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March 2014 Short Term Follow Up Webinar

March 3, 2014

Presentations:

- State Profile Illinois—Claudia Nash, MS
- Newborn Screening Education in Texas—Debra Freedenberg, MD, PhD
- A Parent's Perspective on NBS Education—Kay Kelly
- Health Information Technology (HIT) Work Group—Andrew Richardson

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 or 240-485-2701.

Carol Johnson: My name is Carol Johnson, and I'm from the Iowa Newborn Screening Program. I'm the co-chair of the APHL short-term follow-up work group. On behalf of APHL and the short-term follow-up work group, we'd like to welcome you to today's webinar. As we have in the past, we're going to start today's webinar with a state profile. We've gotten some questions as to why we're doing these state profiles. I thought I'd take a few moments and tell you why. We continue to receive feedback that people would like to know what's going on in newborn screening in other states. Doing these state profiles gives us a chance for programs to highlight how they do things and to educate us on what might be something unique about their state's program. It also allows the state to report their most recent data, such as their number of births or confirmed cases.

Our plan is to have a mix of small, medium, and large state programs to present their information in order to give everyone the flavor of what life is like for your colleagues from around the country, both the great things that we deal with and the challenging things. In the end, we hope that this is educational and informative for everybody on the call. On that



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note, it is my great pleasure to introduce Claudia Nash from the Illinois Newborn Screening Program to do the Illinois State Profile. Claudia, I'll turn the program over to you.

Claudia Nash: Thank you, Carol. Thank you very much and thank you for inviting us to share a little bit of information about what's happening here in Illinois. I appreciate that. We'll just go ahead and ... Are you going to advance the slides for me? I think someone is.

Carol Johnson: Yes, just let me know when you're ready.

Claudia Nash: Okay, go ahead to the next slide. In Illinois, we have about 125 birthing hospitals in the state. That's quite a few hospitals I think compared to some states. We also do try to monitor the non-hostile births, mainly the home births, to make sure that parents are aware of newborn screening and we try to follow up to make sure those babies are screened. We do not currently have a way to match our screening records with the birth records, which is a source of a lot of frustration for us. We know that we're not able to collect some of the data that some states have just by that very problem that we have here.

We give out about 2.2 million dollars annually in grants to about 60 different agencies and those are to local public health departments to help us do follow-up on newborns. They are to genetic centers, and we do have some regional genetics clinics, diagnostic clinics that we fund through those grants and also to pediatric hematologists. We give about 1 million, almost 1.75 million dollars in medical formulas each year. We require no co-pays and no income eligibility. We do not provide any coverage for foods, though, however. Our entire program is funded by the newborn screening fee, which currently is \$88 but will go up to \$90 effective July of this year. You can go to the next slide.

Our time line, you can see there, I think it's kind of typical of most states. We did pass legislation in 2013 to add CCHD screening, although our director has determined that we really shouldn't play much of a role in that and we are not currently collecting any data on pass/fail rates or anything regarding to that. We just said education to the hospitals and that's about it. We will be adding lysosomal storage disorders by July 1, if not before, and we're under mandate to test for seven disorders, although at this point in time, MPS II testing is not available. We are also adding SCID in a pilot in April and we'll be going full-scale by July 1.



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In Illinois, we roughly have 160,000 births each year. We test about 175,000 samples. The follow-up program follows approximately 15,000 abnormal cases and that's also [inaudible 04:33] sickle cell traits, that kind of thing. We diagnose roughly 300 cases a year. In 2013, there are still some pending cases so we're just around 260. Our data in terms of diagnosed cases, you can just look at that yourself. We won't really go over that. It's the next slide as well, but as you would expect, our highest diagnoses are congenital hypothyroidism, sickle cell disease, and CF. Then we do also have a fair amount of sickle cell traits and other hemoglobin traits, about 4,200 per year, and about 450 of CF carriers. Okay, next slide.

On this slide, I'll just mention that we do not have a way really to monitor how many babies died without screening or were screened out of state or refused screening. We do get notified occasionally of those, but we don't have complete data on any of those particular items. As far as our additional activities and new developments, this is in no particular order, but we did, as I said, we added critical congenital heart disease last year. We'll be adding SCID and LSD by summer. We do have three, that should say Quality Improvement Collaboratives, I didn't catch that, for CF, sickle cell, and lysosomal storage disorders where we meet monthly with the subspecialists in each area and just discuss activities at all the centers and what we're doing here at the state.

We have good partnerships with the sickle cell disease association of Illinois. We're involved in Region 4 and we're also fairly well-involved with our Illinois Chapter of the AAP. We have very strong genetic and metabolic diseases advisory committee and a couple of our members actually sit on the secretary's ... Well, now the discretionary advisory committee. We provide for overnight specimen delivery through UPS, which has certainly helped our specimen delivery time tremendously. We also provide feedback to all the birth hospitals by giving them orderly specimen submission reports too so they can monitor their timeliness of specimen submission.

