transferred, what the echo results were, and then also what the specific diagnosis was. It's proving to be quite a bit of work, but we feel like that we're going to catch these babies really quickly.

Marci Sontag: That is fabulous. Thank you. How well is it working? Are people filling it in or ...?

Troi: Yes, it's mandated by state law. It just went into effect on ... The law went into effect on January 1, and we brought up that system. We have been piloting it for about a year with a select number of hospitals, and it was going really well. All the birthing hospitals in the state were already performing the testing in the algorithm. It was just a matter of learning the new screen.

Marci Sontag: There's a question being asked: is the Kentucky Child Screening a web-based data-entry system?

Troi: Yes, and then we will report the positive diagnoses on a monthly basis to our Birth Defects Surveillance Program.

Pam: This is Pam. May I help you?

Marci Sontag: Pam, I think you may have gotten the wrong line since we're on a conference call.

Jean: This is Jean from New Jersey. I just had a follow-up question to Kentucky. With your KY Child System, it's one stop? You can get all the information you need from your electronic database so that the hospitals then don't have to enter into the Birth Defects Registry separately? You can extract what you need from your K ... Is it KY or K1 Child System?

Troi: KY Child, like Kentucky. The Kentucky Child System.

Jean: Kentucky, okay, so ...

Troi: But yeah, all of that feeds into together so we can extract that data really at that time. With those daily reports, we're looking at real-time data, so we can see failed screens. We have two different reports, failed screens and missed screens. Also, as part of our internal system with the hospitals, if it's a failed screen, they're to immediately fax us a copy, print



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it out from that KY Child Screen and fax it to us so that we can take care of the QA and the case-management part of it.

Jean: Yeah, it's wonderful. That is something we are looking at with our new vital-information platform, and similar tabs with all newborn screening will be on there.

Troi: Yes.

Jean: In terms of data interpretation and all that, did you have to get additional staff? Is it birth-defects staff that looks at that, or newborn-screening staff, or someone else?

Troi: It's all of the ... CCHD and the newborn screening. The hearing screen goes through our Commission for Children with Special Healthcare Needs, so we're not involved in that, but the newborn screen and the CCHD are all handled in our office. We consist of a staff of three nurses and a program coordinator.

Jean: Mm-hmm (affirmative).

Troi: It has made a lot of extra daily work, but as we're going along since it's gone live, we've already made great progress in streamlining a lot of that.

Jean: Thank you.

Female: Can I ask you how many births a year does Kentucky have?

Troi: About 56,000.

Female: Thanks.

Marci Sontag: You may have mentioned this, and I may have missed it. Did you have a fee increase or did the legislation come with some funding for this, or how were you able to fund your program?

Troi: There really wasn't any funding for it. Our General Session has just started in Kentucky, so they are proposing an increased newborn screen to also account for the upcoming SCID testing that we'll be adding, as far as equipment and that type thing. Also, our university contracts will need to be increased because of adding cardiology and immunology and



infectious disease for these two different new tests, so we will have to wait until the state budget is approved to see if that is granted to us.

It also would support the actual information system as far as data changes to that system and potentially down the line, hopefully, another nurse for me, but at this point, there has been no funding. The easy thing about that is that the hospitals already had all of the systems in place, so we didn't have to do anything or provide anything for the hospitals.

Marci Sontag: Got it.

Troi: Really, it was just a matter of adding a new tab in our KY Child System and figuring out our internal process.

Marci Sontag: Right. Great. Well, that's a fantastic system. Thank you. Are there any others who'd like to share an example of a data solution to this developing the IT system and public health authority because I think in many cases they really do go hand in hand? Okay, so I'm not hearing anybody jump in. Thalia, let's get to our next Choose Your Own Adventure slide.

Thalia Wood: Okay. Well, I'm going to go back to the original poll.

Marci Sontag: Okay. Can you clear those results and then ...? In this one, we're going to ask that you don't choose the data collection and surveillance since we've already gone down that adventure path.

Thalia Wood: Right. Choose something else, and we'll go on to some additional Choose Your Adventure questions.

Marci Sontag: I love how we can see the real-time responses. It's kind of fun. Once you've voted, you can watch how everyone else is.

Thalia Wood: Wow. Hmm.

Marci Sontag: We'll just give it another couple seconds while everyone's submitting their votes. It looks like we picked good topics because the topics are getting good distribution and everyone's interested in them.

Thalia Wood: Right. It looks like NICU protocols might be winning out, so then I'll go to the questions for that.



