



# NewSTEPS

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## Short Term Follow Up Technical Assistance Webinar

May 5, 2014

### Presentations:

- State Profile Oregon—Sara Denniston
- South Dakota NBS Program Electronic Vital Records and Screening System—Lucy Fossen, RN
- New Jersey Department of Health NBS and Genetics Services Short Term Follow Up Procedure—Yvonne Miller-Watkins, RNC, BSN, MAS
- Matching Vital Records and NBS Data in New York State—Beth Vogel, MS, CGC
- Short Term Follow Up: Delaware Missed Babies—Lou Bartoshesky, MD

### Moderators:

- Thalia Wood, MPH, Specialist, NewSTEPS
- Carol Johnson, Co-chair, Short Term Follow Up Work Group

Please direct all comments/questions pertaining to this presentation to Thalia Wood at [Thalia.wood@aphl.org](mailto:Thalia.wood@aphl.org) or 240-485-2701.

Thalia Wood: Okay. Once again, thank you, everyone. This is Thalia Wood with APHL. Carol, do you want to go ahead and get us started?

Carol Johnson: Hello, everyone. Can you hear me?

Thalia Wood: We can.

Carol Johnson: Okay, great. I'm Carol Johnson with the Iowa Newborn Screening Program and co-chair of the APHL Short-Term Follow-Up Workgroup. On behalf of our workgroup and APHL, I'd like to welcome you to our presentation today.

Again, in case you weren't on the call when Thalia mentioned this, if you are a speaker, you need to hit \*7 to be unmuted. Now, it is my great ...



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Male: \*7?

Carol Johnson: \*7, yes.

Male: [Inaudible 00:00:48].

[crosstalk 00:00:48]

Carol Johnson: Now, it's my pleasure to introduce Sara Denniston, from the Oregon Newborn Screening Program, to present our next state profile. Sara, please go ahead.

Sara Denniston: Hi. Can everybody hear me?

Thalia Wood: Yes, we can, Sara. Thank you.

Sara Denniston: Okay, great. Well, good afternoon. We'll just go ahead and get started. I know we have a lot to fit in our hour. So, go ahead and go to the next slide. So, I am the follow-up coordinator in Oregon. We're also a regional program, so these are the states that we do. You'll see we've a Navajo nation in there, and we've got a Fort Irwin in there. Next slide.

We also do some international facilities. So, for follow-up, it's especially difficult in Guam and Saipan. Usually, I have to wait until after 4-o'clock, my time on the West Coast, and by then it's morning time the next day where they're located. So, with that, we've got a very wide variety of ethnicities. We see lots of different variations in things. Alaska has a variant of CPT-1A, and Hawaii has a Pacific Islander VLCAD variant that we pick up. We also seem to pick up G6PD babies from Hawaii, which is an issue with our GSP machines for galactosemia screening. Next slide.

So, most of the states here have the mandated second screens. Hawaii's the only state that just does 1 screen. In 2013, our numbers are there for the specimens that we ran. So, we're a pretty busy lab here. We just had our regional meeting in April, so all of the coordinators from the states came, and our consultants meet with us, and it's good to actually see everyone in person once a year. Next slide.



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More specifically for Oregon, we've got a little over 45,000 births. We do not math up with vital records. We do try to keep track of our refusals. So, we're estimating we're getting about 99% of our babies screened, which we think is fantastic. We've got 51 birthing facilities, and our lab is still Monday thru Friday, 8:00 to 5:00.

We don't have any Universal Courier Delivery Service. We do recommend overnight delivery. Just like I think with every other state, since the articles come out from the *Milwaukee Journal*, we are seeing a lot of activity in getting those numbers better or getting specimens here faster. We do meet with our consultants every other month, and we do use Neometrics for our computer system and PerkinElmer for all of our laboratory products. Next slide.

This is just a copy of what our double kit looks like. All of the other states look pretty similar, in different colors. We just had our prices go up. We raised them \$10 because we're adding SCID, so that just went into effect. If you go to the NewSTEPS website, I know all of the other kits are there on their website, so you can see examples of them. Next slide.

This is just a picture of our lab. What you don't see, we have rooms for ... We have a tandem mass room. We have a room for our GSPs. We are going to have a room for SCID, and we also have a room for punching. Then, follow-up and data entry are down the hall in a separate corridor of the lab. Next slide.

These are just some of our numbers for conditions we picked up in 2013. You'll see we have a lot of the CPT-1A. That's the Alaska variant for the natives up there. Next slide.

Here is other listings that we've got also. We've been busy already in 2014. We already picked up an MSUD, which we hadn't had in several years. I don't think we've had one since 2011. So, that was pretty exciting, and it was local here in Portland. Next slide.

Some of our activities we do here in follow-up. We do our monthly state reports and provider profiles, and then the state coordinators follow up



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on their end with that information as well. We do daily send-outs of our [unsats 00:05:27], and our insufficients, and our contaminated so the state coordinators can contact their patients and make sure we get repeats in right away.