We've implemented a program where we were asking for repeats on a fairly high number of samples that just had missing information, especially timing of specimen collection and we have actually reduced that by 85% by contacting the hospitals and getting accurate data to correct that before we ask for a retest. We do notify all families of sickle cell trait. We've been working on an HL7 interface with some of the birth



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hospitals in Illinois to exchange data and we're ready to go live with our biggest birth hospital, which is in Chicago, Northwestern University, which they have about 1,000 births per month.

We're starting to look into weekend operations, at least on Saturday, because currently we are not open on Saturdays, either the lab or the follow-up program. This is kind of thrown on at the end. We do follow all diagnosed cases for 15 years. We've been doing that for quite some time. We collect certain long-term follow-up data on each case and then we will share that with the specialists if they're interested in looking at that data further. We're also involved in the region 4 long-term follow-up initiative. I think we all know this, to be successful at newborn screening it requires teamwork from a lot of different components. I think we all are well aware of that and try to reach out to all these groups.

We feel like all of our partners are very helpful to us in Illinois, and we've got a good I think working relationship with everyone. That's really it. I want to thank you for this opportunity again. Feel free to call myself or any member of our staff and we'll be able to certainly clarify anything or answer any questions that you might have. Thank you.

- Carol Johnson: Thank you, Claudia. That was very nicely done. I appreciate your update on what's going on in Illinois.
- Claudia Nash: Thank you.
- Carol Johnson: Thalia, are you going to take over from here or would you like me to?
- Thalia Wood: Can you hear me?
- Carol Johnson: Yes, we can.
- Thalia Wood: Okay, I wasn't sure if I was muted or not. Sure, I can take over. Next we have Debbie Freedenberg that will be talking to us. She will be talking to us from the state of Texas on some of the educational materials that they've developed there. Debbie, are you on?
- Debbie Freedenb: I am on. I am now unmuted. Thank you for inviting us to share with us our educational efforts. We took the approach in this talk about how we bring up new conditions, education related to the conditions we're adding on to newborn screening panel. Just to lay a background, I guess I don't have the slide control ... Next slide.



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Carol Johnson: Okay. You got it.

Debbie Freedenb: Okay. Go back one.

Carol Johnson: You go ahead and advance the slide, Thalia.

Thalia Wood: Okay.

Debbie Freedenb: Texas has over 380,000 births per year and we're a two-screen state, which means that our newborn screening education has to be provided to a diversity of newborn screening providers and stakeholders. There are hospital nurseries, birthing centers, primary care providers, specialty providers, and families. We have a very large number of providers, and I don't think it would surprise anybody to tell you that Texas is a big state geographically. In addition, both the statewide laboratory and our follow-up program is called Clinical Care Coordination Services are provided from the Central Department of State Health Services location, but we're in two different administrative divisions. I will leave it to your imagination the challenges that that can sometimes present. Next slide.

Generally we have about a one to two-year lag from legislative approval to implementation. We can add on any condition that is on the panel, but realistically, we do need startup funding and that usually requires a legislative approval. We start out by identifying subspecialists from around the state. I was going to contrast the last two conditions we added, one was Severe Combined Immunodeficiency and we're about to add on screening for Critical Congenital Heart Disease. I was going to contrast a little bit of the two ways we've approached it.

We start with the ad hoc technical support work groups. We have face to face meetings. We invite all specialists statewide who are boarded in a specialty area to the ad hoc meetings. Obviously not all of them show up. We contact the State Specialty Organization if one exists, both to identify subspecialists that might be appropriate to serve on the ad hoc committees as well as to begin awareness. For Severe Combined Immunodeficiency, we were in contact with Texas Allergy, Asthma, and Immunology Society but we also had a pilot going in. We had some very strong advocates for initiating SCID screening in the immunology community.



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We utilized this work group for technical support. We discussed our processes, flows, logarithms, [inaudible 12:40], lab cutoffs that are proposed by DSHS. For CCHD in contrast, there was no specific Texas Pediatric Cardiology organization, but we did identify Texas pediatric cardiologists who were interested in newborn screening for CCHD. Next slide.

These work groups became really advocates. They were advocates to implementation of screening, but more importantly they were educating their colleagues as well. We had a built-in buy-in to initiate screening of newborn screening system components. They helped us identify critical elements that they felt were important in long-term and short-term follow-up. In addition, they reviewed and provided input on the ACT and fact sheets developed by DSHS that were based on the ACMG ACT and fact sheets as a two-screen state. We do need to modify the ACT and fact sheets frequently, or more accurately, the ACT sheets. They helped us to review the educational materials we were developing. Next slide.

We have taken the task that, as everybody knows, newborn screening is a system. It's not just the program. We have put into place a number of mechanisms that help us share information with the system. We share information with system stakeholders during routine conferences, conference calls that are every six to eight weeks, and those consist of Texas Medical Association, Texas Pediatric Society, Texas Hospital Association, Texas Family Medicine Academy, and the March of Dimes. We have yet to find an OB provider group that's interested in participating. We have a Newborn Screening Advisory Committee. We also communicate with the newborn screening submitters over a newborn screening listserv with well over 2,000 providers and stakeholders. Next slide.

