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Critical Congenital Heart Disease (CCHD) Technical Assistance Webinar

April 11, 2014

Presentations:

- Neonatal Intensive Care (NICU)—Amy Gaviglio, MS, CGC
- Home Births/Rural/Telemedicine—Jamey Kendall, RN, BSN
- Education—Debra Doyle, MS, CGC

Moderator:

- 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.

Marci Sontag: Welcome everyone. I am going to mute everyone. Presenters, when you are to present, it is star-7 on your phone to unmute. We'll go ahead and get started.

Recording: The conference has been muted.

Marci Sontag: I need to unleash myself. For this conference call this afternoon, we will be talking about the events or the lessons that we learned from the CCHD meeting at the end of February, here in Silver Spring Maryland. We've asked three of the attendees of that meeting to help present for us. We're going to start with Amy Gaviglio from Minnesota, and she's going to talk about the lessons that we learned from the Neonatal Intensive Care Unit challenges for CCHD.

Then Jamey Kendall will follow talking about some of the unique populations that we see in CCHD, the home birth, rural birth, and then tele-medicine and potential solutions and challenges there. Then Debra Doyle will finish talking about education and some the resources that are



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available for education, that have already been developed. With that, if there are any questions, let me know.

We're going to start with Amy. Amy you should have the ability to advance your slide. We'll get to the first page for you, and you can press star-7 to unmute.

Amy Gaviglio: Marci, can you hear me now?

Marci Sontag: I can hear you.

Amy Gaviglio: Okay, perfect. First off, I wanted to say thank you to you and APHL and New Steps, and HRSA for hosting such a really great and engaging meeting about CCHD that covered a very ambitious agenda. I think Marci, that you could easily be a meeting facilitator in another life. You were great at getting us through everything. In regards to the NICU portion of the meeting, not surprisingly, this part of the meeting generated a lot of discussion.

To start the discussion focused largely on the initial intent of pulse oximetry screening, which we all know, the target was really for seemingly healthy newborns in a well-baby nursery. The discussion after discussing the original intent, moved to, how to obtain the evidence needed to develop screening protocols.

Or even maybe to accept the current screening protocols, that may work in the very heterogeneous population of [inaudible 00:03:12] Care Unit. In regards to protocols, several options were put forward including having units perform pulse oximetry at discharge or before transfer. Only doing pulse oximetry when infants are on room air, so when they're not on supplemental oxygen, but ultimately there just wasn't enough time.

I think a lot more needs to be done, but no definitive protocol in this population was really agreed upon. It was deemed that further work needs to be done in this area to, like I said before, to get that evidence to develop protocols, and to get the evidence to suggest that whether or not this is beneficial in this population.

As far as potential resources or ways to gain that experience, and to do that data collection, and [guard 00:04:09] that evidence, a few options were brought up. One was utilizing the regional, [inaudible 00:04:15] the



regional genetic collaborative, specifically those states who do have mandates, and who the mandates cover the entirety of the newborn population. It would include individuals in NICU, their special care nurseries.

Another interesting resource that was brought up was the Vermont Oxford Network, which was, for those of you who hadn't heard of it, and I hadn't heard of it, (chuckle) at the time of the meeting ... It's a non-profit, voluntary organization. It maintains a data base that's nation-wide about care and outcomes of high-risk newborn infants. There was some talk about maybe linking with some of that information as we're looking more at developing protocols, and understanding how pulse oximetry is going to work in NICU.

I think for me, and hopefully for others some of these lessons learned will jive with the other people there, but I think in particular that states will need to really balance what they have in policies. Whether that policy is an internal policy or a legislative mandate, they'll need to balance that with what the appropriate practice is going to be in this population. That may very well mean that you have two separate protocols, which is a little bit different than what we're used to within newborn screening.

