



Critical Congenital Heart Disease Technical Assistance Webinar

June 2014

Presentations:

- Pulse Oximetry for CCHD in Babies Born at Moderate and High Altitudes—Mary Kohn, MD
- Implementation of CCHD Screening in a Large Birthing Hospital—Kenneth Kupke, MD
- Newborn Screening for CCHD: Model Practices in Remote Hospitals/ Home Births/ Telemedicine—Lazaros Kochilas, MD and Amy Gaviglio, MS, CGC

Moderator:

- Thalia Wood, MPH, Specialist, NewSTEPS

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

Thalia Wood:

Again, thank you everyone for joining us today for the June Critical Congenital Health Disease Technical Assistance Teleconference. I'm going to read a little bit of an introduction here what was provided by Tiffany Colarusso from CDC who was going to be on the call today and could not make it. What she wanted to say is that, "Hospitals and providers across the country are working hard to implement pulse oximetry screening of newborns for CCHD.

There are some common challenges to implementation we all deal with in some fashion, such as what type of equipment to use, staffing, infrastructure and education, bias from those involved with staff, administration, et cetera, reporting and follow-up screening results.

However, there are also some challenges, which are unique to specific geographical regions or medial case, such as availability of echocardiography, distance to specialty care, variable value of pulse ox. For example, a large hospital screening may not detect new cases of



CCHD because of prenatal diagnosis, adjustment interpretation with algorithms for high altitudes”.

Today we have four speakers to share their experiences with implementation in different settings. Large metropolitan city hospitals, high altitude cities and remote hospitals or home births. We’re going to go ahead and our speakers today are Dr. Mary Kohn, who’s a pediatrician from the University of Colorado Hospital. She will be our first speaker. Our second speaker is Dr. Kenneth Kupke; he’s from Northside Hospital in Atlanta, Georgia. Finally, we’ll have Dr. Lazaros Kochilas and Amy Gaviglio from Minnesota speaking on rural hospitals.

Mary, make sure you press star seven to unmute your phone and I’m going to get your first slide up here and you can advance the slide yourself.

Mary Kohn:

Good morning or afternoon, wherever you are. This is Mary Kohn; I’m the director of the Well Baby Nursery at the University of Colorado Hospital. I would like to speak with you today about some of the challenges to implementing CCHD screening at moderate and high altitudes. Thalia, I don’t seem to be able to advance me ... Oh, never mind. There we go ... Some considerations in the mountain states.

University of Colorado was the first hospital in the state to routinely use pulse oximetry to screen for critical congenital heart disease. However, most of the large nurseries in the metro area are now screening. Our challenges are the same. Starting up were the same as I’m sure you’ve all encountered with logistics, cost, education, documentation and so forth. However, we have a few added features that make the screening a little bit more challenges in the mountain west and the first is the distance to specialists and the second is the transition state at altitude.

Here is a map of Colorado. Just so you can be oriented to what I’m speaking of we’re a big rectangle. The whole eastern part of the state is relatively flat and Denver you can see is right next to the rocky mountains there, the western part of the state is mostly filled with the rocky mountains. When I refer to the front range I’m talking about that area right along the edge of the Rockies from north to south and the western slope is on the border with Utah.



The distribution of providers in Colorado is very uneven. We have about 67,000 births annually and the bulk of the population and the bulk of the healthcare providers cluster in the urban areas along the front range and western slope. Seventy-three percent of the counties in Colorado are considered health manpower shortage areas. There are few providers and many counties have advanced practice providers as their only providers.

In addition to absolute lack of providers, we have the pediatric cardiologist at just a few sites. There are three sites in the state, Children's Hospital of Colorado and Aurora, Pres/St. Luke's in Denver. Aurora and Denver are right next to each other and then Memorial hospital down in Colorado Springs. The first of the two have telemedicine services available. In addition to the distance, which I'm sure is true in many rural states, we also have terrain and inclement weather that may transport very difficult at times.

As we move forward with rolling out the screenings throughout the state, these are issues that will need to be addressed. In Colorado, we're very proud of our altitude. This is a very from City Part looking west to downtown and the mountains in the distance. Denver's the mile high city, at 5,280 feet and Aurora is at 5,820.

Two percent of the births occur on the eastern plain so they're below 4,600 feet. Seventy percent occur at moderate altitude of 4,600 to 5,600 feet in the front range and the western slope. Twenty-five percent occur in areas such as Parker and Colorado Springs that are 5,700, 6,900 feet and there are seven hospitals above 7,000 feet. that account for 3% of all births.

