NewSTEPs

A Program of the Association of Public Health Laboratories™

Critical Congenital Heart Disease (CCHD) Technical Assistance Webinar

July 2014

Presentations:

- History of Newborn Blood, Hearing, and Heart Screening in Out-of-Hospital (OOH) Births in Wisconsin—Gretchen Spicer, CPM, LM
- Newborn Screening: Maryland Community-Based Midwives—Mairi Breen Rothman, CNM,MSN
- Offering and Providing Complete Newborn Screening to Families Planning an Out-of-Hospital Birth in Minnesota—Kate Saumweber Hogan, CPM, LM

Facilitator:

- Sikha Singh, MHS, PMP, Manager, NewSTEPs

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

Sikha Singh: Now that we're recording again, I'm just going to repeat that briefly. We have three midwives speaking with us this afternoon, with the topic of CCHD and Other Newborn Screenings Out-of-Hospital Births. The order of the speakers is going to change just slightly this afternoon. We're going to have Mairi Rothman 00:18 speak with us first, followed by Gretchen from Wisconsin and then Kate Hogan from Minnesota. Next slide please.

Before we start, we just wanted to share with you two examples of recent publications pertaining to home birth screenings for CCHD. This webinar will be available on the [NewSTEPs 00:41] website, so you can go on there as soon as it's available and look at these references. This is one. The other one is from the Journal of Pediatrics, also about pulse-ox screening for out-of-hospital births.

If you have any questions, please let us know. Like I said, you can type something into the chat box at any time and we'll be able to address your question. Following the webinar, we'll have two brief poll questions. We would really encourage you to participate in them as they will be talking

about the future [FECCG 01:13] webinars and the format that we might be adopting moving forward.

To begin with, I'm pleased to introduce Mairi Breen Rothman, and she will be presenting on newborn screening for Maryland Community-Based Housewives. Mairi, we'll be advancing your slides for you. If you could just hit *7 to begin speaking, that would be great.

It looks like we may not have Mairi on the line right now. Let's go ahead and move onto the next speaker, which is Gretchen Spicer from Wisconsin. She'll be discussing with us today the history of newborn blood, hearing, and heart screening in out-of-hospital deliveries in Wisconsin. Gretchen, can you hit *7 so we can hear you?

Gretchen Spicer: I just did. Can you hear me?

Sikha Singh: We can hear you, thank you so much. If you go ahead and present, we will be happy to advance the slides for you.

Gretchen Spicer: Okay, great. Wisconsin has a long and wonderful history of newborn screening, and has worked really well with the out-of-hospital providers for a long time. Just recently, very recently, we've added pulse oximetry screening as a mandated screening. In Wisconsin, we're really trying to look at all three screenings as the newborn screening program, and not so much as individual programs.

This is easy for midwives, because it's always been one program for us. We're very fortunate, because the same person does the screening. Does the prenatal education about screening, does the screening, and provides the parents with the results. This has been easy for us and something that in my work that I'm trying to help promote in the non-out-of-hospital population as well. Next slide.

I have worked as a midwife in private practice for 14 years. I helped with about 700 deliveries. Most of the families I took care of were Amish families. Recently I have stopped doing deliveries and I have been hired by the Wisconsin State Lab of Hygiene in conjunction with the Department of Health Services as the Out-of-Hospital Newborn Screening Coordinator for all three screenings. Next slide. Next slide.

Thanks. I think we missed one slide. If we could go back one. Thanks.

We've of course always had midwives in Wisconsin. Early on there were licensed midwives and then we lost that licensure. Then there were always midwives helping their communities. In the 1970s, there was a

resurgence of out-of-hospital births, and many midwives had become Certified Professional Midwives or were trained.

I'm sorry, weren't certified professional midwives yet, because that wasn't available. Did have training. But there wasn't any certification or licensure available.

In the 1990s, one of the midwives working in Wisconsin was threatened with investigation for performing newborn blood screens. A lot of the midwives had been doing blood screens. They'd been getting the cards from the county Health Departments. In some places they had great friendly relationships, and that worked well. In one instance, a midwife was reported for doing blood screens.

The Department of Health formed a home-birth work group and that was really a wonderful thing. Because rather than this investigation going forward, it got stopped there. Everybody got in the room and started talking about newborn screenings. When the statute was looked at, it was clear that not only were we allowed to, we were required to do blood screening.

I have the statute there for you. It talks about the hospitals and it talks about if a baby is born in a place other than a hospital, then the birth attendant is required. Shall cause the infant to have the screening.

At that point, we started working with the State Lab of Hygiene. We really had several people that were really instrumental in seeing this happen. Dr. [Laessig 05:47], who was head of the Wisconsin State Lab of Hygiene at that time. Gary Hoffman, who was head of the Newborn Screening Program. Really did everything they could.

I remember Dr. Laessig at this first meeting saying, "Just screen the babies. Just screen the babies." Anybody who would express a difficulty, he would say, "Just screen the babies." That was what they worked for, to work around any obstacles and make sure that all of these babies got screened.

The Health Department also, we had some wonderful champions. We had Laurie Tellier and then Terry Kruse and later Katie Gillespie that organized these meetings that really brought everybody together to talk about public health and home births. Next slide.