We also do a lot of outreach for newborn screening educators. We have educators within the programs. Laboratory educators tend to focus on laboratory processes, so for new conditions they would be alerting the stakeholders of new result codes and [notes 14:54] notifications. In critical care coordination, our educators tend to do a lot of outreach. They attend multiple state medical conferences with the newborn screening exhibit and provide information related to screening and multiple brochures. In addition, they can go out and provide on-site education and CE approved newborn screening modules and that can be provided around the state.



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We have a web educator and have a newborn screening newsletter that is put out featuring the condition. Information is posted on the DSHS website and emailed to the newborn screening listserv. Next slide. Then in addition, the medical director, who is me, seems like I do a dog and pony show, I go out and do multiple grand rounds around the state on newborn screening, always incorporating education on the new conditions and on what's upcoming. Most of the organized medicine in our state winds up inviting me to present talks at their meetings at organizational and annual meetings. Often they'll have sessions that are directly related or dedicated to the new upcoming conditions. For example, at the last TPS meeting there was a whole section on CCHD. Next slide.

This is just a picture of our newborn screening exhibit. We do have an LCD screen that's up so that when we need to change information, we can change the DVD rather than the whole exhibit. The people on the screen are Tasha Reese, who is the CCC educator, Joan Strong, who works with Texas Health Steps, and we'll talk a little bit about that. I'm in there. Then we have two neonatologists who are strong newborn screening advocates, Dr. Charleta Guillory and Dr. Alice Gong. I do have to say one thing about our exhibit, though, is we designed it before we really were aware of all the rules that were around exhibits. Our exhibit is eight feet wide and it turns out most tables are six feet wide. We're always maneuvering it to try and get it to fit properly at the various medical meetings around the state. Next slide.

We do have web-based resources as well. As we said, the condition is featured in the newborn screening newsletter. Texas Health Steps has CME-approved online education modules, so these are full generally hour-long CME modules. Texas Health Steps is funded by Texas Medicaid and they have around 50 CME-approved and CE-approved online education modules that are open to anyone who wants to take it, who wants to spend the time reviewing the modules. Often they have pre-test and post-test as is required for CE-approved modules. In addition, we have newborn screening grand rounds and that goes live as well as the webinar when it happens and then we archive the grand rounds.

We develop many brochures and for CCHD a tool kit was developed. All of the information is available on our newborn screening website. Next slide. In terms of developing the educational materials, we develop brochures for providers and families. We already spoke about Texas



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Health Steps and the website is up there. The modules in Texas Health Steps that are related to newborn screening is a newborn screening sickle cell and trait, newborn hearing screening, when to refer to a geneticist, CCHD is in development, but we'll update. Those modules get updated yearly or I think they're soon to go bi-yearly and so we'll always update the modules to include the new conditions. We'll schedule a newborn screening grand rounds with a nationally prominent speaker.

The CCHD we fund in an educational initiative that developed a tool kit for CCHD screening. The tool kit has been posted onto our website. Next slide. This is a picture of our SCID brochure. For the SCID brochure, we actually did one brochure that was for both families and providers and managed to keep it in a level that was appropriate for those providers and the families. Next slide. As I said, for critical congenital heart disease, we funded an initiative that Dr. Gong and Dr. Guillory, whose pictures you saw a moment ago, were the co PI's. The tool kit contains logarithms, brochures for parents and health providers, nurse information, technical information, parent vignettes, and we've re-funded the project now.

We're calling Tex [inaudible 20:03] that's related to newborn intensive care unit protocols in rural hospitals and as many of you know, for the NICU's there really is not a good protocol out currently. Next slide. Some more things that are included in the tool kit is open to anyone. All of the materials we develop are at no charge and open to anyone who wants to access them. Next slide. We also do some internal education with all of this heavy effort on outreach education. We have a monthly Tales From The Crib that's the equivalent of a morbidity and mortality conference. It's actually a pretty popular conference. That's where we discuss cases that didn't go exactly quite as we would've hoped or expected. Sometimes there's some really unbelievable information that comes back to us from the system. It really helps us identify system issues.

In addition, we have a newborn screening journal club that's meeting bi-monthly, or every other month, that is dedicated to newborn screening. Both of these conferences also are CE-approved. Next slide. Then as a segue to our next speaker, we have developed a brochure that's targeted at prenatal providers and this is just a copy of it. All of our brochures are both in English and Spanish except for this one that is really targeted to providers. What we've aimed to do is to bring in our whole system and to do system-wide education, but throughout this all we've really had one consistent message, and that's newborn screening saves lives. In any



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other way we put it, with all the details, that's always front and prominent.

It's a short tag line and it's true and I think it catches our system's attention and helps to involve folks in the newborn screening, both the educational processes as well as the follow-up processes. I'm going to stop here, because I did a fairly very quick brief overview and see if there are any questions.

