NewSTEPs

A Program of the Association of Public Health Laboratories™

Short Term Follow Up Webinar

The Power of Case Studies
State Profile: Wyoming

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John Thompson: Welcome newborn screeners from across the country and globe. We're very excited to have you join us today or if you're watching this archived, welcome also to our 'Short-Term Follow Up Webinar.' We're going to be talking about the power of case studies and I'm really excited to listen to each of our speakers today.

We'll get started first with the state profile, we do this every other month at the beginning of our webinar, it's a chance for a program to share a little bit about how their program is structured, maybe some unique things about them. We're happy to have Carleigh Soule from the Wyoming Newborn Screening Program. She's the follow-up coordinator there, she's been with the Wyoming Department of Health working within newborn screening community for nine years. Carleigh's responsibility for all things newborn screening in the state of Wyoming and regularly interfaces with providers, families, and lab staff to ensure that the program runs efficiently. Carleigh, holds a Bachelor's degree in Social Sciences and a Masters in Human Services with a focus on family studies and interventions. Carleigh, welcome.

Carleigh Soule: Thank you. I'm happy to be here talking about Wyoming Newborn Screening and give you guys a glimpse into my little world. I've titled it, 'Newborn Screening on the Frontier,' because, I'm sure as you know, our population is very small. Next slide.

Our birth cohort in Wyoming is pretty small comparatively to the other states. It can vary between 6,500 and 7,000 births per year. We do have 20 birthing hospitals in Wyoming. The number of first newborn screens, as you can see, is about 6,430 for 2016 and that brings us right about to 96% of newborns screened, receiving a first screen. I think, a large part of that discrepancy between a birth cohort and then first newborn screens is due to our large home birth population that we have currently. Out of the conditions that are included on the RUSP, year to date for 2016, we have diagnosed eight babies. Next slide.

Our process in Wyoming is a little bit different in terms of how we have to run things due to our small population and the fact that we don't have a public health lab within Wyoming that can process our screens. We contract with the Colorado Department of Public Health and Environment for all of our testing so all of our tests are sent down there to be run. We also courier all of our screens from our birthing hospitals down to Colorado daily. The specimens are couriered five days a week for 18 of the hospitals out of our 20 and then for our two largest birthing hospitals, in Cheyenne and Casper, they're couriered six days a week just to make sure that they can get there because we do have a large amount of births at those two hospitals in particular.

As I said before, due to our shortage of specialists that we have in Wyoming, unfortunately, we have to contract out with surrounding states to do our follow-up. For our metabolic diseases we contract with the Inherited Metabolic Disease Clinic in Denver at Children's. We contract with the Sickle Cell Treatment and Research Center also in Denver for our hemoglobinopathies. Then National Jewish Health, which is again also in Denver, specifically Dr. Erwin Gelfand he does our follow-up for our SCID babies, which we have yet to have since we began screening. Next slide.

As I mentioned before, I think, one of our largest challenges is that currently midwives in our legislation are not allowed to collect the newborn screen. We are working on changing our rules and regulations and we're hoping that we're only about a month or so out from actually having that changed so that midwives are allowed to collect the newborn screen. I think, again, that goes back to our discrepancy between our birth cohort and the number of first newborn screens is due to the lack of the midwives being able to legally collect it.

For our follow-up contracts, as I mentioned in the previous slide, we do have follow-up contracts for three of the largest groups on the newborn screen but, unfortunately, we do lack contracts for follow-up for endocrine and cystic fibrosis. Thankfully, the follow-up specialist in Denver that handled the Colorado babies has been handling our endocrine disorders and cystic fibrosis just as they would Colorado babies. They're still calling them out to the specialists and they're still being followed up on but unfortunately, like I said, we don't have any follow-up contracts in place. Hopefully, in the future we'll be able to do that. Like I said, another large challenge is our testing lab and all of our follow-

up contracts are located out of state just due to the lack of specialists. Next slide.

I will say that recently, actually the week before last, we held a Wyoming Newborn Screening Conference in Cheyenne and it was pretty well attended from both a midwife and a hospital staff point of view. We had nine hospitals out of the 20 represented and we actually had quite a few midwives because they knew that our legislation is going to be changing and they're interested in learning more about newborn screening and how they can start collecting it. That was helpful for them to come and learn about the process and what it will look like for them once they start doing that.