I should mention that these mountain communities are very appealing places to live and they're growing rapidly. Implementation of the screening will pose special challenges in the mountain states. Why is altitude a problem? Colloquially we say that the air is centered at high altitude. The composition of gases is the same level and at altitude 21% oxygen and all location but there are fewer molecules. As a result, fewer molecules per given volume and as a result the transitional period takes longer. As you go up in elevation, the transition takes longer still.

I keep tossing this term around and I'd like to just quickly review transition. In the fetus, of course, oxygenation occurs in the placenta, not in the lung and fetal pulmonary pressures exceed systemic pressures.



The reverse is true in adults and even in infants. The baby only gets whatever oxygen or the fetus only gets whatever oxygen mom's system hasn't used first so they're relatively hypoxic. This hypoxic state causes the persistence of this increased pulmonary blood pressure.

Their pulmonary blood pressure coupled with various physical structures in the fetal circulation, shunts the blood away from the lungs and towards the placenta. Once the baby is born, he's exposed to increased oxygen and this increased PO₂, partial pressure of oxygen, causes the blood vessels in the lungs to dilate, dropping the blood pressures below systemic pressures. This allows improved blood flow to the lungs and improved oxygenation.

That's a simplistic description but I think it works for our purposes. At altitude, because of the lower oxygen content in the air, the transition occurs more slowly. We have babies who are born at high altitudes. Not in towns that you've all heard of, Keystone and Vail where 30% to 100% of babies living require oxygen for the first two months of life because their transition period has been prolonged to that extent.

Here in the metro area we have accepted based on a paper that was done when pulse oximetry was new modality back on 1991 by Dr. Liz [Silo 00:08:05] that a healthy term baby could have stats as low as 85% at 24 hours. When we evaluated the national protocols, we assumed that at least 3% of our babies would fail and thus this will never fly here.

We undertook a study at the University Hospital in 2012. Dr. Jason Wright, one of our new natologists sees 1,003 babies apply the national criteria. This was done at 24 hours as part of a makeover. We clumped all of our screening tests or grouped all of our screening tests together. The babies had their weight, the bloodspot and a transcutaneous bili done at the same time.

What we found was that our pre and post [inaudible 00:08:58] was not that low with 97.2% and that really of the first 500 screened only 1.6% failed. Of the second 500, only .6% failed. We then instituted screen for all of our newborns as part of our routine practice. For the first six months thereafter about 0.8% failed. Now at this time, all of these cases were false positives at a rate of .8% is still four times the quoted rate in previous studies, what you see there on the left.



What we learned, another reason that our rate dropped is you can see from the first 500 to the second 500 babies our rate dropped by more than half. That was because our nurses got savvy. Instead of just popping the pulse oximeter on, as you all know who use them, there's a lot of fluctuation in the waveform in the heart rate. They learned to let the baby sit for a while and to take the maximum value rather than an average value.

The thought was that if a baby truly had a mixing lesion they would not be able to attain a saturation above 95% and that there are a good number of babies whose values hover around that and that their average value would be less than 95. It seems like a valid thing to accept if they are able to achieve greater than 95% to accept that that's a passing value.

Our post study experience was we really crunched the numbers were in 2013. We had 11 failures out of 1,263 babies. As you see there we had a variety interesting finding and I'm sure you're all finding there's some other things that you pick up besides critical congenital heart disease that are good to know. I wanted to draw your attention to the fact that seven of these had delayed transition.

We knew that because once the babies would fail the usual three screen we would order an echo but the baby was human dynamically stable. it didn't seem like an emergency and so we would wait often times until the next morning to get an echocardiogram and would screen the baby with a pulse oximeter before doing the echo. Low and behold, they passed at that time.

It seems as though 24 hours at our altitude may not be enough time to enable the baby to completely pass through transition. I'm sorry that I don't have more recent data. One of our persistent challenge is data collection and we're hoping that with the electronic medical record we'll able to do a better job for QI purposes and for collecting data to roll out to the rest of the state.

I want to share a few anecdotes that we've had two true positives in the past several months in the metro area. The first was here at the university. We had a baby that was relatively asymptomatic. That was that a very astute RNs noticed that five hours of life that the baby looked synodic only when breast feeding and pink at rest. Baby had had no



murmur, had had a normal prenatal ultrasound. When she checked the [inaudible 00:12:36] it was in the 70s consistently.