Claudia Nash: Thank you so much, Debbie. Does anybody have any questions before we go on to the next presentation?

Thalia Wood: There's a question that someone's typed in. It says who participates in the Tales From The Crib monthly call?

Debbie Freedenb: It's our newborn screening program, so it's a laboratory, it is clinical care coordination. We have our nurses that are doing the follow-up calls that participate in that and some of our newborn screening administration participates as available. We have had requests from another state to join in by conference call and we did get that approved, but apparently they never called in. Right now it's still staying at the Texas level.

Thalia Wood: Thank you. Somebody was asking too if they could get a copy of these slides. All of these calls are recorded and will be put on the [inaudible 23:20] website and everybody will have access to see the slides as well as to hear the talks. There is another question.

Debbie Freedenb: Sure.

Thalia Wood: How have you incorporated issues around dried blood spots retention times into your educational materials?

Debbie Freedenb: We do have education around that as well. When we do our general newborn screening talk, when I go out and do it or anybody else does it, there is a standard set of slides that we all utilize that talks about our blood spots retention times and what our state law is. Many of you may know that our law flip-flopped a couple of years ago from having to opt out from keeping those spots to now it's an opt-in and we call it a parental decision form. That is always incorporated into any general newborn screening talk or anything that's related to newborn screening education. We do have some separate brochures and we do have



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additional educational material related to that. We also have ... The laboratory does spend a lot of time educating around this issue as well.

Thalia Wood: Okay, great.

Speaker 8: Dr. Freedenberg, this is Jelili. Can you hear me?

Thalia Wood: Yes.

Debbie Freedenberg: Yes.

Speaker 8: Just quick, I wanted to follow up on something you said earlier in reference to adding a new condition to Texas newborn screening program. You had noted that when a commission is added to the [inaudible 25:01] that you have a mandate to add that condition and it takes about a year or two lag time for those conditions to be added pending funding. Is that correct?

Debbie Freedenberg: Well it's as funding will allow. It's usually a year or two after we know we have the funding is the lag time there.

Thalia Wood: Okay, thank you.

Debbie Freedenberg: I have to say, when I was putting this together, I was exhausted when I realized everything we were doing. Now I know why I feel like I'm so busy.

Marci Sontag: Debbie, this is Marci and I'd like to say thank you so much for presenting this. For those of us who may not have a Dr. Freedenberg in our states to do some of this, there are many gems that we each can pull for our own state. We might not have to implement the entire system that you have, but take little bits and pieces of what you've done. Thank you for demonstrating all of the effort that you've put into this.

Debbie Freedenberg: Absolutely.

Thalia Wood: There is another question that came up. You are the medical director for Texas State Health Department, or specifically newborn screening. How did you find time to do grand rounds specifically for newborn screening?

Debbie Freedenberg: I'm the medical director for newborn screening and genetics at Department of State Health Services. I'm not the medical director for the



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whole health department, although it seems like I'm getting pulled into more and more things. We made that a priority for grand rounds. I'm not certain whether you're talking about the speakers that we have coming in, or me going out and doing the grand rounds. I think there are a couple of things that we do have a little bit of advantages. One is when we bring in our medical grand rounds speakers, they're usually nationally prominent folks and they do get a lot of attention. It helps us also educate around the country about our program. It's a win-win situation for us, too.

Certainly when we started up, we had some folks that were prominent within the overall system and then we kind of honed down. For this year, our speakers are ... We already had somebody do a CCHD talk. We are scheduled to do a Pompe talk. We are having a ... [inaudible 27:14] will be talking about basically ACA and system issues with the ACA changes this year. We target our grand rounds around what we think is hot topics or things that we're going to be heading forward. We try to be forward looking so that this also serves as an early warning system for us. In terms of me personally going out to do grand rounds, sometimes finding time can be difficult. I mean, it takes a lot of negotiations as most of you know to find an appropriate time.

I do think that it's really urgent and I know that most states don't have this advantage, but when a physician is talking to physicians, people tend to get more involved and invested and they tend to really respond to things. The other thing it also provides them for is they now have a face, so that when they have a problem with newborn screening, they give us feedback pretty quickly. They know they can call me, or actually they can call anybody in the program, but usually they're calling me. It also helps serve as part of my role as liaison to the medical community and it also helps serve that. The community has been very, very generous in responding and they've put me on some of the medicine ... I'm on the Texas Pediatric, I'm formally on some of those committees and I'm usually invited in to comment on or give a report on newborn screening at some of the TMA committees.

It works all around. It's an all-around system where there's feedback and once you go out and see that, then they start engaging and responding to you, which is great for the program because not only do they become advocates for the program, but also if there's something that maybe could work a little better we get early warning on it. We don't have to



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wait until things explode when they feel free to call [crosstalk 29:14] and address problems.