As I said before, we're updating our rules and regulations that will allow the certified nurse/midwives to collect the newborn screen as well as add CCHD legislation. I believe that we are one of the last two states add legislation regarding CCHD so we're excited to get that started and we are hoping to add more guidance for midwives and birthing hospitals on how to get going with that.

We are piloting our CCHD collection on the birth certificate right now with one of our birthing hospitals that's at the highest elevation because we want to just check and see how that's going. We've been doing that for about six months now. We have been lucky enough to be involved with both NewSTEPs and NewSTEPs 360 on their continuous quality improvement efforts so I look forward to, hopefully, doing that in the future as well. Next slide.

That was short and sweet. That's newborn screening in Wyoming and there's my contact information.

John Thompson: Thank you Carleigh and that's excellent. We're glad to have a window into the challenges that you face with your situation so thanks for sharing.

Carleigh Soule: Sure. Thank you.

John Thompson: We're going to move into our main portion of the webinar and we're going to take a look at the power of case studies. Our first speaker is Beth Vogel. She is a board certified genetic counselor and a research scientist within the New York State newborn screening program. She manages the follow-up unit and is the project manager for the New York Mid-Atlantic Consortium for Genetics and Newborn Screening Services. Beth, thanks for joining us.

Beth Vogel: Thanks John and thank you everyone for joining the call today. I appreciate the invitation from the group to talk about a meeting that we had in the NYMAC region where we used case studies to learn and try and improve upon some of our NewSTEPs quality indicators. The title of the meeting was 'Causes and Solutions of Delayed Diagnoses' and what I'm going to do today is walk you through what we did at that meeting, and how we used case studies, and where

we felt value was added by having those case studies as a part of the meeting. Next slide please.

NYMAC actually is now changed to a regional genetics network as of June 1 and we cover eight state regions, the states are listed there. We're one of the seven networks that are funded by HRSA to improve access to genetic services for underserved populations. Right at the end of our last grant year, in May of this year, we hosted this meeting that was focused on newborn screening and quality improvement. Next slide please.

The goals of the meeting were really to help attendees, which included newborn screening program laboratory staff, newborn screening follow-up, as well as clinicians, and metabolic specialists from across the region, what NewSTEPs is and why the quality indicators are important. We also wanted to understand delays from both the program and the provider perspective. It was important for us to have both the newborn screening programs there and the providers to give their side of the story of where they see delays in the process of identifying and treating babies who have conditions on the newborn screening panel.

Our hope was, that from the meeting, attendees would take home examples of solutions to reduce delayed diagnoses and that from hearing these case studies they would find places that they could improve things. Then also we as a region would find things that maybe we could work together on improving to reduce the time to diagnosis. Next slide please.

This NBS system process map was what we used as the basis for our discussion. I believe this was actually developed by Susan Tanksley from Texas so we thanked her for putting this great diagram together. We spend a lot of time in newborn screening talking about the pre-analytical phase, how quickly we can get specimens collected and received by the laboratory, the analytical phase of how quickly we can perform the testing once it's received at the laboratory. This meeting was really focused on post analytical issues so from the time the newborn screening program calls out the test result until the baby receives a diagnosis of disease or of no disease and is treated and what some of the delays could be in that part of the process. That was our goal. Really to achieve that goal, as I said, we needed to work together with both sides, newborn screening program staff and the clinicians. Next slide please.

This is an overview of the first day of the agenda. NewSTEPs came and gave us a presentation on the quality indicators then we looked at NYMAC's performance. If you go into the NewSTEPs portal not only can you look at your performance as an individual state but you can also look at your region's performance. It can be helpful to look at the performance as a region and try and improve that number so that you can have open discussions without each state revealing their individual performance on each of those quality indicators. We were focused, for this meeting, on the time to diagnosis quality indicator. We spent some time

looking at how well the NYMAC region was performing compared to the rest of the nation on time to get a diagnosis.

We also had a wonderful presenter from an insurance company who was a chief medical officer talk about how to navigate insurance. We know that from talking to our clinicians time to get insurance approval for testing can be an issue in the time it takes to get a diagnosis. We invited a speaker to talk about some tips and ideas for trying to get through that process more quickly. Then finally, in focusing on our purpose for today's discussion, we had case studies. We invited everyone attending the meeting to prepare a case and we gave them a template. The template walked through each of the different topics they were to cover. We wanted some background information on the case, the newborn screen results, the confirmatory test results, and then we wanted them to do a root cause analysis of why the diagnosis was delayed in that case. We asked them to also look at any ideas they have for how the diagnosis could have been achieved more quickly.