The state lab then set up accounts, so that the midwives could get their own cards and submit them under their own name. Versus having to go through the County Health Departments. That was really important. Still

a lot of our Amish families weren't getting blood screening because of the cost, and other low-income families as well.

The State Lab of Hygiene set it up so that we could get free cards for anyone that qualified for Medicaid, but for one reason or another wasn't using Medicaid.

Then when we went for licensure? In about 2003, we started our licensure effort. We had the incredible opportunity to have some support from the State Lab of Hygiene, the Department of Health. [Dr. Catcher 07:20] at the Department of Health was very helpful to us. Our licensure was successful in 2005.

Since that time, the State Lab of Hygiene has just worked wonderfully with midwives. We couldn't ask for more. Many of our Amish families have genetic disorders, and some of them are very crucial that the baby be identified and treatment begun within 24-48 hours. We've had people from the State Lab of Hygiene meet us in parking lots in the middle of the night, to get a sample and take it directly in and test it for these babies that have these really critical disorders. We couldn't ask for more with blood screenings. Next slide.

Hearing screening came along. Very early in 2001, we were working with Elizabeth Seeliger, who is the head of the Hearing Screening Program in Wisconsin. She worked with the midwives to get two ABR machines. We had them in two areas of the state and four-six midwives were sharing those. It was difficult. There was a lot of driving and picking up screeners.

It was great, the families almost all said, "Sure, great, if you can screen the baby." Prior to that, we had been referring families into the hospital for screening, and it didn't happen. A very few families would go in. Most of them just didn't do it.

In some places, there were huge obstacles. In some places the families had to pay a room fee, because the hearing screening was wrapped into the room fee. That was not a feasible solution.

The ABRs weren't very feasible either. They were really delicate. They were often not working. Expensive to repair. Then, the machine we had, they stopped replacing the cable for it. They had discontinued it. Then, about 2005, had no hearing screening program. Once again, went back to almost no babies getting hearing screening. Next slide.

Then hearing screening became mandated. Elizabeth Seeliger again worked really hard to see that midwives had hearing screeners. We decided in the new look at hearing screening, we decided to go with

OAEs, even though they're not quite as good a screener as an ABR. We felt like we could get way more. We could have gotten maybe three ABR screeners with the money we had, but we were able to get 11 OAEs.

We worked with all of the midwives in the state so that everyone had access within a half hour of them to a hearing screener. Again, we still have some transporting issues and driving issues, and we certainly could use more screeners. We are working with the 11 we have.

The midwives all pay $10, for each baby that's screened. That goes into a fund and that's used to cover any expenses, any repairs, and the yearly calibration. We are saving money and we are almost at the point we can buy an additional hearing screener out of that money. That's worked really well.

Most of the midwives are using the hearing screeners. Most of our midwives use ... We track for entering the data on hearing screens. We then, that was working well. Babies were getting the initial screen. For babies that didn't pass? Then we were having a problem. A lot of front families, particular Amish families, were not going on to audiology when the baby referred twice on the OAE screen.

We looked at what we could do for that. Now we have it set up so that there are, in five locations, there are people with ABR screens. Public Health Department in Milwaukee, Wisconsin Sound Beginnings in Madison area. I do it for the western part. We have a person in the northwestern area of the state. We will go out then for families that can't access audiology, or won't. We go out and do a follow-up ABR screen. We're finding that almost all the babies pass on that ABR screen.

We had some areas without any hearing screening, in which we didn't have licensed midwives. We did some outreach clinics. Audiologists and students from UW would go and we would do a bunch of screens. Like 30 screens in a day. That's been helpful in those areas. We're phasing some of those out, because we've gotten hearing screeners in those areas. That's a better option of course, to have the babies screened right away.

We've just placed an ABR with an Amish birth attendant in an area. An Amish woman that's doing a lot of deliveries. Those babies also were not getting hearing screening because the babies go home to their own counties and often the families just weren't accessing any other screening. We're trying that out to see how that will work.

Then the big thing this year was that I was hired as the Coordinator to work on all of these projects. Next slide.

Then heart screening came along. I was fortunate early on to meet John Hokanson, who has been the big champion for us with the heart screening. He had looked at some research that there was a higher risk of undetected CCHD in out-of-hospital deliveries. In fact, a 10 times greater incidence.

For many reasons, looked like it was because there is way less prenatal ultrasounds. Since about 50% of heart defects are picked up prenatally with ultrasounds. The higher prevalence of the plain clothes families. The higher incidence of congenital heart disease in the Amish. Also the shorter post-delivery observation period.

That often most midwives are leaving two to three hours after everybody's completely stable, so you're leaving new parents often in dimly-lighted situations such as Amish homes. That maybe, in that 24 hours, perhaps a skilled observer would have picked up signs of heart disease that parents alone might not. We were seeing this much higher incidence.

John was very eager to include the midwives, so we've had this wonderful collaboration with the SHINE Project. We're seeing in Wisconsin about a 2% home delivery rate. Our Amish populations are growing very fast. With that, our home birthrates are growing. I think we will see probably 1,500 out-of-hospital deliveries in 2014, at least. Next slide.

SHINE worked first with the licensed midwives. In 2011, John came and did a wonderful presentation. Most of the midwives were really enthusiastic and wanted to join the project. In 2012, we started recruitment. Started trainings in 2013. It was great, the licensed midwives were screening babies. That was all working well.

