NewSTEPs
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Short Term Follow-Up Technical Assistance Webinar

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Presentations: Sondi Aponte and Fran Altmaier, Arizona State Profile

Amanda Kimura, MPH, Reducing Time from Referral to Treatment: Strengthening the Weak Links in the Newborn Screening Chain of Events

Jean Becker, MPH, Illinois Newborn Screening Quality Improvement Initiatives

Willie Andrews, BSMT and Jennifer MacDonald, MPH, Virginia's Newborn Screening Transit Time Project

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

Thalia Wood: Once again everyone, this is Thalia with APHL and it is 3:30 so I think we'll go ahead and get started. Like I said we have a lot of presenters, we want to get through everything today. John, why don't you take it away with introductions?

J. Thompson: Great. Welcome everyone. We're glad that you could join us today and if you have friends or colleagues who couldn't join today but would be interested in the content, this will be archived later and those are available. Thalia sends out the link to those periodically.

Today's agenda we're looking forward to, we're going to hear all about quality improvement and different examples of quality improvement initiatives and short-term follow-ups from four different states. First, we'll have our state profile and at the end of the webinar, Thalia sends out a little survey that asks if the information was helpful and do you have ideas for the future. We pay attention to those and some of the comments that we received make us wonder if our intent for the state profile was then communicated well.

Basically, what we wanted to do is that at the beginning of each of these webinars is to highlight one of the states. We all have basically the same mission but we all have really different ideas about how to do it and so this is a chance

for us to learn from our colleagues how they administer and some of the maybe unique circumstances that they face or maybe highlighting some of the projects they've been recently involved with.

That's the intent and I certainly enjoyed listening to the profiles in the past couple of years that we've been doing these webinars. Sondi Aponte and Fran Altmaier from Arizona State will be giving our state profile and following them we'll hear from Amanda Kimura who's in the follow-up group in Washington State. Then Jean Becker will speak, she's from Illinois. Then finally, we'll have Willie Andrews and Jennifer MacDonald from Virginia speaking about some of their efforts.

Thank you so much to the speakers for their time and effort in getting ready for this and we'll turn the time over to Sondi and Fran.

Sondi Aponte: Hi everyone, this is Sondi Aponte and Fran Altmaier. Should we just jump in then, John?

J. Thompson: Yes.

Sondi Aponte: Okay. My name is Sondi Aponte and I'm the quality improvement medication manager with the Office of Newborn Screening. A little about my background and training, I'm a teacher and so I came into public health about eight and a half or nine years ago and got hooked like most of you. My background is in technology and education and now I'm hooked in newborn screening policy, quality improvement, project planning and improvement.

F. Altmaier: I'm Fran Altmaier and I'm the case management coordinator in our follow-up program. I'm a social worker and I've been doing pediatric social work for over 20 years. I've been with the Office of Newborn Screening for three years and specifically as the case management coordinator for almost a year now. We're looking forward to giving you some information on Arizona where it's still over 100 degrees and not fall at all. We'll show you a little about our landscape, next slide.

Sondi Aponte: All right, so this is Sondi again. As you can see, I think that one of the important take home messages from this slide and it's one that we've shared with APHL in one of the coin projects that we were doing for transit time is you can see in the pink, that's Phoenix and Tucson. Those are the urban areas but really, I think, what's more important to see are the front tier, the rural and the Indian landscape.

Big population of 0.5 million, it makes us the sixth largest state as you can see. About 88,000 births, we went flat, we were at about 102,000 births maybe six or seven years ago before the economy tanked and we went down and now we're creeping back up there but 88 to 90,000 births is about what we've been expecting over the last few years.

On the recommended uniform screening panel, as of July 1st with the addition of CCHD we're now at 30 disorders and you can see some of our numbers, 120 confirmed blood spot cases and 122 for hearing loss. The biggest one I just want you to take from there is to really look at how dispersed our community is in Arizona. Next slide.

F. Altmaier: This is some of our statistics for 2014 and we had 88,537 births last year and of those babies, we had 85,000 babies who had at least one valid screen. The next slide shows that we had 80 refused screening and that's just how many were documented. We're pretty certain that there's a lot more refusals and that's an area where we're looking at ways to better document parent refusals.

Unknown status, 3.7% of our babies, we have no documented screens for. The 3,200 babies we suspect are about two-thirds are from the Indian health services and they send their blood samples out of state for testing. Then the other third we suspect are a lot of our out-of-hospital birth population that may be choosing not to do a screen or going for a private lab screen that includes more disorders.

Lost to follow-up, we had eight babies with an abnormal initial newborn screen with no final diagnosis. For no documented second screens we had almost 8,000 babies out of our 88,000 that we have no documented second screen for those.