- Marci Sontag: Okay.
- Thalia Wood: How does that sound for the next part of the call? I've done the wrong thing there. Okay.
- Marci Sontag: The NICU protocols are ...
- Thalia Wood: Okay, so here's the next set of questions. You can answer more than one again, like on the last one, now that we're on the NICU protocols for NICU babies, so if you want to go ahead and vote again here.
- Marci Sontag: These are the challenges that either you see in your state or broadly as you're thinking of implementing CCHD screening. What are the challenges that you see coming ahead of you? How do you interpret data from the NICU and the decision on whether to screen? Do we screen those NICU babies, or do we not screen them? What about screening the babies who already have a CCHD diagnosis? Do you include those in your fix or not? Educating the NICU staff on screening, or is there another topic that's most critical to you for the CCHD or for NICU babies?
- All right. It looks like votes are still coming in, but I think the first challenge that we all see in the NICU is how do we interpret that data from the NICU? We can get some guidance on this. I know many of you have worked on this. Some of the HRSA grantees have been working on NICU issues and others, as well, so if anyone would like to jump in and give your thoughts on how do you address these data-integration issues.
- Thalia Wood: Lisa Hom, you wrote eligibility criteria. Do you want to elaborate on that?
- Lisa: Hi, Thalia. Sorry. I had to find a new button, but I was having some indecision on which one to select because I think for indecision on whether to screen, I think you guys described it as whether or not to screen, but if you do go ahead and decide that you do want to screen NICU babies, what is that eligibility criteria? So I wasn't sure whether I should pick the indecision question or another. That's why I ... I thought I was just shooting it to you, but that was my question. Thanks.
- Thalia Wood: Well, you were shooting it to me, but I thought that was a good thing to bring up because I think that's important, and you write, "We didn't have that as a choice," and that's very important.



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- Lisa: Okay. Yeah, I just wasn't sure if it was part of a indecision on whether to screen. Thanks.
- Thalia Wood: So, Lisa, can we continue to put you on the hot seat?
- Lisa: Sure.
- Thalia Wood: Thinking about that, what do you interpret then as the eligibility of who to screen and also then when to screen for the babies?
- Lisa: Right, because ICU nurses are very used to seeing babies with low Sats, and with some of the guidelines that are out in the NICU, they like to keep their babies ... Any baby who's on oxygen, or even babies that aren't on oxygen sometimes for other reasons because they're in the ICU, they tend to have lower numbers below what sort of a normal-term baby, 35-plus weeker will have, which will be 95 to 100.
- I think that that's where the difficulty comes in on when to screen and how to create that eligibility criteria, whether or not it's you're screening every baby that's off oxygen and greater than 34 weeks, or really just kind of fine-honing so that you don't have a ton of false positives and that it's a meaningful data set. It leads into the other questions that you're seeing in our challenges, such as interpreting the data once you have it and kind of how to screen these babies, so ...
- Thalia Wood: I see there's another question: what about doing screening or echo when not able to be off oxygen? That was a question. Is there anyone that would like to answer that question?
- John: Hi, this is John Hokanson from Wisconsin. Can you hear me?
- Marci Sontag: Yes. Hi, John. Go ahead.
- John: Oh, hey. I can tell you what we've done in our state's largest NICU that's worked out pretty well. Most of the sickest babies end up getting an echo anyway, and if a baby has already had an echo, we don't screen them. Okay? Of the babies that have the test, though, what we would do is have the NICU wait until either they're off oxygen or they're on the oxygen that they're going to go home on, and that is the screening with the same algorithm as everyone else.
- Background: [Inaudible 00:41:59].



- Marci Sontag: Thank you, John. I have a follow-up to that, and I think that we have some phones that are off mute again. If you can remember to please mute your phones. A lot of people said that you can't ... For kids who truly have these defects, if they're on oxygen, they're obviously not going to improve being on oxygen. They're still going to have challenges, so I'm wondering if there could be, in the future, a way for us to collect the data and say, yes, they're on oxygen, pulse ox, and interpret this data differently [inaudible 00:42:36]. It might have an effect. It would still be low-pulse levels.
- Background: [Inaudible 00:42:40].
- Marci Sontag: Please remember to mute your phone. We're having quite a bit of background noise.
- Background: [Inaudible 00:43:02].
- Marci Sontag: It's like someone's having a conversation in the back of the room, and we can hear it. Thank you.
- Debbie: One of the things that ... this is Debbie Freedenberg in Texas again, and we haven't implemented, but one of the things as we're designing our forms and our protocols is that we felt it was really important to distinguish between a prenatal echo and a postnatal echo, in terms of exclusion from screening.
- Again, we were going to put obviously if they've had an echo, they don't need to be screened because they've already had the "confirmatory" testing, but we found that there was some confusion about postnatal echos and prenatal echos, and I was wondering if anybody else wanted to address that or had any experience with that.
- John: This is John again. I don't know if there's any other clinicians on board, but what I've always told the trainees is when someone tells you they've had a prenatal ultrasound, prenatal echo, or whatever, the right thing to do is smile politely and keep working, and if you're suspicious about heart disease, keep being suspicious about heart disease, having seen lots of kids where it was missed prenatally on ultrasound.
- Debbie: Right, and that was the protocols we were putting in place, but we got some push-back with some folks wanting to exempt the kids who had prenatal echos.