Still, we were not seeing a lot of the Amish babies getting screened if they were being delivered by the Amish birth attendants. Or having unattended deliveries, which is fairly common also, in our Amish communities. We outreached then to Amish birth attendants and Public Health Departments.

We brought people together in a room and said okay, how can we get these babies screened? What's the best way? Is it for a Public Health Nurse to come do it? Or for your Amish midwife to do it? We have a combination of some of the Amish midwives doing it. Some of them notifying Public Health to come out and do all of the screenings. Next slide.

Our training, we used midwives. The SHINE Project has two midwives that serve as consultants. We were trained to do the trainings, and we delivered our training program. We basically go through the information about heart disease and transitional fetal cardiology. Then do a hands on. We do some case reviews. Then each midwife signs a Memorandum of Understanding and we place a unit.

Then we do pretty frequent follow-up with the midwives to see how it's going. We get a lot of questions at first, and then usually the midwives are on their own. Next one.

Right now we have 47 people enrolled. Which includes licensed midwives, Amish birth attendants and Public Health Nurses. We record the results on the blood card. Then midwives are asked to do an additional data form, because we wanted to find out a little bit more information about the out-of-hospital. Including the use of prenatal ultrasounds, history of congenital heart disease in the Amish families, and if they're from a plain clothes family.

Those forms are sent in with the card, with the newborn screening card. We're also right now working on a survey of all of the people that have pulse oximeters to see how that's going. Next slide.

That's just our data form. The yellow field on our newborn screening card where we report results. Next slide.

This is some of the preliminary data from November. January through November 2013. That in the out-of-hospital we had three babies that had appropriate fails. One of those had a heart defect. Two had infections, so that's the really interesting thing. I'm pretty sure we've had an additional infection identified since that time. It's been really interesting. One of the things we're finding, it's a very good tool for identifying sepsis early, before the baby's really sick.

Early on, we had some problem with inappropriate passes. They almost all were in the ones. The equivocal and the measurement wasn't performed. One was a fail, but that one was probably not a true fail. I went out, that was an Amish midwife. I went out and saw the baby again. Noted that her numbers, she had had a pulse of 50 within the slow O2 stats.

When I repeated it ... The baby also went in to see the doctor, but the doctor only did one measurement. I went out again a couple days later and did both. The baby looked great; passed. We feel that it was probably just a poor screen.

One fail that wasn't actually a fail. Next slide.

We're doing well on our timing. Most of our babies are being screened in the 24-48 hour window. There are of course a few that have fallen outside that. Next slide.

We are finding this is widely accepted. If parents refuse ... Accept only one of the three screenings? It seems to almost always be CCHD that they will accept when they decline the others. Our plain clothes families seem to be fine with it.

The midwives love it. Every time I do a training, someone will ... Yesterday I did a training, and the students who are all working with midwives said, "Oh, the midwife I work with just loves the pulse oximeter."

They're using them also during resuscitations, in post-resuscitation care. And in decision making about a baby that's not looking great. Midwives are finding that the transporting center, when they do a pulse oximeter and it's not good. They just transport and don't wait around to see what's going to happen with the baby. That's been really, really helpful.

We are having problems with the Amish families. Some are resistant to further evaluation, especially if the baby looks good. We've really worked on that, on kind of a step-wise approach to that. Often having the local family practice doctor that has a relationship with the community see the baby first. Then decide if further evaluation is needed. Next slide.

This is just a breakdown of the different results and what we found on the ones that were pass or incomplete. That I talked about on the other slide. Next slide.

The ongoing challenges? The hospitals have a lower failure rate. We don't know, some of that we think was training and we're seeing a decrease in that. Some of it is this apparently, a little bit higher rate of fails in the out-of-hospital.

The big cost of further evaluation for Amish families is just a big deal. They're uninsured. They have to hire a driver. Often have cows to milk and they have to arrange for someone to come over and take care of chores for them. This is a big deal, if we end up sending a baby that it turns out nothing is wrong.

We had one baby that got more evaluation. Failed a pulse ox. Went into the doctor. Failed there also. Went up to La Crosse. By the time they got

to La Crosse, the baby looked pretty good. They never found anything wrong. That was really difficult for that family.

Again, where do families go? We do have this kind of plan that if the baby looks good. Failed a pulse ox but looks good, that we're often starting with the local clinic. If there any concerns about the baby, of course, the babies are going on there to a medical center.

Our midwives all call SHINE. If they have a fail, they call SHINE. Talk with a Cardiologist. Work together. A Pediatric Cardiologist. They work together to figure out the next steps.

The one worry we have is that we may see community resistance. If we have several babies in the Amish communities that go on to further evaluation and there isn't anything wrong, then there's always the concern that the communities will decide to stop screening. We're hoping that won't happen. Next slide.

We really are working very hard in Wisconsin to have this unified newborn screen program of all three screenings. We've just done a lot of nice things together, particularly for the out-of-hospital. We did a newborn blood and hearing brochure for plain clothes families specifically. Some plain clothes families can't have any photographs in the home, in the most conservative homes. We did a little brochure without any photographs.

We need to add CCHD to that. We brought Dr. Holmes Morton, who is an expert in working with the Amish, to a community meeting in Norwalk, Wisconsin. We have another one scheduled in Augusta in October. To really engage the community in newborn screening.