Let's see. Confirmed cases, from the rest we had 120 blood spot cases that were identified and then we had an additional 18 that were secondary conditions that we were able to identify from our current screening panel.

Sondi Aponte: This is Sondi, one of the comments on that 9.8% for the no documented second screen. There's a lot of reasons why but we've been doing some conferences with midwives lately and we still hear a lot of families saying, at least anecdotally to midwives, that they're choosing to have one screen and which is the best well-timed screen to have. We know there's some issues there but lots of contributing factors for not getting that documented second screen.

One of the ones which probably a lot of people on the phone share is the border, the surrounding counties along the Colorado River, for example, they might deliver in at Kingman or Bullhead City but then they're getting their services across the border in Needles, California for example. We know that that's a considerable contributing factor to that no documented second screen. Next slide.

Confirmed cases by disorder, you can see them here. These are all of them from the primary core panel, probably not a lot of surprises. Our numbers have gone up steadily for congenital hypothyroidism but I know I've read this study so it looks like nationally. Everybody's seeing a really high incidence of congenital hypothyroidism. Cystic fibrosis was the newest disorder added to the panel in October '07 in Arizona. That's it. You can see CAH numbers are fairly high. We

seem to be trending high in that and I'm not sure if others are as well but really interesting that we have seven salt-wasting last year that seems really high to me.

That was 2014 number. Next slide.

F. Altmaier: This one shows the secondary conditions and traits that we've found. We have two point-of-care tests, hearing. We had 122 confirmed cases of hearing loss in 2014. Then CCHD, it's too soon to know. That was the last one added to our panel just this last July and we're just ramping up on beginning to collect the data on the outcomes of that screening while they're still in the hospital.

Sondi Aponte: Just looking at the chart, what you can see is everybody finds a lot of hemoglobin traits. We're not exceptional in that way. We find over 150 here of the hemoglobin trait. What's of note I think here on the chart are the 18 secondary conditions. Those are made up of the CFTR, some of that non-classical CF, [inaudible 00:09:31], some of the Biotinidase and GALT variants. Clinical significance but not on the RUSP panel but we are, we do still document and track those. Then the 120, we talked about a little bit of the primary condition. Next slide.

Exciting new developments, we've been working for a really long time getting CCHD implemented. Finally, got the law and rule which passed, became effective July 1st which basically states that CCHD must be ordered, information and education must be provided to families. The screen needs to be performed before 24 and 48 hours and most importantly, it needs to be recorded, documented and sent to the state.

The two tools that you're looking at are the blood spot collection kit which is familiar to everyone. We had values for CCHD added and after about 18 months we decided through a workgroup committee to include only past fail, did not screen and why to the collection kit. Then for those babies who fail the final screen whether they're using the Kemper algorithm or another policy or protocol within their hospital to document more fully any baby who fails CCHD and you can see a copy of that form on the slide.

SCID, it's also set in House Bill 2491 which allowed us to have CCHD that SCID could be implemented January 2016 but the condition is with funding. To that end, Arizona was awarded one of the grants with APHL this year and next to work toward implementation of SCID.

F. Altmaier: Next slide. That's … let's see. Next slide. Yup.

Thalia Wood: Yeah, thank you so much. It was a great overview, what's going on in Arizona.

Sondi Aponte: Yeah, and then the final slide is just the AZ contact information if you have other questions.

Thalia Wood: Great. Thank you so much to both of you. Okay, not wanting to waste any time since we have a full agenda. Amanda, just do star seven so you can start and just let me know when you want to advance the slide.

A. Kimura: Sounds good, thank you.

Hi everyone. My name is Amanda Kimura. I've been working in the short-term disorder follow-up group at the Washington State Newborn Screening program for a little over two years now. I am going to discuss today how we've strengthened weak links in our programmed newborn screening follow-up using time from referral to treatment for cystic fibrosis as a case study. Next slide please.

Washington State uses an IRT/IRT algorithm that we have modified over the years due to consistent surveillance of abnormal results and discussions with our program consultant. Our lab can test in house for the most common CF-causing mutation, deltaF508, to expedite diagnosis.

At the time of this analysis we were looking for deltaF508 if the baby was unable to undergo a sweat test due to low birth weight or unstable clinical status. In addition, if the family or the primary care provider was noncompliant and the IRT was above a certain threshold we will also then test deltaF508. Next slide.

Now I'm going to take you through the follow-up action done for sweat test referral. At the Department of Health we recommend sweat testing to the PCP, the primary care provider, via phone and fax a memo that include results and recommendation, a requisition form, contact information for the CF sweat labs and educational material on CF. The PCP then notifies the family and orders the sweat test and either the PCP or the family schedules the test.

Once the newborn undergoes that sweat test the sweat labs reports the result to us and the PCP. If the sweat results are positive then the lab also contacts the CF clinic who schedules the family for a clinic visit. We aim to have the sweet test done within one to two days after our referral and the clinic visit to be scheduled one day after the sweat test results are out. Next slide.