We had the clinicians go through, and these were quick, each one was 10 to 15 minutes, and then we had the newborn screening programs go through and give their case studies and perspectives for the time to diagnosis. That really took us an entire afternoon to work through this part of the agenda. Next slide please.

On day two we actually reached out to NewSTEPs and asked them who was performing well on the quality indicator time to diagnosis? They identified Washington State as the state that was doing really well, was closing cases quickly. We invited Carol from Washington State to come and talk to us about their processes and she also went through some cases in Washington when they were able to quickly obtain a diagnosis. Stay tuned because later on this webinar you will hear from Carol and she will share some of the cases that she shared with us during the meeting. It was really useful for all of us so we wanted to share that with a broader audience.

Then finally, we had a review and discussion on day two, which was the majority of the time. Based on the cases presented during the first day a list of root causes was developed and applied to the different pieces of the process map so where in the process does that fall? We reviewed each step one by one and what the root causes were. Then we had a discussion about potential solutions to each of those issues that were raised during that part of the discussion. Next slide please.

Why did we decide to use case studies? We used case studies because experienced based learning or learning by example can really help participants to be actively involved in the discussion. We wanted people to come to the meeting having already thought ahead about where they may have issues, or where diagnoses may be delayed, and why that's happening. They were reflecting on the experience that they've had even before coming to the meeting and preparing their short presentation and case study. We wanted

them to use analytical skills. It was useful not only for programs to share their own, or clinicians, to share their own case but also to listen to other programs share their cases because they can see places where they may not have realized there was a delay in their own program that could be improved upon.

We also wanted the participants to use decision-making and problem-solving from the new ideas that they got from this experience. Not only to sit around and say, "What are the solutions," but to hear the cases and think about real world examples. Then use those real world examples to think about ways that they could improve or things that could be done as a region to improve. Next slide please.

There are some benefits to a regional approach for this. It helped us to highlight issues that were common to multiple states. I think some of the cases we heard things where maybe there was an unusual situation that happened one time with that one case but certainly themes began to emerge throughout our discussion of places where delays were frequently happening in different states, in different programs, with different clinicians. Those were the places where we spent our time trying to talk about solutions. Whereas if we had just one state we wouldn't have been able to maybe see those themes emerging quite as much. Although, I think there's benefit for case studies even within each state and all those same benefits of critically thinking about systematic issues and trying to come up with solutions are still there. Certainly, finding solutions and strategies can be a challenge so having more people working together can be useful. Next slide.

I just wanted to, again, thank you for giving me some time to talk about this. I did not include any of the outcome of the root causes or the solutions that we came up with the during the meeting because the focus of today's discussion is really about case studies but if people have questions about that for future discussions I'd be happy to have some future discussions about that topic as a separate discussion. Any questions now or are we waiting until the end?

John Thompson: I think we're waiting until the end.

Beth Vogel: Sounds good. Thank you John.

John Thompson: Beth, thank you for a great presentation and I'll be in touch with you about those root causes. I'm very interested. I think other people will be to so we appreciate that. Our next speaker comes from our program here in Washington, Carol Nucup-Villaruz. She graduated with a degree, a Bachelor of Science in Biology from De La Salle University and a medical degree, a doctor of medicine, from St. Louis University. She's been employed as a newborn screening consultant in our program for almost 10 years now. She's mastered the follow-up schemes on all the disorders and is currently in charge of following up on the mass spec conditions and SCID, as well as overseeing the dietary and metabolic treatment program here in Washington. Carol, thanks for joining us.

Erin Darby: Carol, if you just make sure that you're unmuted, press *7 and it looks like your screen sharing is almost up.

Carol Villaruz: Yes. Good afternoon everyone. I'd like to thank APHL and the short-term follow-up work group for inviting me to present today as well as Beth and the NYMAC group for spearheading this series of case presentations.

I was planning to share all my slides from my laptop but I wasn't sure if that's working properly right now, Erin.

Erin Darby: We can't see your slides just yet but if you go ahead and press the icon to present and if you're using the dual screen click the display settings at the top and then swap the presenter view with the slideshow view. Does that make sense?

Carol Villaruz: Okay.

Erin Darby: It's coming up now. Great. Then just, yeah, hit swap presenter.

Carol Villaruz: Can and everyone-

Erin Darby: Perfect.