Thalia Wood: Thank you very much. Looking at the time, let's go ahead and start with Kay's presentation and we'll unmute the phones at the end for questions. We actually have a short survey we want to do at the end as well. Let me introduce Kay Kelly. Kay, hopefully you've unmuted your phone, star seven. Kay was a member of Baby's First Test 2013 Consumer Task Force, and she's going to talk to us about some parents' perspectives. Kay, go ahead.

Kay Kelly: Hi, can everybody hear me?

Thalia Wood: Yes.

Kay Kelly: All right, thank you. Thanks for that introduction. It's very much an honor for me to be able to present my project from the Task Force and also give a parent perspective to the group, so thank you for that opportunity. A little bit about our newborn screening story and how I got involved in newborn screening. This is a picture of my family, my husband, my older son who was two at the time, and my little guy was only two days old here. I had had two healthy pregnancies at this point. I was one of those people who read through all the books, took all the classes. As of this point in time, I knew absolutely nothing about newborn screening.

We left the hospital the day after this picture was taken, when our son was three days old. As far as we knew, he was perfectly healthy. There were three pediatricians, three different pediatricians who saw him while we were in the hospital and everybody said he looked great. We took him home when he was three days old and we got a phone call that very night from our pediatrician who hadn't even met our son yet because we were using the pediatricians that were on staff at the hospital since our pediatrician didn't have privileges there.

He told us that our son had screened off the charts for MCAD and gave us all the information we needed to know to keep him safe and all the follow-up appointments we were going to need after that. That night, I went back through the folder of stuff the hospital sent home with us. Although I did find a handout on newborn screening that listed a lot of information about the conditions that it checks and it was very informative, I also found it very heavy. There was lots of medical



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information. It wasn't very easy to read. I could see why I maybe didn't read it with my first baby and I could see how I might not want to read it at all except I had just gotten this phone call and I was really desperately looking for some information.

In the coming days and months and years, the metabolic clinic and our pediatrician were really wonderful, though, and got us up to speed on everything we needed to know. We definitely gained a really deep sense of appreciation and gratitude for newborn screening and the information had given our family that allows us to keep our son healthy and take care of him. That said, I did continue to spend a lot of time scratching my head about newborn screening. Something so very important saved my child's life, yet I knew absolutely nothing about it and that was bothering me.

As time passed, I kept coming back to the things I wish I knew about newborn screening. First, I wish I knew it was going to happen in the first place. How did I miss it, after all those books and all those classes? No one ever mentioned it. I don't remember it happening in the hospital. I just wish I knew it was going to happen. Secondly, I wish I knew why it was necessary. Again, as I said, there were three separate pediatricians who saw my son in the hospital. Everyone told us he was healthy and I didn't realize that newborn screening was there to detect the things that even the best pediatricians in the world can't see just by looking at a newborn. Third, I wish I had a greater appreciation for the fact that these conditions can pop up in any family, even ones that you think are healthy.

My husband I have grandparents who lived well into their 80's and 90's. Our parents are healthy. We're both healthy people, yet it happened to us. I think there's that thought out there, it can't happen to us. We have great genes. Well, it does. It happens. Finally, I wish I knew how supportive the newborn screening and metabolic communities would be. From our son's abnormal screen through his diagnostic testing and even now during his ongoing care, they've made everything seem really manageable instead of overwhelming. There we go. I spent a lot of time learning about newborn screening and in my browsing, I came across this nifty piece of literature from the UK. It's basically a time line that shows all of the prenatal tests alongside the newborn screening tests. I thought it was brilliant.

The recommendations are slightly different from what ACOG recommends in the US during the prenatal period, but the idea really got



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me thinking. I liked that there was this piece of literature out there that covered all the screenings that happened, from pregnancy through to newborn screening. It was all in one place, not in five or six different pamphlets. I thought it would be really helpful for expectant moms to have not only those existing pieces of literature that I feel like the OB's hand you whenever you're getting ready to do one of those prenatal tests, and definitely those brochures that they have really go into depth on those, but I thought it would be helpful also to have something like this that puts them all together, kind of an overall overview view of everything that's going to happen.

That's when the light bulb really clicked for me, because in thinking about the best time frame to educate people about newborn screening, I knew from experience that those 48 to 72 hours in the hospital after giving birth aren't really a great time to add any other information to a new mom's plate. She's tired, she's trying to learn how to breastfeed, maybe she's learning how to change a diaper and dress a baby for the first time like I was with our older son. She's got oodles of family and friends coming to visit. Maybe she's got a two-year-old jumping on the hospital bed and trying to talk on the phone like my son was with our younger son. It's just a really busy time and I feel like anything else added to that already busy couple of days in the hospital will either get missed or just end up in the folder to be read later, if ever.

I had two children screened and I never even knew it happened. However, you have nine months' worth of doctor's appointments during your pregnancy and this seemed to me like a great time to at least start a conversation about newborn screening so that you would know it was coming. When you think about newborn screening, though, you automatically think it's in the court of the pediatrician because they're the ones who care for the babies and newborn screening is obviously a test done on a baby. That said, you may not even see your own pediatrician until you're discharged from the hospital after newborn screening has already happened. That was the case with both of our sons.