We do diet monitoring for PKU patients for all of the states. So, out of our office here, we're sending lancets and the kits for those. With our cystic fibrosis, we're still running an IRT, IRT followed by sweat chloride testing. Once we get SCID up and running, then we'll probably look at moving towards a DNA mutation analysis with that. We've got a new cystic fibrosis consultant at OHSU, and she's really great, so we're excited to be able to work with her. Next slide.

So, we are planning to start SCID, and we were hoping it would be up in May, but we're not quite there yet, so pretty soon. Nevada, it does have a planned departure from our regional program sometime later this summer or later 2014. So, they're going to be doing their own screening. So, I'm working with who they've got hired for their follow-up coordinator there, and their staff, to make that transition hopefully as smooth as possible. We are part of the Western States Collaborative, so there's a meeting in October we always go to. Of course, in October, we'll also be at the symposium down in Anaheim.

So, my ... The last slide is just my contact info. If you guys want to get ahold of me with any questions or comments. Hopefully, that was just a good little starter for today's webinar.

Thalia Wood: Yeah. It was very good. Thank you very much, Sara. So, our next speaker ... Our topic, as you know, today is ensuring all babies are screened. So, now we're going to hear from 4 states and how they go about that. Lucy, have you got your phone unmuted? \*7 to unmute your phone, Lucy.

Lucy Fossen: Can you hear me?

Thalia Wood: Yes, I can hear you know. Thank you.

Lucy Fossen: Well, thank you, Thalia and NewSTEPS APHL for this opportunity. I was just going to quickly go through the next few minutes, an overview



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regarding the South Dakota newborn screening process and our database infrastructure that matches the newborn screening results to the birth certificate. I'm convinced it's the powerhouse that we have. The system is called EVRSS, and it stands for Electronic Vital Records Screening System. This is what helps South Dakota ensure all babies are screened.

So, first, some background. Next slide. South Dakota has about 12,000 births per year, and we use a centralized contract laboratory system. Since 2007, the State Hygienic Laboratory at the University of Iowa has provided newborn screening testing for the South Dakota Department of Health.

Well, today, I'm going to talk about the South Dakota Newborn Screening Database. I don't want to miss mentioning that South ... that Iowa also has a data system, and it's web-based, and it provides real-time access to newborn screening specs and results, and there's communication between the lab and the follow-up staff. It's a wonderful communication tool between the South Dakota Department of Health, and the contract lab, and the follow-up documentation. Both systems seem to work ... function very well alongside each other, but I want to make sure that there's no connection between the 2 systems other than the electronic file that I'll explain in a little bit.

EVRSS is an automated, centralized, statewide system that incorporates web technology. We've had this system since 2002. It's gone through a change in laboratories and expansion of newborn screening tests without much changes to the system. It really works smoothly. This is the electronic birth certificate filing system. Each hospital in the state enters birth certificate information directly into this database.

The hearing screenings and the metabolic screenings are, I'm going to say, attached by a separate tab to the birth certificate record. I'll show you in the next few slides, and hopefully that'll help make more sense and will be helpful. We're very fortunate that the 2 offices, the Office of Data Statistics and Vital Records and the Office of Family and Community Health, which where the programs I work with are housed, they worked together for this system, and I think we really benefitted from that.



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So, the next slide is just the screenshot of the login to EVRSS. I'm going to briefly walk through this, how it works. First, at the hospital level, the collection card has peel-off stickers that are placed on the birth certificate certifier's worksheet. This is the form that Vital Records uses at the hospital level to file the birth certificate. Basically, the sticker goes on this paperwork before it actually gets entered in electronically by Medical Records staff. This sticker is the metabolic unique identifier number that we'll eventually match the birth certificate ... match the birth certificate to the newborn screening results.

Okay. The newborn screening collection card is collected, and then it's sent via to the courier to the contract lab. The contract lab, they do their thing. The specimens analyzed, the results are reported out. The Iowa Lab sends an electronic file with these newborn screening results. They're loaded into the EVRSS system daily, Monday thru Friday.

A Department of Health staff loads the electronic record that we receive from Iowa, and performs a match process function with EVRSS. This process performs a match of the collection card unique identifier number and other data fields on the collection card that are weight point ... They have points and are weighted. So, this match process is designed to match the repeat specimens, as well as the initial.

Okay. I do want to point out that EVRSS is not considered a medical record, and it's not a laboratory report. EVRSS provides the Department of Health with newborn screening surveillance, and the design was just for that. It's the intention is to ensure all babies born in South Dakota receive a metabolic screen as indicated by law. Here's the slide of the peel-off sticker with that ... It's circled. They just kind of wanted to point that out to you.

Next slide. This is just [test 00:12:34]. This isn't real information. It's just from our test database. This is the slide, and if you notice the tabs on the top, those are actual birth certificate information that they received from the certifier's worksheet. If you look across the top, you'll see the metabolic tab is second from the right, which is next to the flags tab.



