NewSTEPs

A Program of the Association of Public Health Laboratories™

Short Term Follow Up Webinar

Long-term Follow-up Systems and Perspectives
State Profile: Hawaii

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John Thompson: We're excited to hear from several of our colleague both in newborn screenings programs and also from the clinical side of things. We will be talking about long term follow up systems and perspectives.

First of all, though, we get to hear from Sylvia Mann from the Hawaii Department of Health. She's going to give us the state profile and just some highlights about the state of Hawaii and the screening program there. Following Sylvia, we'll be pleased to hear from Sue Berry who's at the University of Minnesota, and she'll be talking to us about the utility of long term follow up data systems from a clinical perspective. Then following Sue, we'll hear from Lisa Feuchtbaum, who's with the California Department of Health, and she's gonna talk about long term follow up data collection from a newborn screening program perspective so we'll have both the clinical and the public health perspective. Then following we'll hear from Nancy Vanderburg and Kristi Bentler from the Minnesota Department of Health, and they are both nurses on care coordination and family support topics.

With that stated, we will have an opportunity for questions and discussion at the end. If you have something that comes up during the middle of one of the talks then you can type your question in the chat box and that way you won't forget it and we'll come back to that towards the end.

So, Sylvia? Thank you so much.

Sylvia Mann: Okay. Aloha, everybody. I am going to give you the state profile for the state of Hawaii. Next slide. For those of you who aren't familiar with our state, it is spread across islands in the Middle Pacific. We are the most isolated inhabited landmass in the world. There are no bridges or ferries or regular boats between the islands, and that is Pacific Ocean, so it is not calm most of the time. The majority of people are located on Oahu, which is where Honolulu is. Then for those of you who aren't familiar, we also have an island, we call it the Big Island, but it is the island of Hawaii, and people often get that confused with where most of the people are but that is actually an island named Hawaii, not the state of Hawaii.

Next slide. For our 2016 statistics, we had a little over 18,000 births. We had 70 newborns that died prior to screening, so we had a little over 18,000 newborns eligible for screening. We had a higher refusal rate than normal. We usually run about 40 a year, so we had 51, and the interesting part was these aren't the home births that increased that refused screening. These were actually in-hospital births, so we're researching to see what possibly happened that there was more refusals in the hospital. We had 259 home births, and only six of those accounted for the 51 refusals. In total, we had almost 18,000 newborns screened which gives us a 99.7% screening rate for 2016.

Next slide, please. I just listed down the conditions that we identified in 2016 that were confirmed. We definitely, because of Asian Pacific islander, I think, background in our population, we have more cases of Congenital Hypothyroid. We also have VLCAD but I don't have the mutation analysis to tell me whether or not these three cases of VLCAD had the Pacific Islander mutation which has a very difficult clinical outlook than the regular VLCAD. The Pacific Islander Mutation, generally those kids have nothing, no clinical symptoms, and they end up being fine. We also definitely, because of our Southeast Asian preponderance in Hawaii, have more Possible H disease newborns and so as part of our program for short term follow up, we do offer newborns that test positive for alpha thal carrier to have the newborn and both parents receive mutation analysis so that we can delineate what it is they actually have in their mutation analysis.

Next slide, please. We identify about 30 newborns per month who are alpha thal carriers. These families are offered counseling and evaluation and also offered mutation analysis, which is covered by the newborn screening program. We have a local molecular lab that does a customized panel for us because there are mutations that are found more predominately in our Filipino populations so we want to make sure that we catch those mutations, too. We are not mandated to do the critical congenital heart defect screening in our program. The actually screening is mandated in our state, but the mandate requires the hospitals to report to our newborn metabolic screening program. It was mandated in 2014, I believe, and it's been an interesting road to have all

the hospitals report in some similar manner so that we could actually compile it. It, finally, is going right and currently the data is being analyzed by our research statistician. SCID newborn screening was started in 2015. We had three cases that were detected in 2015 but all three ended up to be not classic SCID and we're still following up the cases to see exactly what kind of immunodeficiency the kids have, working with our partners at UCLA Children's Hospital.