We have a newborn screening integration committee at the state level. We put heart and hearing screening results on our newborn blood card. We're having those collaboration and training meetings with the midwives and public health. We have another one scheduled July 16th for that.

I got hired to do this work. One of the things that we're working on right now, one of my new projects. Is a combined newborn blood, hearing and heart screening. A prenatal education project. Because I feel like that is the cornerstone of any program, is good education for families. That it needs to be done prenatally. That parents need support and resources to make truly informed decisions.

I don't want a family to have newborn blood screening because I think they should. Or, all newborn screenings, because I think they should. Or

because it's a law. I want them to have it because they got really good unbiased information. They learned the value of the screening. They want it for their child. That can't take place right after the birth.

We're working with an OB practice in Madison to start a project to try. We're going to first survey all the families that are at six weeks, without any intervention. See what their understanding of newborn blood, hearing and heart screening was. Then we are going to ask those staff to do education at the 28 and 36 visits. Survey the next group of families at their six week visit, and see if that makes a difference.

Midwives believe it makes a big difference. That's why most of our families are choosing to have newborn screening. We would like to see if it holds true in another setting as well.

We're also looking at, a few families of course do refuse screening in the out-of-hospital setting. We're trying to look at why they're refusing. If there's something that we could do about that. Next slide.

If you have any questions, or more information, feel free to contact me anytime. Thanks for listening.

Sikha Singh: Thank you Gretchen. We're going to hold questions until the end. We're going to move quickly to Mairi Breen Rothman. I have the great pleasure of introducing her. She's going to present on newborn screening in Maryland Community-based Midwives. Mairi, please go ahead if you're still with us.

Mairi Breen Rot: Can you hear me?

Sikha Singh: Yes.

Mairi Breen Rot: Okay, great.

Thanks for inviting me to do this. My name is Mairi Rothman, and I am a Certified Nurse Midwife doing home births in Maryland. With a partner, Erin Fulham. Our practice is called M.A.M.A.S., which stands for Metro Area Midwives and Allied Services, or Mujeres Ayudando Mujeres A la Salud, which means Women Helping Women Toward Health in Spanish.

The history of newborn screening in our state. You can move to the next slide. Is that ... whoops. Go back one. There we go. Is that we have CNMs and CPMs working in Maryland. Both kinds of midwives are trained and nationally certified to do newborn care. That's included in licensure for Certified Nurse Midwives.

CPMs are not licensed in Maryland at this time, although they're working towards being licensed. There is a lot of support in the state for licensing them. In the meantime, they've been quite responsible about doing newborn screenings of various kinds. Or making referrals to places that will do the screening for them. Can you move to the next slide, please?

As far as metabolic screens go, they are supposed to be in Maryland after 24 hours, and then between 10 days to two weeks. The reason that they started doing the later one is because, as you know, the PKU needs to be done after 24 hours of milk feeding. What they were finding is that with a lot of people breast-feeding and with a lot of people leaving the hospital early, is people didn't have enough protein to have a reliable screen.

They started doing that second screen. What they've also found is that with the second screen, there are more thyroid disorders being picked up on that second screen than the first one. Of course also cystic fibrosis requires two elevated readings for a diagnosis. That's what they're doing in Maryland right now. That's the law in Maryland.

The newborn hearing screen law requires hospitals to test babies before they leave the hospital. But of course that law doesn't apply to community-based practices. We're now saying community-based instead of out-of-hospital because saying out-of-hospital is still referential to hospital verse. Community-based refers to home births and birth center births.

We also now have a law, since last year, about CCHD screening. That requires hospitals to do the CCHD screening before discharge. The home-birth midwives in our state are in voluntary compliance with that law, as are the birth center midwives. Can you move to the next slide, please?

Let's see, some midwives do do the first screening at three days. We do a three-day home visit. Those midwives have an account with the state lab to hand in their blood spots. Some home-birth midwives don't do them because they don't want to, or because it just doesn't fit in with their practice. They refer to pediatrician to do the PKU or the metabolic screen.

I know in my practice, we don't do metabolic screens. We have our pediatricians do them. Every once in a while we have a pediatrician who doesn't want to do the three-day one. In that case we get our blood spot form from them and use their account to do the screen. Then pediatricians do the 10-day. I don't believe we have any home-birth or birth center midwives doing the 10-day screen. Some people refer for both of them. Next slide.

For the newborn hearing screen, in Maryland hospitals are required to do this before discharge. Most home-birth and birth center babies are seen by six weeks for the hearing screen. Which still allows time for early intervention. Our understanding is that early intervention doesn't really start until about three months anyway. By waiting a little bit, we reduce rates of false positives.

Infants with a really gross hearing deficit will usually be seen before that. Because they're obviously not hearing. If they have a partial deficit, it can be picked up at that time.

We have not had any positive screens for hearing deficits in our babies up to six weeks, as long as I've been in the home-birth practice, which is the last seven years. We're thinking that it might be partly that when you do it in the 24-hours following delivery, there is still fluid in the ears. Maybe that's why there are so many more false positives in the hospital. I'm not really sure about that.

We refer our babies, our families, to either have it at the routine pediatric visit. Which some pediatric practices do offer newborn hearing screening. If they don't, there are a number of really excellent pediatric audiology clinics in our area. One at Georgetown and one connected to Holy Cross Hospital. I think one in Wheaton, Maryland. It's not difficult to find a good pediatric audiology clinic to go to for the newborn hearing screen.