We, at our program, we maintain a couple of Excel spreadsheets that helps us monitor day-to-day follow-up and provides a valuable source of data for analysis. One tracks all newborns with at least one abnormal result. We record demographic info, NICU status, IRT value and [agent 00:14:38] collection. If we refer an infant for sweat test we also monitor the sweat lab, date of referral and other pertinent information.

We keep a second spreadsheet for all diagnosed CF cases where in addition to all the previously mentioned information we also record sweat chloride value, the date of diagnosis, the date of first clinic visit and other relevant clinical

information. We are able to obtain this data fairly easily because of the close relationship we have our state's CF centers. Next slide.

These tracking spreadsheets have really helped us in periodic reviews of our CF newborn screening algorithm. In January of 2014, we had reviewed data on 19 and been diagnosed with CF between 2012 and 2013. On average, sweat tests were performed five days after we had recommended sweat testing and first clinic visit scheduled four days after the sweat test if you see in the red and that is far from our goal stated in the earlier slide. Our clinical consultants and newborn screening staff agreed that these numbers had to be studied further. Next slide please.

Using, again, our tracking spreadsheet we conducted a retrospective secondary data analysis. Our study sample included all non-NICU infants requiring sweat testing between January 2011 and December 2013 and that totaled to 86 infants. We stratified the data by the three CF centers in Washington State. Next slide.

Some of the results of our findings can be seen on this graph. We had grouped the interval times between referral and first sweat test into three categories. One to two days considered optimal in the green, three to seven days not as fast as we would like and that's in yellow, and anything after one week would be too long and that's in red.

As you can see in this graph here that the majority of the referrals to center 1 and center 3 and the orange and purple took longer than one to two days. Next slide.

In addition to that, time between first sweat test for … in between decided time from referral and first sweat test we also looked at other key data dates such as positive sweat test to first clinic visit and just the overall days from when we first recommended sweat test to a resolution letter that was a negative or positive sweat test.

The two takeaways from this table is that one, it overall for … across all CF centers, on average, that those numbers did not meet our goals of one to two days or one day respectively. Another takeaway is that the numbers varied widely amongst CF centers so you have one clinic that can get sweat test done within two days and another center taking 12 days. Next slide.

We also looked at quantity, not sufficient results and so these results just showed that … gave the number of infants that were sweat tested, which out of all the infants sweat tested, 10% had QNS results and that all true positive cases with QNS results had at least one copy of deltaF508 listed. Next slide.

We presented our findings to our program consultants who include the Washington State CF center director. He then forwards the summary of our

findings to the other CF centers in Washington. Since then the CF centers had implemented changes and were collaborating with each other to improve follow-up for these infants. This was around August of 2014.

Just a couple of examples, CF Center 1 had kind of uncovered an influx of new nurses and laboratory staff who were under educated about sweat testing so retraining was happening. Sweat labs in 1 and 3 were in contact to discuss collection methods to help improve CF center 3 QNS rates. Next slide.

At the DOH we also had recognized ways that we can improve our processes. We've decided to tighten up follow-up procedures for referrals which is calling to confirm that the provider's clinic receive the referral paperwork within an hour of faxing it. Since all babies who ended up … with QNS results who ended up diagnosed with CF had at least one copy of deltaF508. We now test for that mutation immediately after QNS result is reported to us.

We also noted a lack of education on sweat tests among primary care providers so we have planned to include information about this concern in our referral memos to emphasize that sweat tests can be performed early on newborn. Next slide.

What has happened since then? Have there been any changes in reducing time from referrals treatment? To answer these questions, I pulled data using similar criteria to the initial analysis and the data point started in August of 2014 after the CF center director reported our results to June of 2015. The sample size was 29 infants. Next slide.

These next following graphs you'll see show each CF center's performance comparing the baseline graph seen earlier with the new data from this past year. The two main takeaways is that, from the graph, is that the trends continue to fluctuate by CF clinics with some clinics taking a little bit more time to get these babies in first sweat testing. Next slide. Also, that the sample size is small. For this one here you'll see that this CF center 2 took more time than in the past to get these babies in for sweat testing but their sample size is also at 7 in the light blue. Next slide please.

Also for CF center 3, the sample size is also, again, small at 7 infants but we also had seen a marked improvement shift over in getting these infants into sweat testing in a more timely manner. These trends were also similar for the other data points from days from referral to resolution. Next slide.

This also just shows just some of that data I've mentioned before and the red is the baseline numbers and then the black are some, is data afterwards, from 2014 to 2015. There's just some, again, some improvements and some delays in sweat testing is the trend but again, small sample size is something that should be noted. Next slide.