Then, the next slide ... Basically, this metabolic tab has all of the information that's on that collection card. Further down, if you scroll down, this screenshot is just some more fields that I'll talk about later as we do some report ... surveillance reports. But, it has the diagnosis, the case status, when treatment started, and comments.

Okay. So, next slide ... So, just consider these things. The lab analysis and reporting out of results averages, for South Dakota, about 5.5 days. In South Dakota Vital Records, the birth certificates are filed within 7 days, so that's state statute. There's no enforcement of that. But, Birth Certificates are really pretty good about getting those results in.

So, like I said, it's really a workhorse, and it provides great information via reports. So, whenever you want to run them, the system is live. Birth certificates are filed every day. Newborn screening results are loaded Monday thru Friday. Just to explain this part, I just wanted to highlight 2 of the reports that EVRSS uses to ensure that all babies are screened and not missed. That would be ... First is the Never Tested Report, and this report will pick up the home birth.

See, once a birth certificate's filed and no metabolic results are matching to it, they'll show up on this report. It'll pick up home births, refusals, poor quality because they're considered not screened if there's no valid test; if they were transferred and no ... and the hospital of birth did not collect a newborn screen; they were discharged without a newborn screen; the deceased. Then, the system errors I'll explain in a little bit.

But, all ... The next slide ... This is what a Never Tested Report looks like. It gives the hospital's name where the baby was born, who filed the birth certificate, the date-of-birth, and the mother's maiden name. That's very helpful for name changes, and so there. But, this report has also picked up problems with the system.

If there's problem with the electronic file, we're not getting those results. This report is what shows us the most information, but even though that's pretty rare. So, we have a potential here, now, when you manipulate the date-of-birth range versus the day you run the report,



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you can manipulate those dates. We can pick up a baby as soon as 7 days of age as a possible Never Tested baby.

The second report, next slide, is the Unmatched Report. Now, this report is the reverse. It's metabolic results that we have, but there's no birth certificate. Generally, those are out-of-state births, which we could begin program ... state program to state program coordination to ensure the follow-up, and especially if there's any abnormal results on those babies.

There's births without a birth certificate. They're reported to Vital Records, so they do appreciate being aware of those reports, and they could then in turn work with the hospital to get those results. Then, some do require a manual match. There's not enough points for the match process to work. By manipulating or taking a look at it, you can manually match the correct record to the birth certificate.

Then, I had already shown this slide, but the metabolic tab on the birth certificate, those data fields, really help the follow-up findings and medical determination, the date of collection, test results. These are the fields that we're able to run these reports for surveillance.

Next slide. We run reports on abnormal results. We can do a year's worth of diagnosed babies, case status. Just to move on, the Summary of Findings of 2013, there were 12,922 births. We had 11 refusals, 2 lost contact, 51 expired, and 64 were confirmed from ... They were all presumptive positive, and they were determined negative for a newborn screening disorder, and 16 were actually diagnosed. So, every baby is accounted for, or there's documentation of the follow-up for any baby that's lost ... that we've lost contact for. We still have 2 babies, in 2013, that are pending a short-term follow-up diagnosis.

So, next slide is just my contact information if you have questions. I really went over this fast, so please feel free to call me or get ahold of me if you have questions.

Thalia Wood:

Thank you, Lucy. That was really very informative. Yeah, I think we're going to move right along. We'll have questions at the end. So, our next





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speaker is Yvonne Miller from New Jersey. Yvonne, did you unmute your phone? Don't forget, it's \*7 to unmute your phone.

Yvonne Miller:

\*7.

Thalia Wood:

Yeah. Yvonne, is that you?

Yvonne Miller:

Yes.

Thalia Wood:

Okay, good. Go ahead and start, Yvonne.

Yvonne Miller:

Hi. Okay. You ready?

Thalia Wood:

Yes, we are.

Yvonne Miller:

Okay. Good afternoon, everyone. I'm Yvonne Miller-Watkins here in New Jersey Department of Health Follow-up Program.

Okay, next slide. Okay. Currently, in New Jersey, the newborn screening lab is open Monday thru Saturday and holidays for UPS deliveries. The only holidays that we're not open are New Year's Day, Memorial Day, Independence Day, Labor Day, Thanksgiving, and Christmas. On Saturdays and holidays, the most time sensitive procedures are performed with reduced staff. Critical abnormal results are also reported on Saturdays and holidays. We require that all hospitals send their specimens via UPS overnight service. The New Jersey Department of Health provides the UPS account, which is paid for from the newborn screening fees.

New Jersey Newborn Screening Regulations require that hospitals ship specimens to the laboratory within 24 hours of collection, or they could be referred to the health facility's evaluation and licensing for investigation. The blood spot card is assigned a unique number, which includes the Julian Date. As you see there, the "Y" represents the year. The "D" is the day of the year. The "X" is the total number of specimens received for that particular day. This number serves as the patient's lab ID number and the initial specimen number.