As I mentioned I think many times already in my three-minutes of talking, that more evidence is needed in this population to save screening guidelines. To do that neonatologists are really are going to have to be intimately involved in each phase. I think in general newborn screening programs do a really good job of being connected with their neonatologists, just because of the nature of what we do, and the fact that many of our screened positives are in this population. I think understanding what pulse oximetry looks like right now in the NICU's, is going to be very interesting. They're looking at a continuous monitoring model, whereas the pulse oximetry screening is kind of a one-and-done hopefully, model. Some of the cardiologists brought up that in the NICU they maybe shooting for lower stats that may actually be an okay thing. So are the cut-offs going to need to be different in this population as well?

That was something that I was not aware of. I think that will be an interesting perspective. Again, speaks of the need to have this community involved at each stage when you're looking at how you're going to screen this population. Some other NICU considerations that I



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thought of and that came up as well, especially in this population, and it's true in a well-baby nursery as well, but pulse oximetry as you know can detect other issues besides CCHD.

There was a recent article published on the impact of routine pre-discharged pulse oximetry screening, in a region Neonatal unit. It was published in March, and talking about what else they were able to pick up with pulse oximetry. Things like sepsis pulmonary hypertension and pneumonia. That may be something else to think about as well is, what are we going to do with those types of findings.

They weren't the target but there certainly still important to pick up. This was also one of the first recommended screenings that was really targeted for one population. I think it is requiring us to think a little differently about how to implement it, and make sure that we're implementing it appropriately for everyone.

Then finally, because of the lack of evidence that's been looked at in this population, that any data collection that is done will likely need to be a lot more robust and capturing a lot more of what's going on with the child and the timing, in order to make some really good conclusions about how the screening would work in that NICU. I think that's kind of what I came up with from what I got from the meeting, and hopefully that was helpful.

Marci Sontag: Thank you Amy, that was very helpful. You very nicely highlighted the challenges that we face, and there were lots of different protocols that were presented at a certain time, or do you screen them at a certain time, do you at discharge, or when do you screen? I think there's lots of potential options and challenges. You also put nicely that we really do need data.

Amy Gaviglio: Yeah.

Marci Sontag: Those who will be able to [inaudible 00:09:11] that NICU [inaudible 00:09:14]. If we're going to collect the data, if you're going screen the NICU, we'll have to have time, and we'll have to have data on those NICU babies to do it. Then for those of you who are collecting baby level or aggregate level data at the state level, and you know how many of those baby's that you screened or didn't screen, were in the NICU, so you can



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get a good feel for how successful you're screening both in the NICU and outside of the NICU.

There's lots of additional opportunities and thoughts for how do we collect data, and what do you do about the, the hospital calls them "The bouncers?" The babies who are born and they just go down to the NICU for a little bit and come back up. What if they miss that 24 to 48 hour period, how will are they accounted for before they get discharged and you track so they are not [being 00:10:01] screen.

I guess what I'd like to do is open it up now to others to ask questions. If you have a question of Amy, or the whole group. Amy gave us a summary for us, but if you were at that meeting, if you have some thoughts or questions that you'd like to ask about the NICU discussion, you press star-7 to unmute your phone. I'll give you ... Go ahead if they have specific questions related to the NICU.

Debbie F.: Hi, this is Debbie Freedenberg and unfortunately I joined late so I didn't hear most of the presentation, but I did just want to let folks know that we are in Texas working on a NICU protocol through our Texas Pop-2 [00:10:50] project. That is in the midst of being designed and executed, because we recognize it's, I'm sure it was stated previously, that the NICU babies are a very different population for CCHD screening.

Marci Sontag: Debbie, some people might not all know about what Texas Prop-2 is about. Could you just tell us ... I think that's important to help inform people of who is sitting at the table to help you inform that NICU protocol.

Debbie F.: Sure Marci, but you're breaking up. I just heard parts of what you said. I'm Debbie Freedenberg. I'm the medical director for the Texas Newborn Screening and Genetics program. We have funded and been part of now, it will be two projects. The first was what we call Texas Pop-1, which was Texas Pulse Oximetry project, which I believe was presented at the CCHD all state meeting, although I was not there. Then we have refunded the group and asked Dr. Shirley Degiliary and Dr. Ellis Conn, both of who are neonatologists. They're kind of designing their hospitals and their models now, looking at NICU babies in terms of providing guidance and what the best logarithms for screening NICU babies are. That's very [inaudible 00:12:20] ... On the first model they use both Rural hospitals and Tertiary care hospitals and they were in South Texas. Some hospitals were part of



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large systems and others were not. We'd included a very diverse setting for the position of the neonatal care.