We also follow-up at six weeks to make sure that that's been done, or that an appointment already exists. Next slide.

For CCHD screening, I was contacted I guess in 2012 by Deborah Badawi 30:59, from the Department of Health and Mental Hygiene. Who wanted to know if I wanted to serve on a task force in Maryland looking at CCHD screening. They wanted a representative from community birth practice. Then the following year, last year, they did pass a law requiring hospitals to do CCHD screening before discharging a newborn.

I belong to an organization called the Association of Independent Maryland Midwives of Maryland, which is a group of home-birth CNM and CPMs. When the law came out, we made a decision that we wanted to comply voluntarily with this law, even though it doesn't apply to us. We of course feel really strongly that community-based born babies should not fall through the cracks of good screening.

Most midwives, I don't really know any community-based midwives who are not doing CCHD screening. We normally do a routine prenatal, or I'm sorry, postpartum visit at 24 hours. Then often at three days as well.

If a family does have a pediatrician who does not have a neonatal pulse oximeter, then we're also visiting at 48 hours and doing the CCHD screening at that point. Then having them visit their pediatrician on day three, instead of day two. Sometimes they have their metabolic screen at that point as well.

Some midwives do refer to pediatric provider at 48 hours if the pediatrician has a pulse oximeter and does the screening in their practice. Which quite a few of them do.

We sort of have a collaboration going on, where we figure out in advance of the birth, as part of the prenatal screening. Does your pediatrician do CCHD screening or not? Then schedule our postpartum visits accordingly. Next slide, please.

Where we sort of trained ourselves to do the screening, was with these documents that you see listed here. I'm happy to email those to anybody that emails me. I'll give the email at the end of my presentation. That's where we got our information. We haven't had any in-service training or anything, so we've all figured out how to do it on our own.

The algorithms that we use are either ... Next slide, please. Either this one, from the CDC guidelines. Or next slide please. This is the CCHD screening tool kit that Children's National Medical Center put out.

If you go to the next slide, you can see the algorithm in that tool kit. Those are both pretty useful and clear. Next slide, please.

This is the pulse oximeter that we're using, from Hopkins. We all bought them at the same time, so we got a nice break on the price. It's pretty easy to use. You have to get the hang of it, but then it's pretty easy to use. Next slide.

We've really only been doing it, probably a little bit less than a year. On the midwifery front. I don't think a lot of pediatricians were doing it with home-birth midwives before that either. We got a lot of our advice and suggestions from a midwife named Louise Aucott, I think in New Jersey. Who was part of the research that started CCHD screening. She gave us a lot of good support and advice and information.

Currently it's being done by eight home-birth midwives based in Maryland. Four of them CNMs, four of them CPMs. Then we do have a large practice of CNMs in Virginia. Seven midwives who do come into Maryland to do births. They're also doing CCHD screenings.

So far none of us have detected any congenital heart issues. My understanding is that it's very variable, according to geographic region. Someone was telling me at a conference I recently went to, that the Indianapolis area has this hugely higher rate of CCHD compared to other parts of the country. Their suspicion is that it's environmentally related. Which is kind of a horrifying thought.

So far we haven't detected any. We feel good about having set an example for the community-based midwives in DC and Virginia. Who don't have a law mandating this yet, but I think probably will in the near future. Next slide, please.

Just some suggestions that I have for the future, in my area. We would love to see some workshops or in0service sessions. Once you start trying to do CCHD screening, you start to have questions. It's great, once you've tried it a few times, to have some tips from someone else. There's always room for learning more about it.

Certainly we'd love to get some CEUs for it. If anybody has ideas about that, it would be great to get an email. If you could go to the next slide, please.

That's really all that I have to add. If anybody wants to contact me, this is my email address and phone number. I would be happy to answer questions. I don't know that I can answer them, but I'd be happy to receive answers to questions, too. From anybody that wants to contact me. Thank you for listening and for inviting me to participate.

Sikha Singh: Thank you, Mairi, so much for that presentation. We do have one question on the screen right now. I believe that you have to leave early, is that correct?

Mairi Breen Rot: Is the question for me?

Sikha Singh: Yeah, it's for you. I'll go ahead and address it to you. How many community-based births occur in Maryland per year?

Mairi Breen Rot: We have one birth center in Annapolis, and I think they do between 25-30 births a year. I don't know, you could do the math. I mean a month, I'm sorry, a month. That would be something like 360.

Then I would be guessing at a number? I would say it's probably somewhere around 1,000, maybe less than that. It's not a huge number, although the number has increased by 60% since 2004. It's definitely trending upwards. Might be 1,000-2,000 in the whole state of Maryland.

Sikha Singh: Okay, then one other question just came in. Do you have any idea of how much the Hopkins pulse oximeters cost?

Mairi Breen Rot: When we first looked at them, they were $180. Then since we contacted them with 18 orders, they gave us a break on a price. I think it was $135, and they waved the $18 shipping charge for each one. That was great. We just got this huge box of pulse oximeters, and we had to distribute them. We felt good about making it more affordable and making sure that everybody had one.

Sikha Singh: Okay, great. One other comment, from [Kathy Harris 38:39], she noted that NYMAC has an ACM and approved curriculum that they're very interested in presenting free of charge. That's some information that we can share on the list serv otherwise later on.