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Next slide, please. Okay. On this slide, I just wanted to say, there's no matching currently be conducted between the newborn screen samples and the EBC. We have no way of knowing who is missed, which is evident on this slide, which shows the number of collected newborn screens compared to the EBC data of 2013. We have no common data, no good common data. The medical record number is not always accurate. Mom's last name and the baby's date-of-birth are sometimes different in the 2 databases.

As you can see, there's a wide variability in which database has more infants. For instance, sometimes the newborn screen has more, which is evident in January and July on the slide. Sometimes, the EBC has more, which is evident in March, May, and September. Okay? There were 1,839 more entries logged into the EBC in 2013, and there are more than one cause for this discrepancy.

Okay. Next slide, please. Okay. To ensure no child left unscreened, we plan to initiate the Vital Information Platform. This system captures all pertinent demographic information from birth on. This system is currently the Electronic Birth Certificate, which is in a DOS-based. It's not in real-time. It does not include the newborn screen. But, it does include the EDI and the CCHD programs. We plan to call it the VIP [inaudible 00:22:08] hospitals this summer in 2014.

The VIP will [inaudible 00:22:13] for the hospitals to record the newborn filter kit number or reason that the number is not available, for instance, if the baby expired, if the baby was discharged before their filter was collected, if the baby was transferred to another hospital, or if the parents refused, or any of those reasons. We will have access to a read-only database link, which will have entries from the hospital that are input within 5 days of birth.

Next slide, please. So far as initial data matching, the lab will do a weekly match utilizing the VIP database. In the event the kit number is missing or has been logged incorrectly, a search will be conducted using mom's last name, the baby's date-of-birth, or the MR number. The goal is to find infants in the VIP who does not have a newborn screen. We will not do reverse matching.



Okay. Next slide, please. Next slide, okay. On this slide, I just wanted to provide a little visual of how we're going to take a look at the different reasons that a newborn screening sample might be received and may not be received. Any babies in the VIP with no kit number will be considered potentially unscreened. Any babies in the VIP with a kit number that is not logged into the newborn screening lab will be considered a potentially delivery issue. Babies with newborn screens and no VIP could also, we're figuring, be a homebirth or a data entry issue.

Next slide, please. Babies with no screen ... no screening tests identified. If we find that the baby has expired, then we won't do any further action on that one. If the baby is discharged without a screening being collected, the lab will notify the hospital or birth with directions to contact the parents to bring the baby back for the initial filter collection. The lab will then generate a written documentation of missed screen to the hospital of birth, and then they will merge that record over to the follow-up program, and we will do further action from our side.

Next slide, okay. If the baby was transferred, before screening was collected, to another facility before the initial filter was collected, the lab will contact the hospital of birth and request that the transferred-in hospital be notified to collect an initial filter and forward that filter to the state lab. The case will then be merged to follow-up, but the lab will also ... if they wish to have the responsibility of checking the database for a submitted filter.

So far, at that follow-up, we'll do the following if a baby is transferred. Follow-up will send a letter out. We will send a letter at 2 weeks, and we will send another letter at 4 weeks contacting the PMD and the parent to make them aware that an initial filter was never collected. We will check the Neometrics System, the CMS and the MSDS, after 2 weeks, to see if there's a filter there. We'll go back, and we'll check again at 4 weeks. After that 4 weeks, if there's no initial filter in the system, then that case will be closed out as lost to follow-up.

Okay. If parents refuse screening, the newborn screening follow-up program will do outreach teaching via a letter to the parents. We will



also send a letter to the PMD. Then, we will check back in the Neometrics System at 2 weeks. If there's no filter, initial filter, we will check back again at 4 weeks. If there's no initial filter, then we will send a final letter, and then we would close that case out. We won't continue to do additional follow-up.

So far as data monitoring, with the VIP System, we plan to conduct monitoring ... data monitoring utilizing the system. That will include collecting data on babies that were transferred without sampling, [inaudible 00:26:57] areas with parents that refused. We'll also take a look at ways to improve hospital performance through training. The newborn screening lab, they'll maintain each hospital's rate of unscreened transfers as a quality assurance measure.

Okay. These are the collaborators from New Jersey Department of Health Newborn Screening. Susan, she's here in the follow-up program also. Donna McCourt, Irwin, and Scott ... They're in the Newborn Screening Lab. Okay?

Thalia Wood: Thank you very much, Yvonne. I have one quick question that was typed in. I think I'll go ahead and ask it before we go on to the next presentation. Somebody wanted to know, "On the graph you showed, were those receive dates or birthdates?"

Yvonne Miller: Which one? With the [inaudible 00:27:46] ...

[crosstalk 00:27:46]]

Thalia Wood: On the graph that you showed.

Yvonne Miller: The Julian Date?

Thalia Wood: Yeah, on the graph that you showed.

Yvonne Miller: For the Julian Date?

Thalia Wood: Yeah. This one, right here. They wanted to know, "Did you use birthdates or receive dates?"