Carol Villaruz: Hear me and see the slides? Okay. Great. Anyway, again, I'd like to thank everyone for this and this has been inspired by the goals and objectives of NYMAC. Just a brief background. As you know, Washington is a two screen state and although the second newborn screen is not mandated we get about 95% compliance. We're excited to start screening for X-ALD, hopefully, this coming September of this year. We also use Neometrics software for our database and we rely heavily on our action managers for our day-to-day follow-up tasks.

Just an overview on the newborn screening stats here in Washington. We have about 90,000 births per year and, doubling that would be, 180,000 specimens processed per year. About 3% of that are reported as abnormal results and we have about 2,100 false positive cases per year. Out of all those results we get about 150 to 200 cases of true positive per year.

For our newborn screening program to be successful we use several resources. We link our newborn screening with our birth certificate database. We have contacts with the medical records, laboratory, and clinic staff. We update those contacts in our directory. We utilize interpreters or translators in cases where there's a language barrier. Again, we utilize Neometrics to check for older sibling information, if that's not available on the newborn screening card. We also obtain assistance from the nurses from the county health department. In cases of adoption or foster cases we use the assistance from the social worker, the case manager, the discharge coordinators, and the attending specialist of the

patient. Once we get all that information we coordinate the referral with the specialty clinic.

These case studies were handpicked to address the most common problems that some of our colleagues from the NYMAC have encountered. We're trying to share this so we can share how we problem solved, eventually we solved each case.

Case number one is an initial GALT of 1.77, which was ported on day of life six. There was a primary care provider and clinic information on the card. However, when we called the clinic the staff were unable to get hold of the family. I contacted the neonatologist from the hospital, he was able to get hold of dad. Unfortunately, when the neonatologist was able to speak with the dad the patient was already admitted at the NICU and he was admitted because there was this severe form of coagulopathy and they couldn't figure it out. We recommended diagnostic test the Gal-1-PUT was 1.2 and also we requested and recommended DNA. Both the diagnostic tests were confirmatory of classic GALT. On further literature review there were only three cases of GALT that presented in this pattern.

Case number two is a final TREC of zero, which was reported on day of life seven. If there was a clinic or primary care provider on the card it was incorrect. We tried to call the family but it was a non-working phone number. At the back of my mind I was thinking if this was a family who had used Medicaid what would be the best possible clinic they would go to? I thought it would be the community health center or clinic and luckily it was the correct clinic, we tried it the first time and it was the correct one. At the same time, the immunologist was also able to track down the mother's obstetrician so he and I simultaneously located the correct clinic and primary care provider.

On review of the family history the parents were half siblings we recommended flow cytometry the absolute lymphocyte count was 396 and so the final diagnosis was classic SCID. Everything went well with the follow-up, unfortunately, when the molecular diagnosis came out the immunologist counseled the family telling them that there was only a 50% chance of survival even if they do a stem cell transplant so the family opted to not do any further intervention so that is the sad part about this case.

Moving on to the third case this was a 17OHP of 210 nanograms per milliliter reported on day of life seven. Again, the clinic and the primary care provider on the card was incorrect. We requested the medical records for a demographic face sheet. We noted the correct primary care provider and the parents' address. We recommended immediate diagnostic test. Treatment was initiated before serum results were reported so treatment was done on day of life seven. The serum 17OHP was a confirmatory of congenital adrenal hyperplasia, the salt wasting form.

Case number four is a TSH of 467.08 on New Year's Eve reported on day of life 13. Again, the clinic and primary care provider on the card was incorrect so, again, we had to call medical records. There was no primary care provider from medical records so I had to call the parents and ask for the primary care provider. We recommended immediate thyroid function tests and I also coordinated the referral with the on-call endocrinologist. The serum TSH was 1,208 so treatment was initiated on the same day of referral, on day of life 13. The parents were thankful upon meeting them on the thyroid night so everything went well on this case too.

Case number five is an initial leucine of 497 with also an elevated leucine to alanine ratio, the patient was not on TPN, this was reported on day of life six. Again, the clinic and primary care provider was incorrect on the card. Called the hospital of birth, located the correct primary care provider. When I called the clinic the nurse assured me that the family were on their way but apparently only the dad showed up at the clinic to get the lab order. Apparently, there was a language barrier, they needed an Arabic translator to communicate with the family. The plasma amino acid leucine was 2,800 and so the biochemical geneticist decided to admit the patient on day of life seven and they started treatment as well. Obviously, clearly this was a classic MSUD.