Mairi Breen Rot: What's NYMAC?

Sikha Singh: NYMAC? It's the New York Mid-Atlantic region for genetic screening. It's one of the national coordinating center, one of the seven collaboratives.

Mairi Breen Rot: Okay. Yeah, that would be ...

Sikha Singh: Another question. Are the oximeters approved for neonatal use?

Mairi Breen Rot: Are what?

Sikha Singh: Are the Hopkins pulse oximeters approved for neonatal use?

Mairi Breen Rot: Yes.

Sikha Singh: Do they meet the FDA recommendations?

Mairi Breen Rot: Yes, they do. We researched it very thoroughly before we decided what to buy. We found pulse oximeters ranging in price from about $22 to about $2,000. Talking with Deborah Badawi at the HMH, and also with Louise Aucott, we were looking for the least expensive one we could find that would actually do the job. We came down to this one and one that cost $400.

The only difference between the two was the $400 was motion ... I can't remember. It was the only one that was certified motion sensitive or something like that. Really, what that's useful for is if you're going to leave it on the baby, to be a monitor. Then that's an important feature. It's not an important feature for just doing a brief test. That's why we ended up with that particular model. It works well.

Sikha Singh: Okay. Great, Mairi. Thank you so much for your participation today and I anticipate you may have some more questions. Thank you for sharing your contact information as well.

Mairi Breen Rot: [inaudible 40:29]

Sikha Singh: I'm going to move on right now to the next presentation from Kate Saumweber Hogan from Minnesota. Kate, can you please dial *7 to unmute yourself?

Kate Saumweber: Yes, can you hear me?

Sikha Singh: We can hear you.

Kate Saumweber: Great. My name is Kate, and I'm here to talk about offering and providing complete newborn screening to families planning an out-of-hospital birth in Minnesota. Can you advance, please?

A little bit about me. I'm a Certified Professional Midwife and a Licensed Midwife in Minnesota and Wisconsin. I'm the owner of Twin Cities Midwifery, which founded in 2010. Which is a solo midwifery practice, serving families planning home births in Minneapolis, Minnesota.

I'm a graduate of Bastyr University's Department of Midwifery, formerly Seattle Midwifery School in Seattle, WA. I'm a board member of our state professional organization, Minnesota Council of Certified Professional Midwives. I also sit on the licensed Midwifery Advisory Council to the Minnesota Board of Medical Practice. Next slide.

I'm also a Mom. I have a one-and-a-half year old. Next slide.

I wanted to start with where our current standards are at. Currently out-of-house midwives in Minnesota offer and provide metabolic, hearing and CCHD screening as part of routine newborn care. We discuss the options prenatally. We really value informed consent, so we talk a lot about what the screens are looking for. How they're performed. Pros and cons. Answer all the family's questions at the end of pregnancy. Once that newborn time comes, they already know what they're planning to do.

We provide the screens between 24 and 48 hours of birth. In Minnesota, midwives usually provide home visits on day one and day three. Then additional visits after that. Usually we do all of the newborn screenings right after 24 hours. We time that 24 hour visit so the baby is at least 24 hours old.

In our state, it's only recommended to do one metabolic screening. I know some states do two. For us, all of those screens generally happen at the same visit.

In my practice, 100% of babies are being screened. I can't speak for all my colleagues, but I know most of them have that same 100% rate of babies being screened. The data that we could find on statistics around out-of-hospital babies screened is sort of limited. What I was able to find I'll present in future slides. Next.

I joined this community of birth workers as a student. About 10 years, in 2004. At that point, midwives were not able to offer all of the screens. There were a lot of obstacles that we've overcome, and obstacles that I'm sure other states are maybe still dealing with.

At that time, CCHD screening wasn't available. We didn't have hearing screening machines. There were the following obstacles for metabolic screening.

There was an out-of-pocket cost to the family. The family would have to order and purchase the card that was around $106. We could bill that claim to insurance, for reimbursement, but often insurance companies and specific plans would exclude licensed midwives as a covered provider type.

Or, the other piece of the insurance problem was most of the home-birth midwives are out-of-network. Even if we bill insurance, we're covered at the out-of-network rate. Even though it's a state mandated test, a lot of times it wouldn't be covered. The family would still have to pay for that cost up front. It may or may not be reimbursed. Most of the time it wasn't reimbursed.

There was also a lack of a relationship between the broader midwifery community and the Department of Health. It wasn't our Department of Health's problem at all. It was really the midwifery community just wasn't very organized. Now our organizations have really regular meetings. We have really regular ways to communicate and disseminate information. Ten years ago we just weren't at that place.

You can imagine, busy midwives. Most of us are solo midwife practices. Some of us have two midwives in a practice. We're spread out all over the state. There just wasn't a really good organization of us at that point. The Department of Health would have to be trying to connect with each practice individually, instead of connecting with us as a community.

If a family chose not to have us do the metabolic screening, most often because of financial reasons, then we would refer them to get it done at their pediatrician. Usually our families see their pediatrician for the first time around one to two weeks. That's when they establish that first visit. In Minnesota we are licensed to provide all of the newborn care for healthy newborns, through six to eight weeks.