This baby was picked up, clinical brought. Had it been missed as it easily could have, this baby would have been picked up by the routine screening at 24 hours. Another even more important case is that one that was picked up by colleagues at Lutheran Hospital and that was one of the double [inaudible 00:13:04] ventricle.

This baby was completely unsystematic and on the 24 hour screen had a 95% saturation in his right hand, 91% in the foot. [Inaudible 00:13:15] more than 3% difference between the two sites so he was rescreened, twice more. Subsequently the gap between the two values closed but both values dropped below 90%. The baby had an echocardiogram and low and behold had a double outlet right ventricle.

This is a really important case for us because in the past our assumption would've been that 91% was a perfectly fine stat and this baby would surely have gone home and had been missed. I just want to tell you an anecdote about a typical failure and that is a baby who was here last week who had a 24 hour stats of 91 and 97. Failed on that basis was rescreened at 25 hours, 85 and 85. Then for some reason the third screen was delayed until 33 hours and you can see the baby passed easily.

What we're finding is, once again, that waiting until the baby has had time to fully transition may be a better answer. However, we like most of you are under pressure to get our discharges out as quickly as possible so it's a little bit of a balancing act. Now we're trying to decide where we should go from here. Should we continue to follow the current national recommendations and to perform echoes on all those babies which had stats less than 95%?

Well, since we have less than one failure rate it's doable but we have many locations in the foothills of the mountains where greater number of babies are surely going to fail. As I mentioned, that will be a costly and inconvenient situation. We're considering three possible alternatives and we have studies underway to look at these and to help us to decide what the best way to approach it is.



The first is to change the lower limit to decrease the failure rate but will we miss true positives. I think in that case that I just showed you from Lutheran, the answer is yes, we would have missed a true positive had we lowered the lower rate to 90% and even 92% I believe that we would miss some. I think that's a risky proposition.

In order to look at that we're looking at a retrospective group of babies who had critical congenital heart disease before the screening began and presented to Children's Hospital to try to determine what their initial pulse oximetry values were. We'll get a better sense of what that looks like hopefully within the year.

Another option is to try and mimic sea level by putting babies who fail the first screen in a 26% oxygen hood for an hour to simulate sea level conditions and then recheck the stat. one of our affiliate hospitals in Colorado Springs is doing just that. The third possibility is to just do what we've accidentally stumbled upon and that is to recheck after several hours prior to an echo. Our next approach here at university is to the national protocol but for those who failed a third time to recheck in four hour and then another four hours until an echocardiogram is available. This way we hope to determine the sweet spot, the point at which the screening will be most effective.

In summary, the experience in Colorado and other mountain states is different from that of many of the early adopters. The reason is that altitude alters the progression of normal transition. We're undertaking a multi-center study to collect more data from nurseries at various altitudes in order to determine the best practice for our state. That's the end of my presentation. Thank you.

Thalia Wood: Thank you so much Dr. Kohn. That was an excellent presentation. I think we'll hold questions until the end since the phones are muted and so we're going to go ahead and go on to the next presentation. Dr. Kupke go ahead and push star seven to unmute yourself and you should be able to advance your slides.

Kenneth Kupke: This is Ken Kupke, I'm a neonatologist and a clinical geneticist in Atlanta. I was asked to present a bit about our experience of implementing a CCHD screening at a large birthing hospital system. I'm at Northside Hospital. Let see now, how do I advance the slides here? can you hear me?



Thalia Wood: Yes.

Kenneth Kupke: I'm trying to figure out how to advance the slide.

Thalia Wood: Okay. If you want me to, I can go ahead and advance for you.

Kenneth Kupke: Okay, go ahead. We're a tertiary community hospital system and in the metropolitan and Atlanta area in Georgia a regional leader in obstetrics. The staff have more than 150 obstetricians and 18 perinatologists and 12 neonatologists. There's a very high volume labor and delivery service and there are three campuses in the northern suburban Atlanta area. Next slide.

The Northside Hospital has a combined annual live birth number in 2013 18,361 and it's divided between the main campus, the first campus, in Fulton County at Sandy Springs 14,688 and then 20 miles north in the town of Cumming, in Forsyth County 2,570 live births and in Canton, a much smaller hospital, 1,103.

The Sandy Springs campus has a level three nursery and it had a level three nursery for dating back to the 1980s. The Cumming location had a level two nursery that just in the last year or so has increased to a level three capacity. The Canton facility is at a level two, has a level two nursery.