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Yvonne Miller: Receive dates.

Thalia Wood: All right. Thank you very much.

Yvonne Miller: Okay.

Thalia Wood: Okay. Our next speaker is Beth Vogel from New York. Beth, have you unmuted your phone?

Beth Vogel: Yes, I have.

Thalia Wood: Okay. Go ahead and tell me when you want me to move the slides.

Beth Vogel: Okay. Thank you. Good afternoon. I'm Beth Vogel. I'm the follow-up supervisor at the New York State Newborn Screening Program. I'm going to tell you a little bit about a project that we did to match vital records and newborn screening data. Next slide, please.

Just a little background information ... There's about 250,000 births per year in New York State. We're a little bit unique in that the vital records data is processed by New York City and Upstate New York separately. So, we actually have 2 separate data systems to contend with for matching data. Next slide.

So, the procedure in New York for how we started with this process of matching vital records and newborn screening data ... Before we even started, we were able to get the laboratory ID number added to the data that was collected for vital records for both Upstate New York and New York City. So, there is a field in the electronic vital records database, used by the hospital, where they can enter the lab ID number. Much like other states, they can also enter a reason if they do not enter a lab ID number, for example, if the baby expired or if the parents refused, so that we still receive a record.

The Upstate Vital Records Data and Newborn Screening Data were compared between April 2008 and April 2011. The initial match was done using the lab ID, and then an additional match was done using



demographic data. Any records that did not match, we were able to analyze and look for trends. Our initial goal with this project was not necessarily to follow individual babies. Though, that's ultimately what we would like to do. But, it was to look for trends and see what the scope of unmatched infants would truly be. Next slide.

This next slide shows what the process looks like. I'm not sure ... So, the ... At the hospital level, the data is written on the newborn screening collection card. Or, now, some hospitals enter that electronically. Then, someone here at the newborn screening program enters the data, and that's our newborn screening dataset. At the hospital, someone also enters the birth certificate data into an electronic system. That's called SPDS for Upstate. Then, that data is matched electronically through a program developed at part of the Health Department in New York.

The ... For this 3-year study that we did, we found 2,702 unmatched records. However, once we excluded deceased infants and refusals, we had 1,705 unmatched infants. That represented less than 1% of babies born during that time period that did not match in the database. So, that was our group of infants for us to look more closely at and try and figure out, "Where weren't they screened? Is there anything that we could do to improve? Or, were they in fact screened and we just didn't match them using our system?" Next slide.

So, the remainder analysis is what we called our process to look at those 1,700 babies. We started by grouping them into whether they were a hospital associated birth or non-hospital associated birth. We had 778 infants who received care at a hospital. We went through the list of these infants, and were able to find that 130 of them were transferred to another hospital within New York State and actually had been screened. But, one of the matching criteria was hospital of birth, and so some infants did not match because the hospital of birth was different than the hospital that submitted the screening specimen.

There were also 26 babies that were transferred to a hospital in Pennsylvania and did have a Pennsylvania screen, but we didn't have record of that here. For the non-hospital associated births, there were 927 infants that were not matched, and 88.6 of those were home births.



51.9% of the home births had a common, Old Order Amish last name, so we were able to figure out that many of these babies were likely Amish. Next slide.

So, what did we learn from doing this project? We learned that greater than 99% of babies born in Upstate New York are screened, with a high match rate using our criteria, including lab ID, and then demographics as a second tier match. We then had a pretty significant effort required to determine if the unmatched infants were in fact not screened. It takes a lot of ... It took a lot of time to do that matching and trying to figure out what happened to those 1,700 babies.

It also appeared that a large number of our unscreened infants were from Amish communities. So, we are planning some outreach to those communities, as well as developing some brochures to distribute to the local counties regarding newborn screening. We also, for infants that were not born at a hospital, realized that about 20% that were unmatched were actually hospital transfers, and that's an education point for us for our hospitals regarding collecting a specimen prior to transfer. Next slide.

So, our next steps for this project are to perform matching on data from the New York City Vital Records, which we recently obtained the ability to access, and also to develop a mechanism for automated, ongoing, real-time matching. Our ultimate goal is really to be able to find individual babies that were not screened, and perform follow-up, and try and get a screen sample on those babies. But, we're not quite to that point yet.

I think our first look at the New York City data will be to try and figure out what the scope of the issue is and what would be reasonable to do for follow-up. So, we also need to develop some protocols for following up with unmatched infants and, similar to what New Jersey discussed, "What could we do, and what would be reasonable to try and get a sample from these babies?" So, we've got a lot of work to do, but have made some steps in getting towards this making sure every baby gets screened, which is really important for us.