I felt like a piece of literature that bridged that gap between the prenatal provider and the pediatrician could really help improve newborn screening education and bring it out of that incredibly busy time in the hospital. My wheels were turning a bit here. As I mentioned, I was spending a bit of time searching for newborn screening information and I found the baby's first test website. I noticed that they had this consumer



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task force on newborn screening, so I submitted an application and I was selected to be part of the 2013 consumer task force. For those of you who aren't familiar with it, this is an initiative funded through Genetic Alliance by HRSA.

I spent a year learning about newborn screening with these nine other wonderful moms from across the country. We represented an array of different conditions that newborn screening detects, and it was a really great group to be a part of. We were really good support for one another and it was just a really fun year and a great experience. This picture of us was taken at the APHL conference in Atlanta last year. Shortly after that conference is when we were able to embark on our projects. Each of us was given a \$1500 contract to develop a project that would help raise awareness about newborn screening in our communities. I'm sure you can already guess where my project idea was headed.

My project goals officially ended up being preparing expectant parents for newborn screening, giving them an appreciation for the life-saving value of it, providing a unique really targeted resource to prenatal providers that makes them feel comfortable introducing newborn screening to their patients, even though the test is going to be done on the baby much further down the line. Encouraging parents to learn about newborn screening, ask questions, and actually take notice that their child has been screened. Again, this is such an important test. Finally, to give families something really approachable that doesn't make these disorders seem super scary.

I had a lot of great support on my project. Babies First Test again provided the funding and my fellow task force moms were a really great sounding board for ideas throughout the process. I decided early on that I wanted to work with student designers to keep the cost down. I didn't have a lot of money to do the project, and I thought that would give me a good opportunity to do some education along the way with those students. I found a design program at Metropolitan State University of Denver. They were looking for clients for class projects and they were just really wonderful to work with. The students were amazingly creative, enthusiastic. It was a really great experience I think both for me and for them.

Michelle Merlin is a student in that creative computation course that I worked with in the fall and she ended up coming up with the winning



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design, so I'll give her a specific shout out here. She's a really, really talented young lady. Really bright future ahead of her in the design world and she did a great job designing my project. I also had great advisors with Marci Sontag with New Steps, Laura Taylor with the Colorado Newborn Screening Program, and Erica Wright with Children's Hospital of Colorado and the metabolic screening program there. Erica was actually the genetic counselor that we worked with during my son's diagnosis and she's been a great resource in a lot of respects to us over the last couple of years. She's just wonderful.

The Colorado State Newborn Screening Advisory Committee was also really helpful. I literally came to one of their meetings and spread a bunch of design concepts out on the table and they passed them around and marked them up and helped me select the winning design. They were a great resource to me as well. The assignment we gave to the students was to create a time line that includes both the prenatal and the newborn screening information, again, trying to be that bridge between those two areas. I packaged all of the ACOG recommendations for them and had my advisors help me make sure that we were stating everything accurately from a medical standpoint.

I do not come from a medical background, so I wanted to make sure we were saying the right things so the prenatal providers would actually want to use this literature that we were developing. The students were really creative. We had a lot of different concepts to choose from in the end. In their creativity, we also wanted them to be conscious of how the information was presented. We wanted it to be really approachable, upbeat, positive, without a lot of medical jargon that could make people put it aside and say, "Oh, I don't want to read this. This kind of stuff doesn't happen to us."

We didn't want them to copy something that was already out there, because the idea was that this would be the bridging resource between existing materials. I had a limited budget and I knew I couldn't print a huge amount of hard copies, so I wanted them to think about a design that would be easy for someone in a prenatal practice to download from the web, print on their office printer, and distribute without me needing to be a middleman in that process. It ended up being a national flash Colorado focus. I was part of the national task force, but I live in Colorado so that's where we ended up on the focus.



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Here is what Michelle designed for us. It is a two-sided color trifold brochure. We did some research with a handful of doctors' offices and all of them said that they had the ability to print something like this along with having a literature rack to display it in waiting rooms or patient rooms. Trifolds are pretty standard in the medical offices it seems like, so that's what we made. You're looking at the front cover on the right, the back cover in the middle, and the inside fold on the left here. Some nice features that were designed into this are the ability to personalize it with your medical providers.

There's a check list over on the left to check off the tests as they're completed. Again, we didn't include a whole lot of information on the prenatal tests because there are stand-alone brochures on each of them that are already being used, so we just give more of an overview and a time frame when the test is going to happen. Also it's just a nice summary. We felt like this could be hung on a refrigerator or a bulletin board and referred to throughout pregnancy. On the next slide, this is the inside of the brochure, which is primarily about newborn screening. Some aspects of the design here are it's just a very simple, straightforward overview of newborn screening. It talks about what it does and why it's important. There's some info graphics that give quick reassuring facts about newborn screening.