The Cumming facility is rapidly growing because the demographics of where young families are moving to is lending itself to rapid growth there. The Sandy Springs campus because it is so large, it's quite sprawling. There are nine different newborn nurseries and there's a very large NICU with 125 beds. Next slide please.

As I'm sure everybody is aware of the timeline for universal newborn CCHD screening dates back to the FCCHD recommending universal CCHD screening back in September 2010 and then the workshop in January 2011. Then Secretary Sebelius endorsed the recommendation for universal screening September 2011 and [inaudible 00:20:56] publication in October 2011 summarized the workshop and the algorithm. Next slide please.

What I'd like to discuss today is kind of our step and our implementation in this large hospital system some of the challenges we encountered and



then just a summary of what we sort of experience today. In April, we assembled a multidisciplinary team and started holding regular meetings with neonatology, pediatricians, nursing leadership from the regular nurseries, the newborn nurseries, as well as the NICUs, respiratory therapy and our newborn screening coordinator.

We have the advantage of having a newborn screening coordinator at Northside Hospital who is the clearinghouse for all newborn screens. That filter paper specimens, those results and making sure that every baby gets one done, interfacing with the state lab, as well as taking on some of the data collection for CCHD screening as well. Sharon Quarry's on the line today.

Now in April then we then stood up and encountered our first challenge, which was trying to figure out the right pulse oximetry product to use. Here before, the hospital had been using a pulse oximeter for many years that was largely driven by sort of economic factors, they fact that were using products from the same company that brought their price way down for using the disposable probes. Next slide please.

There was a lot of concern that that pulse oximeter product was not very good for motion, especially in newborns. Our NICU nurses had been kind of trained to be able to screen out motion artifact but we were quite concerned that when screening was done in the newborn nurseries that we would end up with lots of false positives. We conducted literature review of different pulse oximeters. We had the vendors come in and demonstrate and then we did some product trials in the hospital.

A decision was made after that to hospital wide change to a completely different pulse oximeter product that was in fact motion insensitive. We encountered some resistance on the part of different parties within the hospital, both for kind of economic reasons as well as for just sort of inertia, status quo, comfort. I think also for other reasons. Then it's this reason had to be overcome with kind of reiterating the scientific evidence. Next slide.

In June 2012 we purchased the pulse oximeters and the probes, we developed hospital policy and procedure for universal screening. We presented this to the newborn services committee where the pedestrians are represented for the well-baby nurseries. Next slide please. Then we evaluated what the implications would be for the workload to roll this



out in the newborn nurseries and in the NICUs. We projected what kind of volumes would be occurring, et cetera. Next slide please.

That's where we encountered our next challenge. Next slide please. During the time studies, we assessed how much workload was associated with screening and there was in fact a bit more workload and so additional FTEs had to be requested from hospital administration to cover that extra workload. In addition for the newborn screening coordinator office we added additional 0.7 FTEs and it took a little bit of time to get the approval from and convincing to get the approval from the hospital administration. Next slide please.

Also in the summer we developed order stats and medical record forms for tracking the results, developed a plan for roles and responsibilities for the staff for screening and we had meetings with the pediatric cardiologist about when we would be able to obtain the echocardiograms for failed screens. Next slide. Then we also designed a database to track the outcomes of our normal screens. Next slide.

As part of that, their challenge was just sort of administrative informatics thing. We added to the EMR a test failed results. We added the CCHD screen results to the daily newborn screen monitoring form performed by the newborn screening coordinating office. We developed a process for communicated failed screens to neonatology and cardiology.

In our facilities, if a baby fails a screen or the algorithm fails the screen for the algorithm they get transferred to the transition nursery and the special care nursery if they're not really symptomatic. Then there they end up getting a cardiology consultation and echo usually within six hours or so. We set up an Excel spreadsheet to track the misses or refusals and the outcomes of failed screens. Next slide.

In July also we developed some patient education materials for parents. In the fall we undertook the staff education, competency and training, which was the fourth challenge. Next slide please. In all we trained 715 nurses in the use of the new pulse oximeter. Then trained 300 nurses in the CCHD algorithm and how to document it using computer based learning modules. Next slide. We enrolled the screen in December 10, 2012 at all three campuses and today I have data from December 10, 2012 through April 2014, so 17 months of data.