We performed some case reviews where it took longer than eight days to have a test performed. Themes that appeared included geographic challenges where we have some families from the central part of the state having to drive two to three hours to have a sweat test done. Again, PCP education was another challenge where providers felt that they had to wait until babies were of a certain age to have sweat test performed.

There are difficulties in contacting families and our department could have had more tighter follow-up performed for QNS results such as having our program clinical consultants involved earlier and so we've been in contact with our program consultants about these challenges and are working together to implement further changes. Next slide.

What happens after evaluation? We'll continue to monitor and evaluate our performance. We provided the data I just showed you with the CF clinics and we'll plan to repeat our analysis next year so we'll have a bigger sample size to analyze from. We received a really good news from our program consultants that they were awarded a grant by the CF Foundation to implement remote sweat testing at a hospital in the central part of our state so hopefully this will help reduce the time for sweat testing for infants in that region. Next slide.

Final thoughts, we've observed that clinical consultants were crucial in facilitating changes at each of the CF centers. In addition, this project would have been very time consuming if we had not had the consistent surveillance of abnormal results. These two factors help us provide a solid foundation for continuous evaluations and improvements on follow-up procedures. Also, this has worked well to help us improve follow-up for cystic fibrosis and the infrastructure for quality improvement can be used for any newborn screening condition. Next slide.

Thank you to current and former colleagues of the Newborn Screening Program for their support, particularly to John Thompson, Sheila Weiss and Mike Glass. Thank you to our CF centers for their continuous collaboration and support, particularly Dr. Gibson, Dr. Rosenfeld, [Corrine 00:25:02] and Kendra. Thank you to APHL for the opportunity to present today and I'll hold questions till the end but here's my contact information. Thank you.

Thalia Wood: Thanks Amanda. That was a great overview of what you did and just to let folks know the next two presentations are a result of a question that went out to the listserv on quality improvement in programs and I've reached out to Illinois and Virginia to give these talks, so Jean, are you on, do you have star seven?

Jean Becker: I do, can you hear me?

Thalia Wood: I can so you can go ahead and start, thank you.

Jean Becker: Okay. My name is Jean Becker. I work in the follow-up program in Illinois, I'm one of the nursing supervisors and I've worked in the program for a little over two years as well.

The first slide talks a little bit about the data in Illinois so I'll just briefly give you an idea of where the birthrate has been in Illinois. The birthrate has been declining. In 1990, there were 196,000 babies who were born in Illinois. That proved to be the high mark for Illinois in the past 24 years.

For seven years, the state's live birth numbers fell consistently until 1997 when it hit 180,000. The numbers huddled around that mark for 11 years and then when the 2008 recession hit, not only did people leave Illinois seeking jobs, they took their babies and future babies with them. Illinois live birth quickly fell from 180,000 in 2007 to as you can see we've hit a new low of 155,000 in 2014.

I did look it up and Illinois is now ranked 37th in the country as of 2013 in the number of birth. I know Arizona said where they were ranked in size in the country. I did just check and we're fifth in the country by population according to the 2010 census so it'd be interesting to see where we continue place out. You can see that the lab has tested 177,000 newborn specimens and reported about 19,000 abnormal newborn screens. Those included 4,700 high level abnormals. That would be your Biotinidase, your endocrine, your cystic fibrosis, galactosemia, hemoglobinopathies, amino, organic fatty. We do, do SCID in the state and as of June, we've been doing five lysosomal storage disorders.

That also includes about 8,700 borderline abnormals, 2100 NICU abnormals with amino acid, and acylcarnitine elevations, 3900 [MSEPs 00:27:46] which can include contaminated specimens, specimens collected too soon or received in the lab over 14 days. With the implementation of LSDs in June we diagnosed about 400 cases a year. The next slide.

These are the QI initiatives I'll be discussing, quarterly reports to all hospitals who submit newborn screening specimens to the Illinois Department of Public Health Laboratory, our courier service changes and submit a report. The next slide.

We provide this quarterly report to birth hospitals regarding timeliness of newborn screening specimen submission. In the past year about 75% of the birth hospitals have requested this report we provided monthly. We post it on our website so anyone can see it. They take it very seriously. This is what the report looks like. You can see it lists our statewide numbers on the top half and individual birth hospital numbers on the bottom half. Those are by hospital. Then the next slide.

This is a state quarterly report so the top half is the overall state report which we select statewide how many specimens were received and within how many

days of collection, the percent of valid and satisfactory specimens and the number of submitting hospitals. Next slide.

The individual hospital timeliness data. The bottom portion of the report reflects each individual hospital's performance and tells them the total number of specimens we received from their birth hospital. In less than three days from collection, four to five days, greater than five days to 14 days, and greater than 14 days. The data excludes weekends. Since we were not open on weekends we didn't feel it was fair to penalize them for it.