- Thalia Wood: Yeah. Thank you, Beth. You have a lot more births in New York than a lot of states, so you have a bigger job there. There was one real quick question before we go on to the last presentation. They want ... Somebody wanted to know if you could share your matching algorithm.
- Beth Vogel: Yeah, absolutely. Yeah, I'd be happy to send that along to you, if you'd like, so that you can ...
- Thalia Wood: Sure.
- Beth Vogel: ... post that on the website.
- Thalia Wood: Absolutely. That would be great, Beth. Thank you.
- Beth Vogel: Okay, sure.
- Thalia Wood: Okay. Our last presenter, and then we'll have ... I have a question for all of the speakers, at the end, after Lou presents. Then, we'll get into discussion. Lou, are you unmuted?
- Lou Bartoshesky: I guess.
- Thalia Wood: Okay. Yes, I can hear you. Tell me when you want me to move the slides.
- Lou Bartoshesky: Okay. I'm from Delaware. I'm the pediatrician consultant to the team. We have ... We're like South Dakota, about 11,500 births a year. We're going to sort of go through the steps of what we do, how to make sure we don't miss any babies.
- So, again, the 11,000 births, or 11,500, are from 6 different hospitals. Hospitals, for the most part, are very cooperative and collaborative with us. What happens is each week, our follow-up team receives a secure file from vital records. This then is uploaded to our Vital Records Reconciliation Program and Natus, and it conducts a match with the newborn screening records so the birth certif- ... The vital records, which is birth certificates and newborn screening records, are cross matched.





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The program then gives us the names of infants not matching between the vitals and newborn screening program. Then, we go back to telephone and fax, and we manually check to see if we received a blood spot for the children, each child, and update their records. We have about 20 records, each week, that don't match, and about 210 babies born per week. We found out most of these are due to ... It says, here, spelling, hyphenation issues, wrong names, occasionally a difference in a birthdate.

Then, we ... So, January 2014, this is 3 months, we've identified 2 babies for whom we did not receive a birth screening. We were able to contact the hospitals, in both cases, or the PCP to get a screen for both babies. Annually, that's about right. We rarely miss a baby in Delaware. We [inaudible 00:36:48], people talked about already, that's in the NICU. People move out of town. But, for the most part, we're pretty good. We figured out it costs us about 3 to 4 hours per week of our follow-up staff time. Next, please.

So, I thought we'd talk about one case. So, this is very recent. One of the infants on the Vital Records Reconciliation List was born on 02/27, but was not in the Natus System and therefore, from our point-of-view, had not received a newborn screen specimen. The short-term follow-up staff reviewed the vital statistics, and it was determined that the baby had been born at the really big medical center. According to the records there, the baby had in fact been born there. It had been discharged from the well-baby nursery, uncomplicated course on 03/1/14. That would be 3-1/2 days ... or 2-1/2 days of life. Next slide.

So, one of our follow-up staff contacted the lab, the newborn screening lab; spoke with the chief chemist at the newborn screening lab, and we speak with each other regularly. So, she went through all of the specimen cards that were received from 03/02 to 03/07. I dare New York to do that, to go through every one every day. She did not locate any specimen cards [inaudible 00:37:59] infant. So, from our point-of-view, the baby did not get screened. Next slide.

So, we spoke to the medical center well-baby nursery. The secretary there was very collaborative and helpful, somebody we know by first



name. She confirmed that the infant had in fact been discharged from the well-baby nursery on March 1<sup>st</sup>. According to her records, a newborn screening specimen had been collected for the infant on 03/01 at 12:40AM. Next.

The ward secretary then reported that the infant's primary care physician of record was [Dr. Ty Cobb 00:38:30], and the secretary also provided us contact information for the mother to the staff as well. The follow-up staff contacted the PCP and spoke with the office nurse, who confirmed that was in fact their patient and that they had no record of a newborn screening being performed. So, they agreed to advise the mother to have this screen collected as soon as possible. Next.

Everything worked out nicely. The specimen was collected that afternoon at the hospital, Outpatient Specimen Collection Center, where all our second screens are done; arrived at the lab the next day by our courier. Our short-term follow-up staff called the hospital, the well-baby nursery, reviewed the case, and scheduled a Q&A follow-up visit with the well-baby staff. The institution is very collaborative and very grateful for our study and welcomed us with, recently, with open arms to [inaudible 00:39:23] what happened.

We don't know what happened. We do have a log that the, it's filled out daily, that should have in there every specimen that's been obtained and if the specimen is in fact in the courier's [pouch 00:39:36] each day. This baby's name was not on that list. So, we assumed that the specimen either didn't get taken, or it got taken at the hospital and got dropped before the specimens were all collected together and put into the transport envelop. Next. Was that the last one?

Thalia Wood: That was ... That was your last slide.

Lou Bartoshesky: So, we have an Amish population in Delaware as well. We have about 100 babies born each year outside of hospitals, homebirths. That doesn't include another 75 or so that are born at a birthing center. So, and the vast majority of the babies born outside of the hospital, as in New York, are Amish babies ... the vast majority. Actually, we can only think of 3 or



4 babies that have been born outside the hospital in the last few years. Although, we expect that to increase.