- John: Are you distinguishing fetal echo from prenatal ultrasound?
- Debbie: Well, they have been calling them prenatal echos, and actually, I'm using it more generically. A lot of them have said that they've done a level-two prenatal ultrasound, and they should have corded if it was there, but we all know that they do have missed cases. So I'm using it more in the generic, but even the focused heart echos, we felt that we know that sometimes it's really hard to see things and that that child we would not want to exempt from screening.
- Tiffany: This is ...
- John: I would agree.
- Tiffany: Yeah, this is Tiffany Colarusso from the CDC, and I am a clinician also. I would also add that even if they did have a fetal echo even prenatally, that diagnosis could have changed, and so what you're seeing postnatally may not be what the echo showed prenatally, even if it is a fetal echo, so my comment is, yeah, they shouldn't be excluded, I don't think.
- Thalia Wood: Okay, great. Are there any other questions or thoughts on interpreting the data from the NICU?
- Jean: I think ...
- Thalia Wood: Oh, go ahead.
- Jean: Yeah. Hi, sorry. This is Jean from New Jersey. Just two quick comments. One is we recently had a NICU Work Group Meeting convened in New Jersey to discuss some of these issues, and our panel of experts agreed with Tiffany and John, who said that they agreed that prenatal and fetal echos, they still warranted screening in the NICU, so that's good that we're sort of all on the same page there.
- Then, in terms of the other, our law in New Jersey covers all NICU babies, so currently we are screening babies who've had echos, and we are evaluating that right now. The issue is that our experts have noted that there are not a lot of studies, particularly on NICU population and CCHD screening, and so that's just something I wanted to put out there, that we are looking to try to get some funding and get a project together to look at some of these NICU issues in more depth.



Marci Sontag: Thank you, Jean. Jean, I don't think we've really confirmed this with you yet, but we would like you to talk a little bit more about the results of your work group that you had in New Jersey at the February meeting, so people can get a little more details of what the experts that they convened ...

Jean: Okay.

Marci Sontag: ... said to the NICU issues, so that will be up and coming as I kind of tease her. Thalia, I think the next most common thing on our initial or our last branching question was to talk about quality-improvement issues.

Thalia Wood: Okay, let me find that poll.

Marci Sontag: Go to quality improvement and ...

Thalia Wood: Okay ... I'm having a little trouble getting the poll to come up for some reason.

Marci Sontag: Okay. As we're waiting for technology to catch up with our brains, these are quality-improvement issues, and, really, the way we may have phrased these questions here are for the quality improvements once you have data from the newborn screen. How do we improve the quality next? What are the biggest challenges to quality-improvements for CCHD? Is it analyzing the data and the need for support? Is it getting hospitals to change once you have the data, responding to implement any change or quality improvement, or changing the algorithm? You know it's not going to work, and now what do you do? How are you going to change that algorithm and make a difference, or is there another challenge?

These are all quality-improvement issues that we're dealing with at the post end, after we've instituted screening, but obviously there are other quality-improvement issues that we could deal with earlier, as well. Okay, so the biggest, I think, hands down is that analyzing data needs support. We get the data; we know that there's something that's going on, and now what do we do with it because we don't have anybody who's there to help us analyze that data and get results out?

Are there solutions that any of you have that you'd like to share? What would you suggest that we can do locally with our data? Well, I guess almost 60% of you said that this was a challenge. This is incredibly



important for us to know. As an epidemiologist working kind of at the national level, it's great for me to know and know that many of us are dealing with the same challenges across our states, that we see the data, we know there's a problem, but we don't really know how to analyze it and what to make of the data once we have it.