We have been providing these reports for about six to seven years and the hospitals really appreciate the feedback. They work with their perinatal network administrators who work within their member hospitals to improve their numbers. We did look at the specimen timeliness to include weekends to see if we could meet the advisory committee's revise recommendations for timeliness. Specifically, they went around whether or not the specimen was received in the laboratory within 24 hours of collection but no later than 72 hours after collection.

In our 2014 numbers, approximately 26% of our specimens were received within 24 hours and 96 reached the lab within 96 hours. We know we have room for improvement and we think by continuing to provide this report to the hospitals in the perinatal administrators that will be able to improve those numbers. We do know that by batching specimens by the submitter, only having a five-day work operation, delayed loss or damaged specimens can all contribute to the timeliness problem.

The next slide and this was the last four columns on the report that the hospital see. It gives the number of clerical and lab [inaudible 00:31:10] and missing information on the blood card. The next slide.

This is our second initiative that we've changed over the past year, our courier shipping change. Illinois provides UPS overnight courier service with Saturday pickup to all of our birthing hospitals. There's about 125 in Illinois. Due to three instances last year where specimens collected and shipped from the birthing hospitals were lost or destroyed in transit, we had the hospitals switch from using envelopes which seemed to be more easily lost or caught in the conveyor belt system at the UPS sorting facilities to using boxes which we hope would result in fewer loss or damaged shipment. Since the change in April, the lab hasn't received any damage or lost specimens. The next slide.

Here is an idea of the volume assessments in male that has received in our lab. It became quite comical as the lab would send us pictures every day of their mail. I have a few I'll share with you. On day one they only received six boxes and you can see it steadily went up within two weeks. They were receiving 51 boxes a day. At the very bottom of the slide you can see the most specimens the lab received since they started accepting the new box system was 1209

specimens. The least amount of boxes was 35. The most boxes in any day was 117 and the most damaged boxes was 14. The next slide.

That was the first day and you can see how damaged some of the boxes were coming in. They talked about one of the staff actually hurt her wrist trying to even open the boxes because they weren't used to have field. They were … Okay, you can go to the next one. I think this was day two so the boxes were just coming in, in volumes so I think they've got it figured out now. Okay, you can go to the next one.

Finally the lab is working with PerkinElmer to make changes to their limb system to be able to develop an automated daily submitter report which would notify hospitals of specimens received by the laboratory. The hospitals will receive this daily notification to compare our list against their send out logs to ensure that specimens have been properly received. Since the lab is unaware of specimens when they are shipped, it's critical that the hospitals are tracking and monitoring these shipments.

These reports will be electronically faxed to hospitals and if no specimens were received, the report will reflect that as well. Then I think the last one is my contact information if you have any questions. Thank you.

Thalia Wood: Thanks so much, Jean. That was very informative. Yeah. We'll hold questions to the end and we'll ride in to Virginia and are Willie and/or Jen on the phone?

W. Andrews: I think we're both here and I'm going to …

MacDonald: I'm here.

W. Andrews: … start it off.

Thalia Wood: Okay. You go ahead and just let me know when you want to advance slides.

W. Andrews: Okay, great. Hi, I'm Willie Andrews and I'm the director of laboratory operations at the division of consolidated lab. I have actually been with consolidated labs for 28 or so years, first 13 of which I managed the newborn screening laboratory. Now as the director of lab operations, newborn screening is in a branch of the organization that I support.

Our current group manager is sitting beside me, Kim Turner. She's here to keep me on if I get off track. I will share that our organizational structure in Virginia is a little bit unique in that the laboratory is not within the Department of Health. We are actually under a different agency which is the Department of General Services but we work really hard to maintain a strong partnership with the Department of Health and our teammates at the Department of Health who are responsible for all the follow-up and education and a variety of other things.

In that spirit of partnership, Jen MacDonald who is the nurse manager of newborn screening and I are going to tag team this presentation. I'm going to take the first part and then I'll turn it over to Jen. Next slide.

Just like everybody on this call, our awareness was heightened after the Milwaukee Sentinel Journal article and we began to look at how we could assess our transit time and look at potential quality improvements around that. At the time that all of that happened we did not have a report, we could not pull the data out of our limbs. We did work on developing a report and our first annual assessment for the year of 2013 for our average hospital transit time we were sitting at a 2.78 day average. Next slide.

Where that's not parable I think as we looked at the data we found that we definitely have room for improvement in areas of concern. In Virginia we have 57 hospitals that are submitting samples to us and in that first report, 37 of those hospitals were sending their samples in a fashion that was less than three days but that left 20 hospitals that were sending them greater than three days or having a transit time greater than three days.