Marci Sontag: Okay, thank you.

Cathy: Hi, this is Cathy Moline from the Virginia, and I would just like to ask one question if possible about Vermont Oxford.

Marci Sontag: Go ahead.

Cathy: Okay. Does Vermont Oxford actually have a space in the data base for actually CCHD screening, of the right hand [inaudible 00:13:11] prior to discharge, and that kind of spread sheet information at the current time, or doesn't need to be added?

Marci Sontag: Is there anyone on the phone who knows that answer who's familiar with the data [base 00:13:23]?

Female: Not me.

Amy Gaviglio: This is Amy, I'm on the site right now and I'm trying to see what they have but I can't see what their actually data base looks like. My guess would be that it is not ... Well I don't know that specific question. I'm not sure.

Cathy: This is Cathy again and I agree, maybe I'm not sure that it's there, but I think it's a great place to really work with our colleagues at Vermont Oxford to see if we couldn't get that added, so that we can get national data done all the same way. I think a lot of the majority of NICU's are involved with the Vermont Oxford, is my perception.

Certainly not anything that I can document, but would certainly like to see us working very closely with that Vermont Oxford data base. Would you agree Amy that that might be a good place to start?

Amy Gaviglio: Yeah, I hadn't heard of it before the meeting, and I've been doing some looking into since then. I think it is really cool. They do have over 900 centers in the network. They're collecting over 50,000 infants a year, which is fantastic, and a nice population size for that particular population. Yeah, I think if we are able to add some pieces in there I think it could be very beneficial. Especially for the outcome data and the care



data that screening programs struggle to get sometimes in this population.

Cathy: I agree. This is Cathy again, I agree with you. They are a wealth of information, and really some outcome data's as to how we might be able to get heat in the aggregate from across the country, because they'll all would be collecting it in the same manner.

Amy Gaviglio: Right.

Marci Sontag: So I don't have my notes in front of me but there was a person who said they would look into that for us, and so I will get that back out to the group. Were still kind of culminating everything and getting all the information together, but there was someone who was going to look into the Vermont Network for us.

Amy Gaviglio: All right.

Marci Sontag: There was a comment, I don't know if everyone can see it. It says, "Michigan has a NICU protocol developed with the help of neonatal intelligence and cardiologists available on our website. If states would like to look at Kerri Airguard. There's actually quite a few states that have those protocols. That's part of what we're pulling together from the meeting, is the resources that were shared were developing kind of a common resource center off of the new [Sepsis 00:16:09] website that will kind of have been born at this meeting.

Then we will continue to grow with other resources. If you have additional resources please sent them to either myself or to [Thalia 00:16:20] and we will add those to that resource. Michigan, and many of those who are grantees as well others have really developed some great resources related to NICU protocol and other things. Are there any other NICU questions? Okay. Let's move on. Jamey if you would like to unmute.

Jamey Kendall: Can you hear me?

Marci Sontag: I can hear you.

Jamey Kendall: Okay, I am discussing Home Nurse, world Nurse and tele-medicine. I do not find in my notes that got to tele-medicine too much. There's some, mostly you were talking about midwives and home births, and remote



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hospitals, and the challenges with those. The three challenges that we did discuss mainly were screening resistance, and regulated or unlicensed midwives, and midwives in general home births, and large geographic areas with no access to cardiologist or NICU's. You talked about the training of remote hospitals, how important it is to build relationships with them. To have just awareness building of the screening, maybe face-to-face training with them. Again and again relationship-building was brought up as an important mode of increasing screenings.

It may be good to have a mentor hospital. I know in Kansas here we're doing that, where we're trying to find small rural hospitals that are screening and those that aren't screening. Help match them up so that they can give each other support, because they know what it's like to be in a rural hospital without all the resources that are available in the urban areas.