Case number six is an initial C8 of 14.67 reported on day of life six. Again, the clinic and primary care provider was incorrect on the card. I called the hospital of birth, located the correct primary care provider. Unfortunately, upon connecting with the clinic we learned that the baby was readmitted due to severe hypoglycemia, hyperbilirubinemia, and dehydration so the attending doctor didn't have a clue what was going on. As we reported the newborn screening results they clinched the diagnosis of MCAD, we recommended some diagnostic tests, and they were both confirmatory of a classic MCAD.

Case number seven is a C14:1 of 1.92 reported on a late Thursday afternoon on day of life eight. There was a clinic on the card but the staff couldn't get hold of the family. We also tried the parents' phone number but it automatically goes to voicemail. One of my colleagues alerted all the hospitals in the area in case the family would show up if the patient was already symptomatic at that time. John, thought of using our personal cell phone and called the family and left a voicemail. Fortunately, mom got the message, unblocked her cell phone, and called us back. Apparently, there were transportation issues as well and there was no dry ice to ship the specimen. We coordinated diagnostic testing with the nearest hospital and the diagnosis of true VLCAD was arrived the following week, which was a Monday so everything went well for this case too.

In conclusion, we try to exhaust all resources before closing the case as lost to follow-up, we try to be flexible and creative, we reinvent ways, we provide clear recommendations for a follow-up, and we collaborate effectively through communication, networking, and using proper channels. We promote and strengthen outreach activities.

Anyway, I just want to make a note that if you've noticed there were some cases there where we acted on an initial value particularly if we have a high index of suspicion for that case we don't wait for the final results to come out and we start to do the follow-up process. I'd be happy to answer any questions at the end of this webinar. Thank you.

John Thompson: Awesome job Carol. Thanks so much. That's a world wind through a bunch of cases that we've seen here in Washington and Carol did a nice job of finding different ways ... highlighting different scenarios in which the creative follow-up folks were able to do, were able to get by the barriers that presented themselves originally in the case. Thank you Carol.

Our next speaker is Christen Crews and she is the public health nurse supervisor for the Virginia newborn screening program. She supervises and solves activities for the dried blood spot and CCHD programs and she is also a member of the NewSTEPs short-term follow-up work group. Christen, thanks for joining us.

Christen Crews: Thank you. Am I unmuted?

John Thompson: You are.

Christen Crews: Great. Thank you everyone. Next slide please. I had the opportunity to attend the NYMAC meeting a couple of months ago where we discussed case studies. We came back home and we decided to go ahead and look at implementing it with our program here. In Virginia, we have a monthly staff meeting, it's a face-to-face joint meeting between laboratory and follow-up staff. Next slide please.

I provided a sample agenda of what our monthly meeting looks like. We discuss program updates, we have conference and training debriefing and this is for both our scientists as well as our follow-up nurses. We discuss future events and planning, and then with our new initiative we have our case study review, and then follow-up discussion. Next slide please.

The cases that we are proposing to select the case study review we're looking at cases that have delayed diagnosis, issues with follow-up, complications with testing, rapid diagnosis of time sensitive disorders, and an unexpected outcome. The cases are nominated by both the scientists in the laboratory staff or the follow-up stuff. We're going to skip to the next slide, one more slide. Sorry, I had a different cut slide.

When we start off with looking at the case study we do some background investigation. We're requesting medical records from the birthing hospital, from the primary care physician, as well as the consulting specialist if applicable. We're finding that we are getting different bits and pieces of the puzzle for the baby depending on who you request it from so we try to gather as much information as possible. Next slide please.

Our case study presentation components include a presentation of the patient, the root cause analysis, followed up with a group discussion. We'll go through and break that down. Next slide please.

For the presentation of patient the information that we share to the group are maternal or other applicable family history, if they have any siblings that are carriers or have been diagnosed, any complications with the prenatal period, any issues during hospital admission, the actual newborn screening laboratory results, the presumptive disorder that was recorded, the age of the baby at diagnosis, any follow-up actions that occurred. Then we also have the root cause analysis and then the group discussion. Next slide please.