Of that 20, three of them were greater than four days and one of them was greater than five days so we began to look at why is that happening. We've had a courier system in Virginia since the '90s so we had thought that that was taken care of timely and adequate transport of our samples but it became obvious that we had some gaps. One of the things that we started looking at was we actually, when we brought up the courier back in the '90s, we looked, I guess, at how to make the best bang for our buck so to speak, and hospitals that had infrequent bursts we did not send a courier to them.

The first thing we saw was that okay, some of our 20 hospitals that had a longer transit time were those that did not have the benefit of a courier. The first thing we did was implement courier or by February we were able to implement those additional routes to those hospitals that had not had benefit of courier before. Then … but we looked at some of those hospitals that had courier and we still were having problems and we realized that to make a strong impact and to really benefit timely receipt of the samples we were going to have to pick up another day because our courier was running Monday through Friday. Now, as of March of 2014, we added a Sunday pickup as well. That helped us. Based on the data, we could also tell that that wasn't going to enough and there was more to do. Next slide.

I think one of the things we realized is that we needed to enhance and expand how we were communicating with our hospital partners and to establish additional lines of communication. One of the things that we did very first off was say, okay, if we're going to want to provide information and start implementing quarterly reports and things like that we need to make sure that we are sending them to the right people. We sent out an informational form and said this is the current contact we have on file for your facility. We also took

that opportunity to ask questions about, do you know how the courier works, and do you know where your courier pickup is and some other questions where we thought we might have gaps in some of our processes.

Once we gathered all of that data and we made sure we've gotten feedback from all of our hospitals, we did implement a quarterly report card process to give feedback and heightened awareness around what was going on at each individual hospital. Next slide.

Our report card, very similar to others even that we've heard about today, talks about the average transit time for the past quarter for that facility. Of course, it's going to say how many samples did you submit in that quarter but it will also say how many of them were less than 24 hours, how of many of them were collected after transfusion, how many of them did we deem unsatisfactory and then we break down why we rejected them. Next slide.

In addition, we wanted to make sure that we had opportunity to talk about information or announcements or just general issues that needed to be communicated across all hospitals. We have the opportunity on our report card to give that general information an update. We also have an opportunity if there's a particular problem with a particular hospital, we can talk about that in the comment field for that facility individually. Next slide.

This just shows a copy of our current report card and as I say it gives some data. Up at the top is the average transit time and then at the bottom gives us an opportunity to talk about things that are new, things that have been occurring over the last four that might be problems, anything like that. You can see there's plenty of real estate at the bottom of that form if we had something to specifically talk to Lonesome Pine Hospital about, we could talk about that in this report as well. Next slide.

This is another type of information that we could send out and do send out with our report cards. Now I will highlight a couple of things about this particular graph. Currently, we are sending this information, I guess I'm going to say anonymously or we're not identifying the hospitals right now. Obviously, when this comes to your hospital you can see what your transit time was and how that compares with the other 56 hospitals across the state but we don't call out anyone on this report and I think that's something that we've seen in the spirit of transparency we're going to probably change in the future.

Another thing that I wanted to point out is that right now our goal is at two days. We know that there is interest in us getting to 24 hours but I think we recognize in our program that that's going to take some major programmatic changes. I think we feel confident that we can get to two days just by educating and boots on the ground and trying to communicate and educate. Right now, I would say that's our preliminary goal.

Let me take this opportunity. This is actually quarter 2 of 2015. As I've told you when we started we were looking at an average transit time of 2.78 days. As of the second quarter of 2015 our state average is now at 2.33 days so we did make some impact with the things that we have implemented so far which we're pleased about. I mentioned earlier that in the beginning we had 37 hospitals, that their transit time was less than three days. Now we have 54 hospitals whose transit time is less than three days and our highest transit time right now is 3.3 days.

We're pleased that we've been able to … again, that our efforts have improved and we continue to work to improve them more. Next slide.

This is kind of a busy slide but it shows, I mean it's intended to show what happened throughout the year of 2014 as we made changes and sent information and tried to educate our hospital personnel. I guess if we use the very last hospital that's number 57 where we have the most dramatic impact you can see by the blue line within quarter 1 they had an average transit time about six days. By quarter 4, which is represented by the red bar, they actually had a 1.8 day transit time. Obviously, adding the courier and adding an extra day made a huge … and just the awareness of what our goal and expectations were made an impact. We did see some folks back side you'd like to see, the red always the lowest and the first improvement across the board but I think in general, for one year's efforts, we were pleased about that. All right, next slide.