We've been lucky enough, so far, that babies born outside of the hospital, as far as we know, the family or the midwife [inaudible 00:40:34] birth certificate forms. So, they do make it into vital records, and so they should be picked up by our system. So, that's where we are. We have a fair amount of personal follow-up on other cases when this doesn't work as well as this one. Again, we do a lot of this by hand by our loyal, short-term follow-up team.

Thalia Wood: Great. Thank you very much, Lou. One question to all of the speakers, all the speakers can unmute your phones right now, is how do you deal with adopted or safe haven babies?

Lou Bartoshesky: Well, in Delaware, if they're born in a Delaware hospital and they're adopted from there, we actually get the specimen the same way we do anyone else and ask the hospital to let us know about the adoption agency and follow-up. We haven't had a safe haven, as far as I know.

Thalia Wood: Beth, do you have any way of dealing with that, in particular, in New York?

Beth Vogel: We've had some phone calls. We get, maybe, every couple of months we get a call about a safe haven baby. We usually tell them just to collect a specimen because we have no way of knowing whether that baby was screened or not. They hopefully probably were, but we just tell them to collect one.

Thalia Wood: Yvonne, in New Jersey, do you have anything that you do differently [inaudible 00:42:01]?

Yvonne Miller: So far, the adopted babies and the safe haven babies, I'm not sure. I know ... I'm not sure of any cases that we had that were safe haven babies. So far as adopted, usually it's the adopted parents name that go on the initial filter kit, but we ask the hospital to just put in the remarks box that that is ... that baby is adopted so that we will know that when we enter that information in the lab, that that baby and the parent is ...



The parent is not the natural parent. So, otherwise, when we go to do the EBC information, sometimes we run into a problem when we enter that information.

Thalia Wood: Okay, thank you. Lucy, how about for South Dakota?

Male: Unmute.

Lucy Fossen: Am I ...

Thalia Wood: Yes.

[crosstalk 00:42:57]

Lucy Fossen: [Inaudible 00:42:57].

Thalia Wood: Now we can hear you, yeah. Thank you.

Lucy Fossen: I don't have a lot to add. I just ... My thoughts are that the South Dakota facilities are really pretty good about communicating with the Department of Health, the Newborn Screening Program on those unusual circumstance of safe haven and adoption. We're kind of able to kind of connect the dots.

Like, I think it's been mentioned, it's usually encouraged to put any of that on the collection card. The birth certificate, in our state, it is the birth mother, and we've encouraged the hospital, even in those situations, to put the birth mother on the collection card. But, there have been instances where the mother did not want any ... The birthing mother wanted nothing written down, and we just worked with the facility because it was just an unusual circumstances.

Lou Bartoshesky: If we have an international adoption and the primary care notifies us, we just say, "Go ahead. We'll do it." We do it, actually, well after several months; probably longer than we should.

Thalia Wood: I think that's going to be a topic for one of our future calls.



Lou Bartoshesky: Yeah.

Thalia Wood: It looks like there's been some questions asked over here on the side. One of them is how many states link their blood spots to [hearing 00:44:17] and CCHD. Marci, do you want ... Carol, do you want to unmute your phones and see if you want to lead the discussion? Do you want me to unmute everybody's phones and have a discussion now?

Carol Johnson: This is Carol. We could try that and see how much feedback we get.

Thalia Wood: Okay. [Inaudible 00:44:36].

Carol Johnson: Otherwise, if somebody has something ... If we have too much feedback, then we'll just have to go back to the \*7 if somebody has anything to say. So, we're going to open this up. Does ...

Female: The conference has been unmuted. The conference has been muted.

Thalia Wood: Okay. That did not work. We tried to unmute the phones, and people will have to just \*7 if you have a question. I do have another ... So, one question, of course, is about linking hearing and CCHD on the blood spot, or linking with the blood spot data. I don't know how many states do that. That's something we could probably do a poll later and ask.

Marci Sontag: Thalia, this is Marci. Can I just address that real quick?

Thalia Wood: Sure.

Marci Sontag: So, that is a question that we are trying to record within the new [inaudible 00:45:31] repository. So, in the how do you link, how do you connect between EBC, CCHD, EDI, all of those types of information? So, many of you have probably received an email from [inaudible 00:45:45] trying to schedule a time that we can call you and walk through some of those data repository questions and really get some of that data entered. Recognizing that it's not fun to necessarily sit and enter information on your state profile, and it's state profile information that is not covered under the memo of understanding. This is publically available information. But, we're just trying to collect in a uniform manner.



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So, many times it's hard to enter data on your own, so we're ... We, at NewSTEPS, are going to reach out, call you, and spend 30 to 45 minutes on the phone. It'll be [inaudible 00:46:19] or [Calima 00:46:20] going through some of these questions. So, hopefully, in the coming weeks or months, we will have a lot of that information to be able to share back out and report to all of you.