The number of eligible babies for screening during that time was 26,027, broken down as you can see. Next slide. It was estimated that roughly 4% of babies would not undergo the screening due to either having an echocardiogram obtained for other reasons, death or transfer prior to screening, refusal, which we had pretty hard numbers on. only six and or missed the screening. Therefore, we estimated approximately 25,000 newborns were screened during that period of time. Next slide.

The number of failed screens of the 25,000 babies were 15 but when you looked at those really two are not really true screen failures by the algorithm. They actually had passed but they were misinterpreted. One baby had a normal echo, the other baby had pulmonary hypertension and ASD. Then there were 13 true screen positives, seven with the normal echocardiogram, three with pulmonary hypertension, one with an ASD, one with mild left ventricular hypertrophy and two trisomy 21 babies. One who had an ASD and one who had complete AB canal.

The trisomy 21 babies, routinely they get echoes anyway, usually per the order of the physician but because the order the order stats call for universal screening the screening was done even though they were destined to get an echo anyway. Next slide. We detected no cases of CCHD during the 17 months. We had the 13 screen positives, which comes out to be a range of 0.5 per 1,000 newborns, which is in line with what other people have reported.

During this period of time we had 72 cases of echo proven CCHD at the hospital requiring [inaudible 00:31:21]. In looking at those, 63 were prenatally diagnosed and led to a postnatal echo, which led to the [inaudible 00:31:33] use. Nine were postnatally diagnosed, so we're weighted heavily towards prenatal diagnosis of congenital heart disease due to a high utilization of prenatal ultrasounds as well as being a referral center for a large part of Georgia for complex cases. Next slide please.

There was one false positive that we encountered, an infant with coarctation of the aorta who was diagnosed after the normal screen while the baby was still in the hospital. Our true false negative rate is now down because we don't have an effective comprehensive system right now for babies with normal screens but we are working to develop such a program through working with a pediatric cardiologist.



There is essentially one center in Georgia at Emory University that repairs the complex congenital heart disease babies. They are looking at the possibility of giving us feedback from their database where they do have a birthing hospital as a field and that could be correlated with our database to figure out what our true false negative rate is. We're looking forward to getting that implemented hopefully in the next few months.

That's my talk. I think our experience whenever we implement anything in a large hospital system it's like turning a cruise ship, it takes a long time, there're a lot of players involved and there's fair amount of complexity. This endeavor was no different than anything else we've tried to enroll in that regard.

We're pleased that we haven't really found much congenital heart disease that we had been missing but we know it's there because we know we have missed cases in previous years. I think it's just a matter of time until we find one through screening. That's the end of my talk.

Thalia Wood: Thank you so much Dr. Kupke. That was great. Once you've spoken you and Mary if you want you can push star six to remute your phones. Dr. Kochilas, go ahead and push star seven, you're up next. Can you unmute your phone? Lazaros, can you unmute your phone, star seven?

Lazaros Kochilas: Yes, can you hear me now?

Thalia Wood: Yes, we have an echo though. Do you have your computer speakers on by any chance? I think that ...

Lazaros Kochilas: How about now?

Thalia Wood: Any suggestions? Go ahead and say something again. I was kind of echoing back.

Lazaros Kochilas: [Inaudible 00:35:11]

Female: Have him call in and get off of his computer.

Thalia Wood: He's called in. He's on audio. Because you're using your phone you need to mute your speakers on your computer.

Lazaros Kochilas: All right, let's try again. Can you hear me now well?



Thalia Wood: Yeah, that's much better. Thank you so much. Go ahead.

Lazaros Kochilas: All right, so hello everybody. I wanted to talk briefly about the way how in Minnesota we are getting right now with the asymptomatic babies with the positive newborn screening that they are in remote hospitals and small centers scattered around the state.

Minnesota is a pretty big state but the big organized part of the hospitals and delivery care actually is just located in the southeast area of the state with three major medical centers taking care of children with congenital heart disease. Not so much of connectivity or accessibility to other parts of the state who can be actually quite far away.

We can advance to the second slide, please. Here we have [inaudible 00:36:47] this diagram the action plan when we encounter a baby with a positive pulse oximetry screening. When look at them a little bit separately the ones that are the left side of screen have a very significant level of desaturation defined as the oxygen saturation level being less than 90%.

We found obviously the children that we needed to act quickly because it can be quite significant underlying [inaudible 00:37:19] most centers were at the sea level so we don't have to worry about the things that we heard from Mary Kohn about it being an effect of altitude. We think that with this we really need to move quickly with the careful and comprehensive evaluation we most likely needed to transfer the baby to an appropriate facility where several diagnostic tests can be performed and the treatment [inaudible 00:37:51].