While we were working with the hospitals about their transit time we wanted to make sure they understood some of the tools that we had available for them and that included how they should handle their samples using the barcoding system and the tracking website and the way … We don't use our UPS but we use a private courier but they have similar capabilities and we found that a lot of our hospitals weren't taking advantage of them so we sent out packets to try to educate from that perspective as well. Also, we have a transmittal form that does allow the hospital to fill out what samples are in what envelope and then we'll send a copy of that back and we modified that form after feedback from some hospitals to try to improve our tracking capabilities, and all that under the guise of trying to make sure if there are bottlenecks or weaknesses in the process, we need to be able to track the samples to find out where those weaknesses are. Next slide.

That's just a copy of our transmittal form and yeah, so no need to belabor that. It's just the form that we had. While we were talking about all of this, we were not only talking to the hospitals but also to our courier leadership. Both from observation as well as feedback from the hospitals, we had some concerns that maybe they didn't understand the importance of what was happening with the handling of newborn screening. We have gotten some feedback that I don't think my courier comes every day or they don't come at the same time every day or whatever the case may be. We took it upon ourselves to bring in our

courier leadership and educate them as to importance of the newborn screening program.

Then I guess similar to the box method, we had concerns about envelopes getting lost by the courier and so we provided these large pouches, bright yellow pouches that are air permeable but just up, when they go into the hospitals they are to put their samples that they're picking up into those pouches and then those pouches get put into a large unit and delivered to us. Next slide.

I think we recognize that we had things that we could fix quickly but I think we also recognize that we were really going to have to continue to discuss and to educate our hospital personnel. I think we recognize that face-to-face time was going to be needed in a lot of case. To talk more about how we develop that, I'm going to turn you over to Jen MacDonald and she's going to talk to you about our site visits.

MacDonald: Thanks Willie. I hope everybody can hear me. It's a pleasure to be presenting with the lead today to all of you on our QI project here. My name is Jen.

Thalia Wood: Jen, just one quick thing. This is Thalia, we have about 10 minutes left or 12 minutes and we wanted to have a few time for questions so if you can get to the slides rather quickly.

MacDonald: Sure, I can breeze through them, no problem.

Thalia Wood: All right, thank you.

MacDonald: My name is Jen McDonald and I am the public health nurse manager here at Virginia Department of Health and I oversee all the newborn screening programs including dry blood spot, CCHD and our birth feedback surveillance program. Here at VDH to go on about this site visits we were in year three of a HRSA CCHD grant and so one of our grant requirements was to visit 20 birth hospitals to improve their compliance with reporting and assist and fine tuning of their CCHD screening processes. We decided to get more bang for our buck and just said, why not include dry blood spot info in the mix so that each program conducting their own site visits to the same places. We thought combining them would make much more sense.

We organized an internal workgroup and it was a combination of DCLS and VDH staff. We had a CCHD rep, all of our short-term follow-up nurses shared in this responsibility and went out on site visits and out some input, and gave input I'm sorry and DCLS rep was also included. Next slide.

We split that 20 hospitals site visits and we based this on a combination of the highest transit times that DCLS found and the lowest rates of data entry into our

electronic birth certificate record for CCHD results and the dry blood spot ID numbers.

We had all regions of Virginia represented, north, south, east and west and got four to five hospitals in each of those regions. We developed a site visit questionnaire which covered some compliance expectations for both of these programs and we sent that survey to the site ahead of visit via email. Next slide. This is just the first page of this screening site interview and if they could send it to us via email or fax it to us before we left we were able to review this and hone in on any specifics we wanted to discuss while at the site visit. Next slide.

We asked for as many participants as we could in these site visits on the hospital. Of course, the unit manager from the nursery and NICU, unit educators and the nurses, lab representation because we realized in some hospitals lab technicians collected newborn screens not just the nurses, risk management, QA presentation and the registrars who actually inputted data into our electronic birth certificate. Next slide.

We divided our site visits, it seemed like, into three parts. First was the data review and we reviewed survey answers from that questionnaire. Then we did provide them with the latest quarterly report from DCLS that Willie described and we also provided them data on their percentage of babies, next slide please, percentage of babies with documented CCHD screen results and dry blood spot ID results. We've also pointed out their rank among the other hospitals without naming names of course but these are what the two data reviews look like. Next slide.

Part two was usually a group discussion. We provided information to all participants in the meeting and this includes sort of like a quick references for their units. We included the code and regs for each of the programs, quick reference guides, training materials and contact information. Regarding dry blood spot, we actually talked to the staff a lot about the CLSI collection guidelines, how to collect and how to dry and what constitutes unsatisfactory samples.

We're trying to change the culture here in Virginia of just not calling it the PKU test. We want them to refer to it as the dry blood spot so we had to do a lot of reminding during our hospital visits. Next slide.

Part 3 which I think was very helpful, if we were lucky enough, we did get a tour of our unit. It really helps staff to visualize where the rubber hits the road so to speak so we would see the nursery and if there was a NICU in the birthing hospital we'd get to see that. We'd get to view where the sample drop off and pickup areas were and discussed where the courier picked up and these were really extremely helpful to us. Next slide.