The next area on unregulated and licensed midwives we talked about again, identifying a champion that would help the midwives maybe a champion within the midwife group in your state. Instead of the state coming in and doing training, maybe they can do it jointly, or that if you have somebody that will pick up that training and go with it, that's a member of their group that may be easier.

We talked about offering small community grants, or there are opportunities maybe through Lyon's Club, or some other organization that may have monies available that you can help to assist with purchase of some of the hand-held pulse oximeters. Then we talked about the large areas that do not have access to cardiologists and NICU's. We talked about promoting education.

When you're looking at further training in the facilities versus, are they going to do additional testing, or automatically transport that baby out for the Pediatric ECHO, and work with pediatric cardiologists either in your state or outside your state, to help facilitate transports and to make those decisions. Around the table we talked about the importance of once a baby does fail the pulse oximetry to do an assessment of the baby to rule out the other obvious conditions that would cause that pulse oximetry to be mono, sepsis or pulmonary conditions.

First off, always have the physician look at the baby before you're making another transport or anything. Make sure you have a phone number



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close or a consultant that is available for the [inaudible 00:20:46] hospitals. The pediatric cardiologists that were with us were talking about the fact that if a baby has a murmur, try and help them understand what they would typically do on a murmur.

I think that the facilities sometimes get so intimidated and scared they're going to find something, that for them to step back and look at the big picture. How did we do this before and what do we do when a baby is sick? Call the neonatologist, talk it out with them and try and develop that procedure. We talked about adult [sonographers 00:21:27]. Wisconsin has a great program on their website Wisconsinshine.org.

They have ECHO training as one of their components. It says that, I'm reading off their website, "The website is designed to assist cardiac sonographers in performing the initial neonatal echocardiogram as part of a comprehensive evaluation for hypoxia. Sonographers performing these ECHOs may not regularly image pediatric patients and they have limited familiarity with the differences between congenital echocardiography in adults.

This is available for adult sonographers, and there are two credit-hours available. It's good to look on there and offer that as an opportunity for those facilities that may want to enhance the ECHO capabilities in their area. Then they talked about the importance of even an adult sonographer, should be able to tell if something is going on and if the baby does need to have a transfer.

Again, I think I talked already about the home birth and the collaboration, work with a champion within the midwife community, and then also helping to send equipment. The comment was made that sometimes the less expensive hand-held equipment can be less reliable. We talked about some, I have written down the [Maso 00:23:19] model for about 500, and that appears to be a pretty good piece of equipment. I think that's all I have.

Marci Sontag:

Thank you Jamey. Are there other questions from anyone? Questions related to [home birth 00:23:41] and tele-medicine. Star-7 to unmute. If anyone else has some additional information that they gained from the meeting and would like to share, please do so. One thing that I would share just too sort of extend that adult sonographer idea, is I think all of



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the cardiologists in the room, and the neonatologists that are physicians agreed.

It's really important that the baby gets the right evaluation, but it might not be to the point of diagnosing a CCHD, but rather to make sure someone is looking at that baby to say "Yes this baby needs to be flown to a tertiary care hospital, or taken by ambulance." Or "You know what, this baby is okay and can spend the night here or could go home."

It's really trying to figure that piece of it out and be able to distinguish which direction you're going to send that child. The adult sonographer and the idea on the Wisconsin website, I think that has worked well for them. Any other thoughts? Some of the tele-medicine pieces that I don't think we've spent a lot of time talking about at this meeting, but I heard in some of the small groups, were the use of telemedicine to transfer ECHO.

The ECHO is done remotely, and a [inaudible 00:25:25] hospital, and transferred to a larger Tertiary Care Center, in which the cardiologist evaluates the ECHO and then can have a conversation. They can actually do the ECHO transmitted electronically, and interpret the ECHO for the local ECHO tech or neonatologist or adult sonographer who is doing that Echocardiogram.