If you have an abnormal screen, that gives the impression in the sense to parents that you don't have to panic, that many of these babies are going to grow up healthy thanks to the information you're getting through newborn screening. Then also in that blue box on the bottom right, there's a personal story, Mother's Voice, that's actually our story there that pulls the whole packet together. What's next? I'm very excited to start getting copies in the hands of expectant parents. The PDF is posted to a number of websites. Everyone on this call is welcome to post it to your website as well. The idea, again, is for prenatal providers to be able to download and print copies to distribute to their patients. The more places that they can find it, the easier it will be for them to do that.

I'm also making rounds with a lot of interested clinics and hospitals and even some baby boutiques to talk about newborn screening and let them know that this resource is available to provide them with some initial copies to get started passing out. I would be thrilled to work with anyone on the call to do more awareness things like this, webinars, speak to screening programs or prenatal care groups, write articles that you can



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distribute in newsletters or use in mailings, post for social media and blogs, any of that stuff, and anything to help spread the word that this is a resource that we can use to start the conversations about newborn screening earlier.

Then one other quick thing that I wanted to mention was another newborn screening educational resource developed by one of my fellow task force moms, Sarah Lockey. She's from Iowa and she's a CCHD mom. Her project idea was for a coloring book that can be distributed to siblings when they come to visit their new baby brother or sister in the hospital and it includes a lot of information about newborn screening in very simple language that children can understand. Plus, as you can imagine, if parents are reading it to their children, it helps educate the adults around them as well. Anyway, this is just a clever idea that has also gotten a lot of traction and there's a link here in the presentation where you can download her resource too if this is an area that anyone's looking to do some more outreach in.

In closing, thank you very much for this opportunity to talk about my project. I mentioned that I have this enormous debt of gratitude for newborn screening and I really do feel like every chance like this that I get, it's my way of giving back to the screening system that I feel like has given our family so much in terms of information that helps keep this guy healthy and is going to let him grow up healthy. Thank you, thank you very much for the work that you do and please let me know if there's any way I can be of any assistance to anyone in the future. It would truly be my pleasure to continue giving back like this and really appreciate the opportunity. Here's my contact information. Feel free to send me an email if you have any other questions.

Thalia Wood: Kay, this was awesome. This was great information. I think this was very valuable that you shared this with us.

Kay Kelly: Thank you. Thank you so much.

Thalia Wood: Absolutely. I think quickly since we are kind of winding down on time, we'll have Drew give his quick update on ... We want everybody out there looking at this webinar to know about this new work group that started at APHL and so we'll have Drew give a brief overview of this work group, and then we'll open it up to questions. Drew, are you on the phone?



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Andrew Richards: I am. Can you hear me?

Thalia Wood: Okay.

Andrew Richards: Hello?

Thalia Wood: Yes, we can hear you, Drew.

Andrew Richards: All right, great. This work group was an APHL health information technology work group. Our very first call was in December, so it's fairly new. We're still getting everything organized. To give you a little bit more background of what it is, it's probably on slide two which is our members and participation. We have representatives from state newborn screening programs spanning from the laboratory to followup information technology ... Basically all the little bits and pieces of the whole system. We've got experts in all of those arenas as well as representatives from most of the newborn screening information system vendors. You can see those there. Some of those I'm sure you're familiar with if you're not using in your state, [inaudible 46:32] OZ systems.

Another thing that we've brought in to the fold is these information technology projects, especially with newborn screening, everything starts in the hospitals. The hospital information systems have the data, so we've already identified that we needed to bring in these hospital information system vendors, the Cerners, Epics, McKessons, what have you, that are prevalent in most hospitals around the country. The next slide. I'll go over some of the goals and what we plan to do as a group. The big thing right now is we're collecting and distributing health information technology questions to experts in the subject matter area. In another slide I'll give you some email addresses if any of you all have any questions related to that, where you can send those questions.

We're also working on creating a guide for newborn screening related health information technology projects, enhancing knowledge, increasing awareness of these projects. I've already undergone a lot of networking with some folks in other states that have really opened my eyes to some things that we were doing right, we weren't doing so right that we need to keep our eyes on. These projects are so massive and they span so many different backgrounds. A work group like this I think is almost a necessity for a new program to go through a newborn screening related health information technology project.



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Of course, this work group is also going to serve as a resource. It gives us something that's going to happen in your state soon or you're planning and you have some questions about how to do certain things, go ahead and send those on to the work group and we will get them passed out to the experts and get them answered and get them back to you. Go ahead to the next slide. Here you can see how to get involved. We are increasing our usage of the APHL health information technology listserv. There should be some more questions going out that way. Of course, you can see the planning committee with all of our email addresses here. I'm the co-chair, Pat Scott is the chair of the committee, and then we've got Careema nationally. The four of us routinely have conference calls and talk about the direction and planning and making sure that we're getting everyone's questions answered.