This is something that, in NewSTEPS, we can talk about internally and say, "How can we provide basic resources? Could there be algorithms that could be available on our website or tools available on our website to be able to help states make decisions locally with the data that they have in hand?" The key there, I guess, is that we have the data on hand, and as we talked about earlier, sometimes that's a challenge, as well, to be able to get that data from the hospitals to be able to make the decisions.

But even if we're getting aggregate data from each hospital and we know what the aggregate data looks like, that this hospital has many more failures than another hospital, what's that next step and how do we deal with that data? For those of you who have already ...

Theresa: Marci.

Marci Sontag: Yeah, go ahead.

Theresa: This is Theresa Finitzo, and I think I would just disagree with a minor, minor way you stated it. I think the quality improvement, analyzing data, needs to occur at the hospital level. That's, I think, the biggest challenge. By the time it gets to public health, your days, with the exception of Kentucky, you're maybe too late. It's good to know about it, but I would think it should be at the hospital level.

Marci Sontag: Yeah, Theresa. That's an excellent point. I think it's both. I think we really need to have it at the hospital level and the state level, and many hospitals are not looking at that level, so if we at the state level can say, "Hey, here's a challenge we're seeing," and put that back to the hospitals to have them help dig a little deeper to find out what the problem is so that they might not be missing the data.

Theresa: It's kind of giving them a heads up to say, "Hey, this is what we saw. You should look to see X. You look to see X, why these cases with a 4% difference between the hand and foot are continually being told to pass or something like that?"



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- Marci Sontag: Exactly. It's kind of ...
- Thalia Wood: The other ...
- Marci Sontag: Oh, go ahead.
- Thalia Wood: I was just going to say we had a comment saying that they agree with Theresa. It needs to be there and at the state, but there's also a question here. Let me go ahead and ask it. "Do folks have statewide perinatal quality-improvement networks taking on CCHD screening? I know Tennessee's doing some. I bring this up because a Q-wide network helps to analyze data, but there's limited support for analysis. Basic resources using the data would be great." The main question was, "Do folks have statewide perinatal quality-improvement networks taking on CCHD screening?"
- Cindy: This is Vermont. Yes, we do.
- Marci Sontag: Cindy, how is that funded? Is that a ...?
- Cindy: It's partially funded through a cooperative agreement with the Department of Health and the University of Vermont.
- Marci Sontag: That's great. Are there others that have that?
- Lisa: I'm sorry. This is Lisa at Children's National. We've actually been working with OZ and D.C. Department of Health in the working facilities here in D.C. to do a demonstration project that is quality improvement where we're drilling down and looking at those ... what Theresa's talking about, the data at the individual hospitals, but also working on quality improvement at the population level by kind of sharing information on false negatives with Maryland and Virginia to try to take a look at quality improvement from a kind of state population level, as well, in terms of whether or not babies are being missed because they weren't screened or because they were actual false negatives due to a lack of theology.
- Marci Sontag: Yeah, that's great, and I think it's that cooperation and collaboration to be equipped to do any sort of quality improvement, find out what the problem is, and then dig into why and really partner with the hospitals and others in the state to help uncover the reasons. Okay. Other solutions to looking for support? I love the crazy little network idea, the



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quality-improvement network for the states that could have that as a resource.

One place ... I work in a school of public health, and many, many cities and states have schools of public health nearby. This could be a place that you could seek resources to help look at the data, that this could be a fabulous student project. There could be faculty that are interested in this. There could be consulting labs that might be able to help with those data at this level or at other levels.

Schools of public health are really here to reach out and help support the communities in which they live, so that might be another option for some of you if you are near a school of public health, to reach out to them. Okay. Any other comments or thoughts on this?

All right, well, the time is five till the hour, so we're going to declare that our Choose Your Own Adventure series for this month has ended. Thank you for taking the adventure with us. We hope it was meaningful for you. I want to tell you that it very much is helpful for us to hear your responses here and to be able to use that to help inform our agenda for next month.

We will not be having a CCHD webinar in February, so please take that off your calendar, as we'll be preparing for the in-person meeting and hope that many of you will be attending that in-person meeting February 27 and 28. Thank you again for your participation, and we look forward to talking to you all soon.

Thalia Wood: Yeah, thank you. We didn't have our last comment. They thought this was a great technique for this meeting, so yeah, thank you for trying something new with us. We appreciate it.

Female: This was fun. Thank you.

Female: Thank you.

Marci Sontag: Thanks, guys. Have a good day.

Female: Thank you.

Male: Thank you.



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Thalia Wood: Bye.

Recording: Thank you. Please stand by.