[Inaudible 00:25:52] and there are [inaudible 00:25:54] talking and everything was fine. On the sign it also said [inaudible 00:25:56], "The Shine Project in Wisconsin also has pretty extensive info on their website for home group providers screening in the out of state hospital setting. Marie says, "Unapproved by SDA, the U.S. [transfer 00:26:07] of hospital-grade phone oximeter has been developed, sensitive and specifically to be used on neonates, should be a good solution for midwives.

So that's great. The website there is also looking [forward 00:26:21] the Shine Project. www.wisconsinshine.org. I would encourage you all to visit that, and come back to review [session 00:26:32] in the coming weeks when we'll have posted that information. Although Wisconsin is already linked from our websites to the Wisconsin Shine Project starting link. Please visit that and look at the resources that are available.



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Okay, any other thoughts or questions? All right, let's move on to the next section then and that's education. Debra Doyle from Washington State will be presenting.

Deb Doyle: Am I on?

Marci Sontag: You are on.

Deb Doyle: Great and you're going to advance my slide?

Marci Sontag: I will ... I think.

Deb Doyle: Amy, I would also like to really congratulate New Steps APHL and HRSA for convening this state public health meeting on CCHD. It was really and truly enlightening for me. I walked away with a whole slew, of very concrete pragmatic ideas, that I could start working on to improve CCHD screening in Washington with all of our varied partners. I really appreciated that. For those of you that were there, you know that education was not one of the break out sessions, so we didn't get a chance to get into smaller groups and really hash out and brainstorm different challenges let alone solutions.

What I did here, was basically thought about it from the notes that had been taken regarding the pre-survey that New Steps conducted, as well as just my own thinking about it in terms of Washington State. The challenges and the solutions, there's an awful lot of overlap, and one that I noticed that's not in there, is not just thinking about multiple audiences, but also think about individuals with different languages that we might need educational materials for.

Let me start with the varied and multiple audiences, because again we're talking about the need to sometimes education policy makers, parents, public health staff, nurses, hospital staff, birthing centers, midwives. Again there's lots of different people, some of them will have a clinical background and some of them won't. Then once you have so many people, how can you get information out to such a wide breadth of those audiences?

For the solutions here, it's really to partner with some of your other organizations. Hospital Associations, the Perinatal Nurse Managers, the Perinatal Coordinators, depending on if you have them in your state. I



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think most of you do. Also taking advantage of materials that are already developed for target audiences. There are lots of different materials that have been developed in state programs.

Certainly HRSA-funded states have done a great deal, thank you, to Texas Pops and to Wisconsin Shine, and New Jersey, and others have really developed a lot of materials that those other states like Washington can borrow from. Then also take advantage of technology. Having a list there. I've created a list there for example that has all of the 61 birthing hospitals in Washington and the CCHD contact person for each.

As I get new materials I can email out those different links to the materials for those different audiences. Again, some of the solutions, they don't have to be costly, but you do want to take advantage of them. Then also tagging on to other trainings. Again if there's other trainings happening from your hospital Association, or for your State Nurses Association, you get the opportunity to tag on something about CCHD within that venue, and that's to your advantage. Another challenge is the lack of expertise, and again I'm thinking of Washington. I'm not an expert on CCHD, I'm a Genetic Counselor by background. I'm certainly familiar with the genetics of a lot of different congenital heart defects, but my expertise hasn't been around CCHD screening, or pulse ox screening. I had to learn the algorithms, and I have to be able to be fluent in them to be able to explain them to others.

I didn't just pick up a book, I talked to other people. I think again one of the solutions here is that you recruit, and you partner with the experts in your state and your territory. The Neonatologists, the pediatric cardiologists, the hospital screening nurses, etcetera. Don't be afraid of what you don't know, just reach out and grab the expertise of those who are willing to work with you.

You'd be amazed at how many people are willing to work with you. the last thing is simply the lack of educational materials. As I mentioned already and has already been mentioned in this call, there actually are quite a few materials out there. At the meeting we got the opportunity to see New Jersey has online educational program.

Virginia has an online educational program that they've been, even though this forum have allowed people to take a look at and demo, and have offered to sell or allow states to link to their program. I would



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strongly encourage people to take a look at the New Steps Educational Resources page. As well as state pages and in my state of Washington, I can even go to Seattle Children's.