Of course we would refer them sooner to see their pediatrician if there were other things going on. As long as baby was normal, healthy, not looking jaundiced needing treatment, usually families would establish care with their pediatrician at one to two weeks.

We would encourage them to call their clinic ahead of time and make sure that they had a card available. Even while they were still pregnant. Even with that, often they would get to their visit and they wouldn't have a card. Or they wouldn't be used to doing it, because they're used to all their families being screened in the hospital.

Then the pediatrician would refer the family to the hospital for screening. This was a family that was specifically wanting to stay away from the hospital, for whatever their personal reasons were. Sometimes they would, but oftentimes they wouldn't go to the hospital for that screening. Because it was another trip, another appointment to make. They might not be very familiar with the hospital. Where is the newborn nursery?

If the hospital was busy, they would have to wait to get the screening done. Sometimes nurses were great and would just do it right away. Other times there's a lot of confusion about how do we bill it? Usually we are doing this on our patients, and this baby isn't our patient. There were just a lot of obstacles to getting these babies screened. Next.

We've come a long way in the past 10 years. Now we're able to order the screens through a local lab. Previously, most of us were using Quest Diagnostics, which is a national lab. Now we order this through one of our local hospitals. They provide us with the cards, just like they would with any lab supplies they provide us, for free. Then we would perform the screening. Then we get it couriered back to them, right away, so that it's really quick for those results to be run.

Then the lab bills the cost directly to insurance, with no cost to the family. The lab is in-network, with all of the major plans. Usually it's covered, so that makes it so that it's possible to just take that financial piece out of the picture. We don't even have to discuss that, when the family is choosing if they want to do the test or not.

The Department of Health has offered the midwifery community the access to free cards for low-income families, or families without insurance. Again, they're sort of taking that financial piece out of the picture. That really was the most common reason that families would decline that test.

The families can get screening done at home, in bed, nursing. Without needing to make an extra appointment or leave their house. Next.

I know this is a pretty fuzzy picture. Apparently not a lot of people take pictures of babies getting newborn screened. I found out when I was trying to find pictures for this presentation. In this picture, I'm performing a newborn metabolic screening, who is just over 24-hours old. She is at home in her Mom's arms. Her Mom is in bed, and she's got her PJs on. The baby is nursing while we're performing the screen.

It's just so easy. The family doesn't have to anything else to get this screen done. It's just part of normal routine care. Next.

The next part of newborn screening would be the hearing screening. Prior to 2012, we would recommend families to ask for hearing screening at their first pediatrician visit, which was one to eight weeks after birth. In my practice it's usually one to three, but it sort of depends across the community.

Often the pediatrician would refer to the audiologist, or a hospital for screening. Because not all of the clinics have screening equipment. It was that extra piece of thing to remember. The extra appointment to make. Extra place to go.

It is cost-prohibitive for each midwife to purchase her own hearing screening equipment. They cost about $4,500-5,000 dollars. In our small, solo midwife practices, that's just not possible. We don't have budgets for equipment that gets that big.

In 2012, the Minnesota Department of Health awarded our professional organization, MCCPM, with a $45,000 grant to purchase hearing screening machines. That's really when everything changed. Next.

Our hearing screening program. I'm sorry that the formatting changed a little bit. There's a little bit of overlap there. MCCPM owns 14 Natus Echo hearing screening machines. Those are OAE screening machines. Those 14 machines are shared between 30 midwives, all across the state of Minnesota.

The Minnesota Department of Health provides on-going training and support. They provide annual training for any new midwives entering our community. New students, new staff. Support staff, like nurses, who would be offering this training to families. Then it's also just a refresher for anyone who would like a recap.

They provide support all year long. They're amazing at answering any questions that we come up with. If we're having any problems, they're always so quick to help us. Incredibly supportive. We absolutely love working with the Minnesota Department of Health with this project. We sort of wish that we just had to deal with them for all the things that we deal with. They're really so lovely to work with.

Midwives pay $10 for each baby screened. That's not per screen, but per baby. If the baby needs a re-screen, there's no additional fee. That is to help offset the cost of upkeep and disposables. Every year the machines need to be re-calibrated, which costs $100/machine. Then the ear tips that we use at every screening cost $1 each.

MCCPM is completely non-profit. Our coordinator, we're all volunteers. Our hearing screening coordinator is volunteer. I was doing it for the first two years. Now there's another midwife and I, we share that task of collecting fees and answering everyone's screening questions.

We absolutely will wave that fee when needed. It's up to the midwife if she's going to charge that $10 fee to the family, or if it's going to be part of her global fee. We really encourage midwives to include that fee in her global care fees, so that there isn't a discussion of finances when families are choosing to do this screen or not. It is up to the midwife for how she's going to pay for that $10. If it's going to come out of her practice, or if she's going to ask the family for that fee.

However, if there's a family that doesn't want to do the screen because of cost, we just encourage her to wave the fee and then do the screen. We really want as many babies screened as possible.

I think there was something else, and it escapes me. I think we can go to the next slide.

This has been an incredibly successful program. In the spring of 2012, this is before we had access to hearing screening machines in our practices, 38% of all out-of-hospital babies got their hearing screened. That would have been with their pediatrician, or their audiologist.

In 2013, if we look at all the babies born out of the hospital, that would be that blue line. 75% of them were being screened. The tan line is babies

born to practices that are part of this program. All of the midwives who are members of our state professional organization, and who have either access to a machine because they're housing it? Or because they are sharing it with another practice. 93% of those babies are getting screened.