We also plan to have some webinars from some of the vendors and some of the states. They're going to talk about some of the things that they're doing or they've done just to share. Those webinars are not currently scheduled, but they will be. We've already started collecting some of the information that's going to go into them. Those should happen in maybe the next couple of months. Other than that, we meet once a month. I'm open to any questions or suggestions that you all may have for topics. If there's something that you've just been wondering and you want to send it on to the work group, by all means please do. The more questions we have, the more questions we get answered and the more people get to find out about what all is involved in these projects and what needs to get done.

Other than that, as I already said, it's a relatively new work group. We've already had some great calls. Our last call in particular, we had a lot of people involved and there was a lot of excitement and interest. We welcome any questions that we can get from you all.

Thalia Wood: Thank you, Drew. That was a great overview of the new work group. Why don't you go ahead and unmute the lines up, everybody, so people can ask questions [crosstalk 50:08]. I don't know what all that background noise was. Marci, do you think they should just type in their questions? I'm not sure what was happening there. Hello? Can you hear me? I'm sorry, I must've been muted myself.

Carol Johnson: I can hear you, Thalia. This is Carol. Can you hear me?



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- Thalia Wood: I can hear you.
- Carol Johnson: Okay. I don't know who all is still with us, but I think yes, people should put their questions in the chat box and we'll do it that way.
- Thalia Wood: Okay, one thing I'm going to put up on the screen, while everybody is typing in questions, is just a one question survey. We would like your feedback of what you might like to hear on future webinars. It's up on your screen now. There is a question it looks like for Kay. It says thank you for helping develop such a great resource for expectant parents. May my state get permission to reprint this brochure for our prenatal providers? We have found that our OB-GYN providers are more than willing to distribute resources to expectant moms. Kay, can you answer that question?
- Kay Kelly: Yes, absolutely. You may definitely reprint it. I own the file, so I'm happy to give it to anyone. If you want a PDF of it, I know you can download it from New Steps or you can email me to get it as well. If you think about it, if anyone wants to use it, if you might want to just send me an email just to let me know how you're using it. I feel like I'd just like to get that information back to Baby's First Test, my funders, to let them know that the project has been successful and is reaching a certain number of people because it helps them to justify the program and everything. If you think about it, great. If not, just use it. You're welcome to it.
- Thalia Wood: Wonderful, thank you. Okay there's another question. This question is for Illinois. Who does the 15-year follow-up for positive newborn screening cases? Do you work with your birth defects registry? Claudia, can you answer that question? Claudia, you may need to do ... unmute your phone.
- Claudia Nash: Sorry about that. Okay, yes, we do work with our birth defects registry but as far as the 15-year follow-up, we send out annual requests to the specialists or to the primary care provider each year. That's done by our newborn screening staff.
- Thalia Wood: Okay, thank you. Okay, so if anybody else has a question, don't forget to just put it in the chat box since we seem to have an awful lot of background noise when we tried to unmute the lines. In the meantime, it looks like several of you are responding to the question on the screen right now. What topic would be of interest for the next webinar?



Responses are coming in quite quickly. I'm not going to close it out quite yet. Are there any other questions for the speakers? Well here's ... Can you discuss briefly the development of the LSD education materials. Was that question for Dr. Freedenberg? For Illinois, I'm sorry. For Illinois. That question's for Illinois. Can you briefly describe the development of your LSD educational materials, Claudia?

Claudia Nash: Yes. We worked basically with ... We have an LSD subcommittee of our advisory committee and we worked with that group and the chair of that group to develop the educational materials. Basically at this point in time what we have is information for the physicians, for the healthcare providers. We don't really have anything specific for families at this time.

Thalia Wood: Okay great. Thank you. Okay, we still have a few people voting on these topics. Anybody else want to ask a question? Don't forget to vote for one of these topics. Marci, did you have anything else you wanted to add at this point? Did we lose Marci?

Marci Sontag: Thalia, can you hear me?

Thalia Wood: I can hear you now.

Marci Sontag: Okay. I've been trying to talk several times and I think I was pressing the wrong button somehow. I don't think I have anything. I think this is probably a great time to wrap it up and [crosstalk 54:53].

Thalia Wood: Thank you to all of the speakers. This was a really fabulous webinar giving us lots of different approaches to education and the Illinois overview was fabulous. Thank you, Drew, for telling us what the HIT work group is up to. We will keep this webinar or this survey up for just another couple of minutes to make sure everyone's had a chance to vote as you're logging off. This will help to inform the work group as to what future topics will be.

Carol Johnson: Right now it looks like [inaudible 55:26] to ensure 100% screening is the favorite one there. We'll have to think about that one.

Thalia Wood: All right, well if there are no further questions, let's go ahead and end this. Thank you all for attending. We had great attendance again. We'll look forward to hearing from you all in the coming months.



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Carol Johnson: Marci, I think you have to do the stop recording because I don't have control of that.

Marci Sontag: I will do that.

Carol Johnson: Thank you so much, everyone. [Crosstalk 56:01].