They've got educational materials, Multi-Care in Tacoma, which is another place where we have a pediatric cardiologist. Again, they have educational materials. You might have state specific, you might have regional specific, you might have national materials you can go to. Certainly the Children's National Medical Center has developed some beautiful materials and they're available in six different languages of Spanish, Arabic, French, Russian, and Chinese as well as English.

The Shine Project has multiple educational materials, the [national 00:32:25] Corporation even offers educational materials. Again, I think there are lots of things that are already out there and you don't have to re-invent the wheel. You really can go and explore some of these other opportunities and then again, partner with your regional or your state colleagues as well. That's really what I had come up with and of course I open this up for others to chime in as well.

Marci Sontag:

Thank you so much Debra. Does anyone have any questions related to educational comments that you'd like to add ... Or applications. Star-7 to unmute. Okay, I'm not hearing any questions. I would encourage you really to reach out to these other programs, the website of the convention. Go to our website, which really shows kind of a hub to link back to a lot of these different locations, Texas, Wisconsin, New Jersey, Virginia, Children's National.

There's so many programs out there that have developed these things, and they're willing to share. That's the beauty of the HRSA-funded projects, and really just the beauty of Newborn screening in this community. People have put a lot of work into developing really good resources and are more than happy to share with the rest of us. Thank you to all of you who have developed these resources.

I can speak for our state in Colorado, we are very closely looking at all of these to figure out how we will be implementing, and what we will be using as we move forward for CCHD screening. Please go out and look at those resources and ask questions of your colleagues. Other take-home questions ... Okay. I'm going to come back to the SDA comments in the



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box in just a minute. Anna Marie, says another Nurse [training 00:34:30] video is with the Newbornfoundation.org.

That's another fantastic resource and there's a lot of information about CCHD screening. [Also 00:34:37] in collaboration with University of, I'm not sure I'm reading the whole thing. [Amplatz 00:34:45] children and Minnesota Department of Health. That's fabulous. Oh gee, the University of Minnesota, [Amplatz 00:34:55] Children. Amy Gaviglio just posted the link so you can click on that link.

I think maybe some of the other [content 00:35:04] is sent specifically to me, and not necessarily to all of you. I'm not entirely sure who is seeing which, so Amy has the link there if you'd like to go see that additional resource. You can go to Minnesota as well. I'd like to open up now, are there other comments or thoughts about the meeting? Things that you'd like to share that you learned, whether you're one of our speakers or someone else.

Please feel free to jump in if there's anything that you would like to share that you took home from the meeting, or a thought that you had after the meeting and said, "Boy I wish I had learned [inaudible 00:35:37] this was a great thing that I gained from the meeting." This maybe about the quietest I've heard this call. You guys are usually a pretty talkative group.

[Inaudible 00:36:04] the question today oh yes, I was just pointing out that the [inaudible 00:36:08] videos for parents are now available on the Newborn Channel as well. That's fabulous to have those resources available on the Newborn channel seen throughout many hospitals throughout the country.

Again, any of you who are posting, you're more than welcome to press Star-7 and chat as well. Kelly, you asked about the resources mentioned today, the sonographer and others, we will definitely post the ones of the resources we've got. We will get to that and actually... Both Thalia and I are away from our home offices, so I'm calling in and Thalia couldn't make it.

It will probably early next week before we get some of those resources posted. Unless I hear other discussion I'd like to prep you for the call in May that will be coming up. That call ... we've gotten a lot of feedback that we haven't talked much about the pulse oximetry equipment. The



SDA has approved some specific equipment, what's out there, what types of different options do states have? Are states recommending equipment to their hospitals or is it a hospital-by-hospital basis?

We're going to have our presentation. The SDA is going to talk about the process that goes into that, and then we'll have some of the vendors speak about what is available. This is not an endorsement by any means, of any product, but really to give you information so you understand what the options are out there. It's a very different world that most of us are not so familiar with. Pulse oximetry equipment, and what is SDA approved, what isn't, and what the SDA looks for.