We love to see what a huge was made in really just a year. I'm looking forward to seeing what our 2014 statistics are, as we've continued to work some bugs out of the program. Our goal is to get 100% of those babies screened. We are continually working to reach out to non-participating midwives. There are some midwives that just, for whatever reason, aren't a part of our organization. Or are, but aren't interested in offering the screening.

MCCPM midwives do offer the screening to babies born at any other practices. In my practice, if a family is born with another midwife. That midwife doesn't offer the screening? She can refer her families to come to me for that screening. I don't charge anything for families that come for an office visit, so that they don't have to worry about paying for it.

Then we also, a number of us offer home visits for families who don't want to leave the house or make an extra appointment to go somewhere new for their screening. Generally then there would be a small travel fee. It is possible for those babies to get screened for free if they'd be willing to come in for an office visit. Next.

The average time of re-screen has also decreased. Prior to us getting the machines, it was an average of 57 days if a baby needed to be rescreened. Now it's 13 days, which is great. The protocol that our organization has, is that we screen at either the one or three day visits. Then again around two weeks if baby needs to be rescreened. That average really falls in line with our protocol. Next.

CCHD screening. I became aware of CCHD screening the fall of 2012. That's a picture of me and my husband, in 2012. I was pregnant and due in December. I wanted to make sure that my midwife, or my pediatrician, would be able to offer this screen to my baby right away. When I heard about it, I thought, "Well, this just makes so much sense. We should absolutely be providing the screens." As a Mom, I want it for my child, so I also want to make sure that I'm offering it for other families in my practice.

In January of 2013, I was the first out-of-hospital midwife to offer routine CCHD screening, and I'm really proud of that fact. I really encouraged the rest of the community to follow with me, and they have. Next.

We were able to easily share resources within our midwifery community. Now almost all midwives offer CCHD screening. We were able to email out the CDC protocol. The different equipment options. If there were discounts, because we were buying in bulk. We didn't have any formal training on CCHD screening. I think that the midwives felt that the protocol was easy to follow. We've sort of answered questions within the community as they've come up.

Some midwives were really slow to add it. They were hesitant. Have to buy a new piece of equipment, and add one more thing to their routine care. Consumer demand changed their mind.

I was always sure to let families know this was a new screening that I was offered. When families were interviewing me to decide if they wanted me to be their midwife, I'd let them know this is something they should be asking their midwives for. Then when they would interview another midwife to consider and make their decision, they'd be asking about that.

Then I would hear from other midwives, "Do you know that these consults are asking if we're offering CCHD screening? I guess that I should offer it." I was like, "That's so great. I'm glad that the community, our consumer base is asking for this. It's really such a simple screen."

It's relatively affordable for a small practice to purchase the equipment. Around $600-900 are the ones that we were looking at and that most of us have chosen to use. Still a good amount of money, but more affordable compared to a $5,000 hearing screening machine.

It's a really simple and easy screen. You can do it while Mom's nursing, while you're chatting about other things you have to talk about at a postpartum visit. The pulse ox can also be used for neonatal resuscitation.

In the last two years, the guidelines changed for neonatal resuscitation that says we should be carrying pulse oximeters. That if baby needs oxygen, we know how much oxygen to give baby. It's really a piece of equipment that midwives should be carrying anyway. Next.

The future? At this point, Minnesota Department of Health is not tracking the results of CCHD screenings yet. I'm sure that's coming very soon. I'm really curious to see what percentage of babies are getting screened. At what point they're getting screened. There's really no reason not to screen that I've been able to find. Through the changes in the NRP guidelines, really midwives should be carrying a pulse oximeter anyway. It's not like they're going to need to buy a new piece of equipment.

That's me there screening a just over 24-hour baby at home. He's snuggled in on his Mom, in bed. Next.

That's the end. I know we're running out of time. I know that we are hopefully able to accept a few questions now. If you have questions that you think of later, you can feel free to contact me at twincitiesmidwifery.com.

Sikha Singh: Kate, thank you so much. That was a very insightful presentation about home birth screening in Minnesota. We did have some poll questions that we wanted to ask, but in light of the time and in favor of opening up the webinar for questions, we'll forego those pools for now. We will be sending some information about the format and frequency of these webinars, so keep an eye out for that.

With that, if anyone has any questions, please dial *7 to unmute. While you're doing that, we have one question for Kate about what is the name of the pulse ox machines that you are using.

Kate Saumweber: Let's see, it was on that slide. I think it's Nellcor? Oh sorry, it's Natus Echo Screen, hearing screening machine.

Sikha Singh: Okay, and we'll navigate to that slide.

Kate Saumweber: Yeah, it's slide 9, and it's just between $4,000-$5,000. We were able to get a discount, so they were about $4,000 a piece, because we were ordering so many at once.

Sikha Singh: Number 9. Okay. Are there any other questions? If so, please dial *7 to unmute. Okay, hearing none, this webinar has been recorded. It will be placed on the NewSTEPs website in the coming weeks. Also, the two publications that we referenced at the beginning of the webinar are now available on newsteps.org. Please take a look at those. If you have any questions, please feel free to contact anyone on the NewSTEPs team. Thank you.

Kate Saumweber: Thank you.