Then we have the large number of 208 failed the pulse oximetry screening they're in the area of oxygen saturations of 90 to 94%. These children, they're all asymptomatic because if they're not asymptomatic then this pathway [inaudible 00:38:13] apply to them it just goes to the clinical pathway that you have a child that has symptoms and that you activated [inaudible 00:38:20] that exist in every hospital that includes the transfer and the time in evaluation and treatment.

Back to this population of children that have the saturation of 90 to 94% or they do have a grade of more than three points between the upper and the lower extremities then we think that it's regional to have a [inaudible 00:38:46] easy access to pediatric cardiologist service. They do



have local availability of services that can stabilize potentially sick newborn.

That includes the use of a secure line, the measures to stabilize them when they're breathing and also the availability of post decline [inaudible 00:09:18] which in the case of the children has congenital heart disease able to regard it as epinephrine. It's a medication that is lifesaving and part of the PCR type of algorithm.

If these hospital they do have all these means to support the child that can change them from being [inaudible 00:39:42] heart disease is present then we think that this [inaudible 00:39:54] and to allow more time for the condition to occur. In the secondary screens, it is quite likely that most of these children, they will actually normalize gradually and then we'll need to see passing requirements for the screen.

The previous speaker actually described this in the [inaudible 00:40:28], there is an additional challenges of the high altitude. We [inaudible 00:40:31] continue to monitor this data in the local hospitals would be a requirement for local support existing there. Then when the children do pass successfully through the condition process then can be discharged with a specific follow up and also with education for the family of what are the signs they have to look for.

Now when we go to the other [inaudible 00:41:05] they are indicating in the [inaudible 00:41:09] with no, meaning that you don't have accessibility to the closest specialist or you don't have this availability to a diagnostic quality echo. You do not have the ability to support a newborn so you don't even have [inaudible 00:41:23] then I think the course of action should be much more active decision to transfer to a proper facility where these things exist.

When I'm talking about transfer to a proper facility, in this case that you have an otherwise healthy looking newborn just with a borderline saturation that is not enough to pass this screening means that the hospital could be in a local hospital that has the ability to offer this. Not necessarily to transfer to a larger distance to a big care center that offers all the [inaudible 00:42:09]. Can I have the next slide please?

There are obviously several barriers implement the delivery of services to the small and to remote hospitals. Once major barrier of course is the



availability of the healthcare profession, more importantly, echo technician.

That many times the technicians are doing this in places that do not have the expertise to deal with young children and with infants. In this case, even if there is some kind of an indication to enhance the level of understanding in the skills of this professional, sometimes there is a little bit of resistance because of regulatory elements that put it on the bottom of the list.

There are also sometimes difficulties to get the connectivity with pediatric radiologist who will be able to impact some of the locally obtained data in any kind of performance. These are things that many of the hospitals are working to resolve. I think at least in the state of Minnesota we have done significant progress in connecting the small places with some of the centers that can offer this type of support.

There is an additional problem with the availability for data [inaudible 00:43:46] echocardiogram because don't forget that the probes for a young infant, they are very different than probes that we use for the adult. The hospitals that deal with adults they do not necessarily put the investment for the quite expensive unit in an infant approach.

[Inaudible 00:44:20] that what I was talking before about connectivity between the remote centers with bigger centers. Again, there is a lot of progress happening in this domain. There is certainly cost involved with the hospitals that take the decision to upgrade and to offer some more coverage for these children and sometimes based on the numbers of children that they're delivering locally. It can really put some financial stress for these institutions because they're not fully justified by the number of deliveries that is at these places every year.

Finally, of course, there are the regulatory medical/legal considerations. There are many places and many [inaudible 00:45:16] that even if we get some additional education about how to deal with echocardiograms or how to deal with small infants in general, they don't feel comfortable that they can offer these services because they may not be covered by the parent professional insurance plan that is available to them. Next slide please.



We did look quite extensively with a survey that we did a couple of years ago for the state of Minnesota to understand the availability of services for children with potential heart diseases in three different centers. First of all, to the centers that was in the [inaudible 00:46:11] metro area. These are indicated with the white bar in this diagram.