We also created some transit time awards to create a sense of pride for a job well done within our hospitals and even a sense of competition. We had two best transit time awards and we presented them to two hospitals this year for an average of 2.09 days and we got to visit with each hospital conduct a site visit. We're also soon going to be going to Lonesome Pine Hospital which they have the most improved transit time. They're a little hospital out way west of Virginia and they actually improved their time from 5.78 to 2.01 and that was really a result of including them in the courier system. Next slide.

I'd like to brag and say that we actually covered over 2,500 miles in six months. I think this is a real accomplishment and I'm really proud of our team for doing this. It really took a lot of team effort, scheduling and it was quite difficult but I think we've all gained just a sense of that we've, I guess, what am I trying to say here? That we've accomplished something by going out to all of these hospitals and gained a lot of information. The next slide please, sorry.

Our process continues. We actually were given the opportunity to attend the maternal and the nursing practice forum and this is a quarterly meeting that happens in one of our hospital systems so we were able to give the same information with respect to data that we give on-site visits to nine hospitals at once, all their nurse managers were present at that.

Based on our visits that we have conducted we recognize that there is a huge benefit and need for us to continue this process. We've committed to visiting all hospitals every three years and in these hospital visits, we will now provide a copy of the CLSI newborn screening dry blood spot collection DVD. We bought 60 copies of those to hand out and we will also supply drying racks during these site visits.

Then we've come up with a site visit training checklist, there's a little sample of that at the bottom that will help prepare staff no matter who you are to prepare for a site visit before, during and after the visit. Next slide.

Willie and Kim also hired an administrative senior scientist at DCLS and this was to enhance communications between the dry blood sweat labs and submitters to stress this collection timeliness and accuracy issue. We also have a transit time review team that meets monthly to assess the data and messages that we want to send out on our report cards and of course, we're working on when improvements to enable Virginia to receive and send data electronically. Next slide.

Our educational efforts, we really want to enhance and increase this so we want to expand our current Virginia newborn screening education module and our website at newbornscreeningeducation.org. Currently, we have modules that cover dry blood spot and CCHD screening and now, very soon, we'll be adding in any module so this can make it a very comprehensive newborn screening education site. It's promoted to all our birthing hospitals. We've done some

marketing campaigns and free CEUs are available at this time to Virginia health care providers but we are seeking funding to allow us to share this nationally. Next slide.

This is just a screenshot of our web page. Next slide. Some other educational efforts that we would like to do is that well, we are making this, at least the dry blood spot education module mandatory for all internal staff including lab staff and our follow-up nurses. Some of our other plans in the next year is to have a comprehensive training course for nursery personnel where they might come to Richmond and have a kind of a train the trainer session and go back to their units so they can share information.

Quarterly webinars we hope to do in 2016 where we would have each program actually talk about a certain topic for our providers in the commonwealth. We would like to start presenting information at prenatal birthing classes. We had one of our nurses go talk to staff at one of our local prenatal birthing classes and we're hoping that they can incorporate that into their curriculum but that's just something that is starting.

We'd like to host a workshop for midwives on comprehensive newborn screening practices and I just sent the send button on a monthly email to nurse managers. We kicked that off this month in honor of newborn screening month and it's just sort of, I'm calling it an eLetter, to just give them quick tidbits on each of our newborn screening programs, things to remember.

I think that's it. Thank you for letting us present on Virginia's QA.

Thalia Wood: Thank you so much. I think that was great. Lots of good information. I do have one question that was typed in to the chat box and it's for Amanda. They want you to let us know the age of sweat test done in Washington. I'm assuming the age of the infant?

A. Kimura: The age. I don't have that information, the median age of sweat testing, off the top of my head but it is around, on average, around three weeks or so of age when the babies are generally tested or have the sweat test performed.

Thalia Wood: Okay, another question just came in for you, Amanda, so don't stop talking. How are the remote sweat test conducted?

A. Kimura: The idea for that was that, initially, was that the hospital that's in Central Washington would have the sweat collected and then they would send that sample off to a CF center that's based … one of the three CF centers for analysis. I think now what may be happening is that they actually just, that hospital may just be purchasing that chloridometer for the analysis as well.

The details are still being hammered out so as of right now, that's where it stands so hopefully, we'll have some more information later on.

Thalia Wood: Great. Thank you. Does anybody else have any last minute questions before we end this webinar? The star seven in your phone if you do. If you think of a question later you can always email me, this is Thalia and I'll pass it on to our speakers.

Okay. I'm not hearing any other questions and we are right at 4:31 now so thank you again so much to our speakers, this was great information and of course, this webinar is recorded and archived on the website if you need to go back and review slides later.

Thanks again to the speakers and everybody have a great afternoon.