This was a screenshot, kind of like a template that we started with when we went to the NYMAC meeting of the root cause analysis where we're analyzing three different areas, the pre-analytic, the analytic, as well as the post analytic. For the pre-analytic phase we're analyzing the days of life at the sample collection as well as the days of life at receipt of the lab. We're looking at issues with hospital collection as well as hospital problems with our transit time. During the analytic analysis we are looking at potential issues or wins during the laboratory testing phase. Then the post analytic we're looking at our diagnostic outcome, we're looking at how old the baby was when they were diagnosed, time to intervention or treatment, and as well as any follow-up challenges or successes.

This graph that I shared was for one of our case studies that we reviewed. It's days to diagnosis by test phase. One of our scientists made the display. The percentage of time this baby’s samples spent in each phase until they were diagnosed. The baby had 5% in pre-analytical, 9% in analytical, and then 86% of the time was in post analytical. Next slide please.

This is another visualization of that same data that was just shared in that graph where we further break down and we're looking at the baby's date of birth, date of collection, date of receipt, the different reporting stages, the follow-up intervention. This was a CF baby so when the baby actually went to the pulmonologist, as well as the final diagnosis. This graphic makes it easier to see the delays. For this particular baby, there was a significant gap between the actions of the follow-up as far as initial intervention. Next slide please.

After the presentation of the case and the review of the root cause analysis we have a group discussion where we're utilizing it to identify opportunities for improvement. As a group, we discuss barriers and accomplishments, and then develop any potential plans of action. Next slide please.

Some benefits of a case study review that we've noticed since we've implemented this process is that it further increases collaboration of laboratory and follow-up staff, it allows for analytic discussion, it improves education of processes and disorders so our laboratory staff are learning more about the

follow-up and the follow-up are learning more about the laboratory processes. It provides quality assurance so if we do identify an issue where it's at the provider level we can go back to the provider and discuss the case with them. It also allows us to reflect on areas for improvement and it also provides an opportunity to see the outcome of the case. In Virginia, we have about 100,000 births a year and it's very easy to be very task oriented because there's a lot of babies to screen and review. I believe that reviewing these cases brings more empathy back into the program and then you can see the effects of your actions by showing the outcome of the baby and I think that it brings greater value to the process as well. Next slide please.

That's it for me today and I have my contact information if anyone would like to discuss implementing case study review in their monthly work group meeting.

John Thompson: Awesome. Thanks Christen. That was a great summary at the end of all the benefits too. Very good. Thank you. Our final speaker today is Sara Denniston. She's the newborn screening follow-up coordinator for Oregon-

John Thompson: Are you okay? All right. Sorry. Sara's the follow-up coordinator for the Oregon State Public Health Lab, which is also the Northwest regional program providing newborn screening to New Mexico, Hawaii, Alaska, Idaho, Guam, and the Navajo nations. She's also a member of the NewSTEPs short-term follow-up work group. Thanks for joining us Sara.

Sara Denniston: Thank you John. Can you hear me?

John Thompson: Yup.

Sara Denniston: I did not put my name on that slide so there is my first mistake. I'm excited about this webinar and it's wonderful to hear the previous presenters because we have more of an informal process here and this makes me want to change some of the things we're doing. Go ahead and go to the next slide.

This is just a review from 2016. We are a regional program so those are all the states we screen for and we had about 126,000 first screens last year. Most of our contracts we all do two screens routinely in the state except for those few ones listed there. Next slide.

We had about 211 confirmed cases last year that we picked up and this is not including our CPT1A DNA that we started for Alaska, which would make our numbers much, much higher. We're just going to leave those out of it for now. Next slide.

We have bimonthly program meetings. It's every other month in person, we alternate hosting them here at the lab, which is where follow-up is also located. Then the next meeting we'll go have it at Oregon Health and Science University,

that's where all of our consultants are contracted out of and they're based up there. Alternate who's driving to which location for an in person meeting.

We take advantage of this time to review recent call outs we've done, the case studies, any trends we've seen, and issues that might've occurred or come up in newborn screening. If they're Oregon babies we picked up recently they're usually seen by the consultants there in clinic so they usually have updates they can give us firsthand in person. Next slide.

It's a small setting. There's usually 10 to 15 of us in a room give or take who can make it for the day and it's nice just to be face-to-face and have open and candid conversations with everyone. It's often these times where we lead to process chains, maybe looking at cutoff reviews or any changes in the lab that we might want to do. We do not currently involve the other states in these meetings right now. Next slide.