Then to centers that may not belong to the metro area but they are part of the big organized healthcare system, which are indicated with a gray color. Then finally, for the hospitals that belong to the third configuration that they are the non-medical localized hospitals and they're independent and not a part of a large healthcare system.

We see a lot of variation with what's available. To make the long story short, I have to say that there is a good number of hospitals out there that they do not have enough resources from the nursery level personal and availability to provide the safety margin that we need in case a baby with congenital heart disease is born in these places.

You have to when you combine both the factors of personal and availability [inaudible 00:47:18] you see that about 12% of the babies that are born in Minnesota they do not have access to this level of service. Now if the number have a different diagnose and don't present it here.

If this number of death translated to the number of centers that did not have this support you would see that about 30% of the centers in Minnesota as of two years ago they did not have neither the personnel nor the availability at the same place to adequately provide safety for a baby with a potential critical congenital heart disease born in either location. Next slide please.

Our suggestions are, of course, is to promote as much as we can the training for echocardiographer, [inaudible 00:48:20] ER assistant to understand the nature findings and the nature of progression of symptoms in the children with congenital heart disease. It is an idea that has not been put in place yet to design a central basic cost of the echocardiography that will be offered in annual basis with some [inaudible 00:48:47] one to two years depending on how confident the audience of this course feel.

To provide this onsite depends on training and some remote website material to enhance the indication of echocardiographic studies and



other studies relevant for the diagnosis of congestive heart disease in newborns.

This probably by itself is not going to work unless there are some incentives for the hospitals and for the [inaudible 00:49:22] including giving the time how many days would be like or two days, every year, every other year to follow these courses. Do additional regulatory status like even if you get this training you still may be vulnerable because of insurance type of issues.

In addition, one of the most importunate perhaps factor that can enhance the delivery of healthcare for these children is the overall enhancement of the medical training for understanding the congestive diseases. Next slide please. I think that's my contact information in case somebody has more questions or [inaudible 00:50:16] some questions right now.

Thalia Wood: Yes, thank you so much Dr. Lazaros Kochilas. Amy, we have about nine minutes left. Do you want to quickly go over your slides or are there any slides in particular you'd like me to highlight? How would you like to do this?

Amy Gaviglio: Yeah, I can probably just go through them really quickly and I can advance them myself I think [crosstalk 00:00:38]. I just wanted to kind of follow up with what Dr. Kochilas was saying in regards to rural hospital, undoubtedly, a challenge of pulse implementation that affects all states is really how to effectively implement this screen in rural hospital.

From a public health perspective, it's really important as a program to understand what you should be expecting by way of your distribution of birth. Not only births but how many positive you will have within different types of birth facilities.

The first slide, it's very similar to what Dr. Kochilas said and that we broke our hospitals down into five categories in order to kind of get a sense of how many births are covered by metro areas. rural hospitals that are still within a healthcare systems that are well connected to tertiary care, rural hospitals that are considered independent and then, of course, the home birth situation.



For most, I think what makes implementation in rural hospitals difficult is really not performing the screen itself. Many of them have pulse oximetry equipment already and they're willing and able to do the screen itself but rather the difficulty of it and what can be done in what timeframe on a positive screen. To assess this we ask each facility to discuss their availability of pediatric cardiac services, again, as Dr. Kochilas has mentioned.

You can see here that our biggest focus from a public health perspective and kind of our biggest concern in how to follow up is they'll have both that are in the variable unknown and known roles. That makes up about 30-1/2% of Minnesota births. We are fairly lucky in Minnesota that almost 60% of our births are in the southern county metro area, which is [inaudible 00:52:34] center. Just knowing that right off the bat really helped us focus our education on those 32% of births that are falling in that little area.

Again, how many babies are we really talking about, this is another important piece from a public health perspective is to know what are you talking about as far as workload, how many babies are you really talking about that are going to be either true positive or false positive screens within this rural health system.

Looking at expected or reported tough metrics combined with birth rates in Minnesota you can see that we are looking at anywhere from 20 to 60 positives per year in rural hospitals, so really not a huge number. Knowing that really also has helped dictate how we've done our done our education efforts for rural hospitals, which I'll explain e in just a minute.

This is a map of Minnesota. It's not a very pretty map; it makes up look shorter and stouter than we actually are for some reason. One issue we see very any specialty care and certainly not just cardiac in Minnesota but specialists are largely concentrated in the southeastern portion of Minnesota and in the Twin Cities. Then, of course, in Rochester the Mayo Clinic, so definitely much of the state far from tertiary cardiac care and it makes us focus on what transfer protocols are going to look like for these rural hospitals.