There's some more questions. Rachel from AAP has posted, "The American Academy of Pediatrics has educational material posted on their website there as well." That's another great resource. Hopefully you can go to the AAP website aap.org.pehdc/cached. Then Matt Reader has posted a question, "Any information available regarding not screening any NICU discharges after 30 or more days of age?"

I put that question back out there to those of you who are doing the screening in those groups. That would be New Jersey, LSU. I think I saw Jean is on. Do you have any thoughts about screening or not screening once babies are over 30 days of age?

Amy Gaviglio: This is Amy. I think that question was asked at the meeting Marci, do you remember? I thought they said that it was still worthwhile to do the cardiologist.

Marci Sontag: I think you're right. I think one of the issues is that by the time those babies who have been in the NICU for 30 days, typically they will probably already had an ECHO and had pretty close follow up. So I think that's one of the reasons why the recommendations for not doing screening in that population, is that there typically being followed otherwise, and getting very close follow-up, because we need to implement the screening algorithm for them.

However, if they haven't already had all of that testing done, and they're being discharged late, I think your right Amy, I think the recommendation was to do a screening pulse oximetry before discharge. Jean's response from New Jersey says, "Currently we are screening all babies regardless of age."



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Anna Marie: Marci?

Marci Sontag: Yes?

Anna Marie: Hi, its Anna Marie.

Marci Sontag: Hello.

Anna Marie: I wasn't sure how to do that with the Star-7. Yeah, so the deal is with the NICU babies, you know babies are in the NICU for all sorts of different things, so making any assumptions about echocardiograms is sort of a stretch really, because they just simply don't all warrant having their heart looked at in that way. I think one of the things that got mentioned at the meeting in terms of doing it at a later stage, is usually when these kids are being monitored on pulse ox, and they're on some ...

Whether they're Premise or have some other respiratory tract or infection or what have you, they've been on supplemental oxygen. I think the theory was that if you were going to screen them before discharge from the NICU, which is also in theory, that they would be transitioning to the floor, not necessarily being discharged immediately to home from the NICU. You would be testing them on room air. That was one of the differentiators I think between, obviously you wouldn't screen them if they were still on supplemental oxygen in any way.

Marci Sontag: Thank you for that clarification, that's very important.

Kim: Hi, this is Kim Piper.

Marci Sontag: Hey Kim.

Kim: Hi. Just to kind of, no pun intended but to echo what Anna Marie just said?

Marci Sontag: Mm-hmm. (Affirmative)

Kim: There's also those short stay babies that maybe are there for low glucose or something like that, that wouldn't have necessarily the full work-up that other NICU babies would.



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Marci Sontag: Yeah absolutely. Jean also commented from New Jersey, "That there's also an argument for standardization of care so that infants are not missed." I think there is one challenge that if you aren't screening the NICU babies, the babies bounce and are out, that have an unusual course, how do you make sure that every baby that needs to be screened or that on a re-point that not every baby is going to have their heart looked at coming from the NICU because they're there for other reasons,

How do you make sure they all get the appropriate care and screening? Then, [inaudible 00:42:10] might be obligated to say, "How do you track that data? Do we know who is getting what and who is not?" How do you, from a surveillance standpoint, know who has been screened and who hasn't? If they haven't is it because they were in the NICU [inaudible 00:42:22] probably. I'll share the comments of the educational materials from the PDC website and a link to that.

All right, any other thoughts or questions? Okay. Well I'm not hearing any. I'd like to thank you all, but to thank the three presenters who presented on their input, and their take from the February meeting. We look forward to the May call, and an announcement ... Thalia will send us an announcement in the coming weeks for that, but that will be talking about equipment.

If you have ideas or thoughts of things you would like to see on a future call, we really rely on a community to help us, guide us to what is important to what you need to hear about. Please shoot one of us an email, and we will reach out to people to help us locate your call. All right, well everyone have a great weekend and we will talk to you all soon.

Female: Thanks you too.

Female: Thanks Marci.