We do have an annual meeting that's probably the most important feature of the regional program. We host it here at the lab every spring, it's two days, usually we try to do a dinner as well. Each state always has representation come, sometimes there's two people from the states that come. We try to make sure that there's always a consultant from each of the specialties if they can make it. Then the lab and the follow-up is here as well. Usually our QA and compliance manager pops in. There's often people from maternal and child health that show as well. Our lab director tries to come as well when he can be here. Next slide.

The benefits of that annual meeting is, again, being face-to-face and hearing about other states and their issues. Everyone seems to have stories to tell and the consultants usually have stories to tell as well from the last year. I find that there isn't really another avenue to share stories like this, this webinar is great, if you get your abstract accepted at the Newborn Screening Symposium that's a great time to share your stories but I feel like a lot of times there's not another avenue to compare cases like this. Next slide.

I'm just going to share these three stories that we've had over the last year that were pretty interesting. In Oregon, I had a call from a naturopath who had seen a baby and he was five months old, small, and sleepy, didn't have a newborn screening done. Mom had, had a home birth with a lay midwife and she'd had four previous healthy children so she didn't think that she needed to do any newborn screening. It turns out that at five months old he was diagnosed with hypothyroidism and that's the first time he started Levothyroxine and mom said it was the first time he'd eaten 3 1/2 ounces and had stayed awake to eat the whole thing before falling asleep. Now, that family is linked up with a couple different specialty clinics at OHSU.

We had another case study where another state had a baby they had thought was diagnosed with methylmalonic acidemia and our newborn screens were

normal. We did one at one-day-old and 13 days old and they were both normal but at eight weeks old the baby was hospitalized. We were given just some of the records from the hospital that our consultants reviewed and it's hard without full chart notes or full information about what happened for our docs to interpret things. It didn't lead to any changes in our cutoffs or anything. Our consultant said it looked more like a cholamine processing defect or a Vitamin B12 deficiency, which we may not always pick those up on newborn screens.

Then another interesting case we had was actually an Iraq family not Iranian so that's another mistake on my slide there. We picked up a newborn girl with PKU and turns out with the home visits, and getting the baby diagnostic testing, and getting started on formula there were two older siblings that were four and seven years old that were born in Iraq and did not have newborn screening and they were both diagnosed with PKU based off of the newborn baby's diagnosis. Now, they're all under treatment.

That case was actually presented at a Grand Rounds round session at OHSU. There was another doctor in that audience who was able to diagnose a child that he had in his care with PKU that had born outside of the country as well. I feel like these are really good examples of why we need more avenues to present case studies especially to each other in newborn screening. I find that the few times that we get together for in person meetings whether the new short-term meetings we've had, or phone calls with work groups, or the symposium coming up that's one of my favorite things is hearing other stories and case studies. I would've loved to been at that NYMAC meeting. Next slide.

That was it for me, if you guys have any questions ...

John Thompson: Fantastic job Sara, thanks so much. I, like you, have been watching and listening and thinking about what can we do better? Thanks to all the speakers. We have about 10 minutes or so to ask any of the presenters questions including Carleigh. If you would like to type them in the chat box then Erin will take care of that. Otherwise, you can press *7 to unmute your phones.

Erin Darby: I do have one comment in the chat box already this commenter admires Washington's tenacity in tracking down primary care providers but the question is, "Is anything being done to educate hospitals on filling out the specimen cards accurately?"

Carol Villaruz: Hi good afternoon again, this is Carol. Thanks for that question. John and Ashleigh can chime in, yes, as I mentioned, one of the solutions, which was on the conclusion, is that we promote outreach activities, we give regular presentations to hospitals or clinics, and we schedule those. We have one colleague from the QA group and one from follow-up and we present from giving them an overview about newborn screening, and we have a focused presentation on how they fill out those cards. I think based on ... the newborn screening law here was revised in 2014 or amended in 2014 and there have

been significant improvements in the way hospitals and clinics comply in completing the information on the newborn screening card.

John Thompson: We provide that information to all of our submitters in a quarterly report on how many times they don't provide ... I guess, the information is not provided on the card but hospitals sometimes put the wrong provider on so we end up barking up the wrong tree, so to speak, oftentimes. If we find one of the submitters is particularly poorly performing in that we'll reach out to them, and train them, and help them understand how to do better. It keeps happening.

Ashleigh Fleischman: John, this is Ashleigh and I just wanted to chime in. One of the things that we've done to help improve getting better information about where the baby's being seen is we changed the request on our card from asking for a specific provider to asking for the clinic or the clinic group. We found that maintaining the database of providers and where they worked, and they moved around, or they work at many different places was harder to track them down that way. By asking for the facility where they're being seen has made it a little bit easier for us to find those babies.