I think one of the most helpful survey questions of the more recent survey of our hospitals we asked was where do you typically transfer your sick infants. What does your sick infant transfer protocol look like? This



information not only gives us an idea of where positive pulse ox patients may go but also from the discussion was rural hospitals on the idea of transfers and that they really needed to look at kids with a positive pulse ox screen as a sick infant and as an infant that falls into their sick infant transfer protocol.

In follow up with this discussion with the rural hospitals we subsequently asked these facilities to provide us with their protocols for how they would follow up on positive screens. Using this information as well as some other information we gathered from surveys specifically what institutions have PEGs, [inaudible 00:55:05], available.

We're in the process right now of creating facility specific guides or kind of what we're calling cheat sheets for the rural hospitals so that they know what is their typical transfer protocol, where is their closest institution that they can transfer to that has PET, that has pediatric cardiac services. Just made them a really easy kind of checklist of what to do when they have a positive case.

We felt that these would be really helpful in a rural hospital given that as I mentioned before only expecting probably less than 50 positive results even in this kind of rural health system in Minnesota. These facilities may only have one maybe positive a year and trying to remember in what to do in that case is not going to be easy when you don't see it on a regular basis. Having this was something new for us and something that we think will be really happy and I'm happy to share that with anyone who may be interested in doing something similar.

Again, a lot of rural hospitals do typically have a transfer protocol, as I mentioned. If an echo can rule this out, rule out a need for transfer, this is obviously better and less costly option. We also assessed not only echo capability and I won't talk about that since Dr. Kochilas covered it, also a willingness to train adult echo techs on basic newborn views. As you can see from our initial survey, willingness was not stellar.

A lot of them are not willing. However, in follow up to this and in more discussion with our hospitals we realized that they were thinking of actually that their adult echo techs would have to be certified in pediatric technician and that wasn't the case. That's not what we were thinking. What we're thinking was more in line with the great training that Dr.



Hokinson did in the Wisconsin SHINE Group on pediatric echo. It's available on the Wisconsin SHINE site.

It's spectacular and I feel like I have to give a shot out to them because it's just such a great resource. We have had some of our rural facilities that on and I think that's going to be really helpful. Again, this is just from a public health perspective and really getting rural hospitals onboard, helping educate them and really helping them work through the processes that they really already have in place and just modifying them slightly for the purpose of positive screening follow up.

Hopefully I talked enough, Thalia. Again, here's my contact information if you're interested in seeing any of our education materials for rural hospitals, any of our survey question or how we put those out to the facilities. We'd be very happy to share. [Crosstalk 00:58:01] ...

Thalia Wood:

Thank you much Amy. Thank you very much for all of the presenters. I think you did an excellent job. If you have a question, you can unmute your phone by pushing start seven. We did have a couple questions that were written in the chat box, which everybody can't see and they were answered. I'll just quickly read those. Do you continue to see NICU babies? Dr. Kupke said yes, if that they have not had a previous echo during the hospitalization, the screens done in the last two days of the hospitalization.

Geri Mattson asked about sharing the templates. Amy, I think you already answered this, that they're available. There was another comment that says super job all presenters. If you any other questions here in the last few minutes go ahead and ask them now.

Again, if you think of any questions later you can always email me. I will get in touch with the presenters. One more call to ask if anybody has any questions before we end the call. Star seven; unmute your phone if you have a question.

Female:

This is Pat [inaudible 00:59:08] from the Arkansas Department of Health and our pediatrician was unable to listen to the presentation. What kind of instruction can I give him? Was this recorded?

Thalia Wood:

The call today? Yes, the call is recorded. It will be on our website along with an actual written transcription within the next couple weeks.



- Female: On the website.
- Thalia Wood: I will send out information about that. I sent that out in the original email about this webinar but I will send that link out again.
- Female: All right. It will be recorded, just for his information. The PowerPoints will be included too?
- Thalia Wood: They will be, absolutely.
- Female: All right. Okay, thank you so much. It was excellent information. Thank you.
- Thalia Wood: Thank you. Any other questions before we wrap up? Again, I'd like to thank all the presenters. I think these were excellent presentations. There's already been a few comments about that. thank you so much for presenting today and for your time and talking to everybody. We'll have another webinar next months. More information will be forthcoming.
- Female: You're very welcome.
- Thalia Wood: Thank you.
- Female: Bye.