Thalia Wood: Thank you. Yeah, we will do that. Then, one of the other comments, it's actually a comment. It's a very long comment, so I'm going to read it out for people. This is Laura Taylor from Colorado who said, "We had a case of a baby in a battered women's shelter that was just a borderline, but we decided to pursue it to see what it took us. We got to the point of being told that we'd need to go to court to break the confidentiality, and the police patient advocate ..." What does that say? "Said he had gone to court many times and had never prevailed. As far as adoption, we go through the adoption agency counselor, and that way we don't have to work with names."

So, that was the feedback from Colorado. I don't know if anybody else has any other feedback. If there's any questions, please, again, do \*7 and unmute your phones, and you can ask a question or you can type it into the chat. [Inaudible 00:47:21] ...

[crosstalk 00:47:21]

Lou Bartoshesky: Does that mean that baby did not get screened in Colorado?

Thalia Wood: I don't know. Laura, do you want to unmute your phone and answer that question?

Lou Bartoshesky: [Inaudible 00:47:39].

[crosstalk 00:47:39]

Thalia Wood: [Inaudible 00:47:39].

Lou Bartoshesky: No.



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Female: I do not know.

Lou Bartoshesky: Okay.

Thalia Wood: I'm not seeing any other questions or anybody else ... Actually, I do have a poll ready. Marci, did you want me to put up the one question that we had for the poll? [Inaudible 00:48:00].

[crosstalk 00:48:00]

Laura Taylor: [Inaudible 00:48:00].

Thalia Wood: Laura, \*7 to unmute.

Laura Taylor: Hi. It turned out that mother left the battered women's shelter, and the baby did get a screen. But, what the counselor told me is, "Yeah, even if it were a matter of life and death, the judge would probably not let us break confidentiality," which shocked me.

Thalia Wood: Yeah, that is. Hmm. Well, I have a poll that I'm going to go ahead and put up here. If the people that are on the phone want to go ahead and vote, you can do that now. It's how do you ensure babies are screened? I don't have a lot of character spaces to put in for the answers, so just use electronic matching for the electronic birth certificate; electronic matching with hospital records; case matching with hospital records; match [inaudible 00:49:02] birth numbers; or no matching. We just wanted to kind of see what people are saying on this poll. So, if the people on the phone, you can click on one of these answers, and I'll show the results here in a few minutes.

While we're waiting, Carol, do you have anything else you want to add?

Carol Johnson: No. I think we're good. Hi. This is Carol. I think we're good. While people are voting, I'll take just a moment to say that one of the things that we're trying to do in this group, when we have these webinars, is to make sure that we're representing various geographical sections of the country, as well as different demographic sizes of states or programs so



that everybody gets a chance to be represented. The reason ... One of the many reasons we do the state profiles is that, number 1, people ask to learn more about what's going on in other states, and it also is a great way to share information. I really do think that we can learn a lot from each other. So, that's why we are continuing to do the state profile.

Thalia Wood: Thank you. This is Thalia again. We also really do appreciate your feedback. I send out the 3-question survey at the end of these calls. We definitely use your feedback. We put the topics that are suggested into your topic list, and we're trying to make sure we do topics that are pertinent to everyone.

Right now, I ha- ... I don't know how many states. Becky asked, "Do I know how many states this poll represents?" So far, there's 40 responses. I don't know if that means there's 40 states or if some of these are from multiples within a state. I have no way of knowing that, unfortunately.

So, I'm going to go ahead and skip to the results right now. [Inaudible 00:50:57] 41, so I'll go ahead and skip to the results.

Marci Sontag: Yeah. So, Becky, this is Marci. That's an excellent question, and this is ...

Thalia Wood: It is.

Marci Sontag: ... definitely not meant to be a scientific poll. This is just to say, "Of the people who are on the phone, what types of things are people participating in?" We will have more formal answers once we have our NewSTEPS suppository populated.

Thalia Sontag: Thank you, Marci. That's correct. So, as you can see from the people that responded, there's actually quite a few that are now matching with the electronic birth certificate, which is great. Marci, did you want to talk about this for a minute?

Marci Sontag: No, I don't think so. I mean, I think this is a interesting ... interesting representation that is actually kind of equal between the electronic matching and no matching. So, hopefully, over the coming years, we can





all work towards getting a method to match and learn from what some of the groups presented today. So, thank you all for your participation.

Thalia Wood: Absolutely. I want to thank the speakers again. You all did a great job. For those of you on the call, if you know people that couldn't make it to the call, we do have these recorded on our website, along with the transcription. We will have that up, hopefully, within the next week or so. Keep checking back there. All of the old webinars are there as well, in case you've missed any in the past. Carol, do you want to just wrap it up and say "goodbye" to everybody?

Carol Johnson: I just want to, again, thank all of the speakers for their hard work ... very, very informative. Thank you, Thalia. You, again, are amazing at running this and keeping us on course, and just wishing everybody a happy May and happy short-term follow-uping. That's my new phrase.

Thalia Wood: Thank you so much. Okay. Well, we'll have another webinar in July. Thank you, everybody.

Carol Johnson: Thank you! Bye.

Thalia Wood: Bye.