John Thompson: Very good. Thanks.

Erin Darby: We have a few more comments on the Washington samples and case studies from a couple of participants. One noted that it took 11 or 12 days for the samples to be received and the question is, "Why did it take so long in Washington?" Then the other, "How are the newborn screens transported from hospitals to the lab in Washington?"

Carol Villaruz: Some of those cases were way back before that newborn screening law was amended in 2014 and so Washington does not have a contract with a specific courier who collect the specimens from hospitals and deliver them to the state lab. It is up to the hospital or clinic to either mail the specimens or have a contract with FedEx or UPS to deliver the specimens to us. After the newborn screening law was amended in 2014 hospitals and even out of hospital births now are mandated to collect the first newborn screen between 18 to 48 hours and once that specimen is collected they're required by law to have that specimen be received in our lab within 72 hours. I think a lot of hospitals have improved their transit times from 2014 to date and John and Ashleigh can also chime in and add additional information. (silence) I'm not sure if I answered the question.

Erin Darby: I think so, thank you Carol. Any other comments on that note? Are there any other questions or comments for our other speakers? Go ahead and press *7 if you'd like to ask a question or type in the chat box. We do have one more comment or two more comments in the chat box already. A question is for Sara. "Do you report transit times to Navajo?"

Sara Denniston: We do. We have monthly report cards.

Erin Darby: Then another note in the comment box. "I attended the NYMAC case studies the meeting and it was fantastic. It would be nice if other regional networks duplicated their efforts." Here's a question for Carleigh. Carleigh, "Do you work only in newborn screening or to you have any other roles?

Carleigh Soule: I actually also coordinate our genetic clinic. As I mentioned in my presentation, we don't have any specialists so that also includes geneticists in Wyoming so we have to contract out with neighboring states. Our current contract, that actually just expired, was with the University of Utah so they would travel to Wyoming and do regional clinics in Wyoming and I coordinate all of those.

Erin Darby: Great. Thank you. Another question for Sara in the comment box. "Does the Navajo nation send samples via mail or via courier?"

Sara Denniston: Mail. It's a couple locations down in Arizona/New Mexico area.

Erin Darby: Another question for Christen. "Are your meetings required by lab and follow-up? If not, do you get a good representation from both?"

Christen Crews: Am I unmuted?

Erin Darby: Go ahead. No, go ahead I can hear you now.

Christen Crews: Great. Meetings are currently mandatory for the follow-up staff as well as the senior scientists. I think we're exploring expanding it out to all of the laboratory staff that are able to attend. It is mandatory for senior scientists as well as the follow-up nurses.

Erin Darby: Great. Thank you. We have a few more minutes. Does anyone else have a question or comment for any of our speakers? You can type in the chat box at the bottom or press *7 to unmute yourself. I don't see any more questions coming in so John, if you're still on the line, do you have any final comments?

John Thompson: I do. Thank you. I want to just thank everybody for joining us. I was hoping that this would be a cool webinar and our presenters did a wonderful job of delivering some great things to think about and three different settings in which case studies have played a major role or are playing a major role in education and improving the services that we provide. It was great to hear from Beth and the meeting that she and her collaborative put together, that was very exciting and a model for the other regions that haven't done something like that. Thanks to Carol for sharing a case study on case studies, so to speak. Then good to learn from Christen about the internal to Virginia, the lab and follow-up getting together, and the benefits for doing that, and finding ways to improve the system together, and really taking a careful look at those difficult cases.

Then Sara, at the end, with using case studies to strengthen the relationships between the newborn screening program and the clinical consultants and the

value. Those were some cool case studies that you shared also. I think Sara articulated that this is really a wonderful opportunity using case studies to teach each other and so there may be ways that we can provide an arena in which we can do this more regularly rather than just waiting to see each other in person or doing it among our own states. We can start thinking about ways to support that type of learning also.

Once again, thanks to everybody and to our presenters. Take care. If you have any questions feel free to reach out to me or to Erin. Unfortunately, Carol Johnson, my co-chair from Iowa, is feeling ill today so she wasn't able to join us but I feel very comfortable speaking for her that she's interested in helping out also. Thanks everybody.

Erin Darby: Thank you John and thanks everyone for joining us today. Please mark your calendars for September 18 for our next short-term follow-up webinar and have a great afternoon.