Next slide, please. A new development, one of the things that we did in Hawaii was since we're starting discussions of adding disorders that have late onset onto our newborn screening panel, we wanted to be able to present information to our advisory committee on what parents might think in Hawaii about screening for late onset disease. We went to our trusty baby expo and had a survey to survey parents that had children less than three years of age. We figured that your memory could not have disappeared that quickly if your child was three, but might not be as sharp if your child were older about newborn screening, and also expectant parents. Both Mom and Dad were eligible to take the survey. We asked them questions about attitude towards screening for late onset disorders, if they want the state newborn screening program to contact them in the future even if the child were older to give them reminders about follow up, and then how they wanted the program to contact them because as we all know, people move, and so mailing addresses might not be the most accurate, and people change phone numbers sometimes, not so often now that you can have your cell phone roam with you, but they do change phone numbers.

We were able to find out the parents are very supportive of newborn screening for late onset disorders, they did want the state newborn screening program to contact them to remind them about follow up, and the number one method that they chose was email. They said that email was great. We thought that with this probably more tech-savvy group, more cell phone use, that text message would be the number one answer but it turned out that text messaging was actually behind email, phone call, mailed in the mail reminders, and then it was text messaging. They maybe don't want the state program to be text messaging them, so that was very interesting, and really will help us as we move forward towards talking to our advisor committee about adding the disorders that have later onset.

Next slide. If you have any questions, it's best to contact our newborn screening coordinator, Gwen Palmer. She knows more about the day-to-day operations of newborn screening and the statistics on a day-to-day basis than I do. Actually, the other exciting news is that we finally have up at the governor our change in administrative rules where we increased our newborn screening fee to $99, which now will help us cover the costs that we incurred as we added SCID to the panel. So, thank you very much.

Erin Darby: Great. Thank you so much, Sylvia. Our next speaker is going to be Sue Berry. Sue, and then John, if you have anything to interject, unmute yourself by

pressing *7, and then we'll move onto the next presentation. Press *7 to unmute yourself. Sue, if you're on, please press *7 to unmute yourself. If you're speaking, we can't hear you yet.

Sue Berry: Can you hear me now?

Erin Darby: Yes.

Sue Berry: Okay, great. Sorry about that. I'm very grateful for the opportunity to talk to this group about... It seems a little ironic to have a short-term group talking about long-term but that is what we will be, all of us, thinking about as we add new disorders that have longer-term implications. This is a chance for us to make this group a little more aware of some of the long-term follow-up data systems that have been developed primarily for research activity to assist in improving knowledge about inherited metabolic diseases. That's what I'm going to talk about.

Can we go to the next slide, please? All right. I think there is some confusion amongst people who have heard a little bit about this, but not a lot about it, as to what some of these initials means and what the implications are. What I'm going to talk about in this particular presentation is what is the LPDR, what is the IBEM-IS, and how are they related. I think that is a point of confusion that I want people to be clearer on and to understand. We'll talk a little bit about the clinical utility of these data systems and some of the advantages and disadvantages of using each of these research strategies.

All right, next slide. All right. I'm going to talk first about the LPDR. The LPDR stands for Longitudinal Pediatric Data Resource. For those of you who haven't run into this before, this is a product of the Newborn Screening Translational Research Network. The Newborn Screening Translational Research Network was funded by NICHD as a contract to the American College of Medical Genetics and Genomics to create infrastructure that would improve research in newborn screening. They have basically three major products that they've developed thus far, the R4S project is part of that, most of you are familiar with that. There is a product to assist research in finding dried blood spots, which hopefully is back on again after the common rule has been modified. That's the virtual dried blood spot repository. Then the third product that has been created is the Longitudinal Pediatric Data Resource.

This is basically a data repository that it a run on a REDCap software data collection backbone. There are several projects that are included in the LPDR for which data is actually in the servers at the Newborn Screening Translational Research Network. There is the project that I've been involved in, Inborn Errors of Metabolism Collaborative Newborn Screening data for long-term follow up for metabolic conditions that are identified by newborn screening. California has a wonderful project that they've completed with regard to hyperthyroidism, you'll hear probably a little bit more about that from Lisa, I hope, and other

things about how California's been very instrumental in helping develop the public health infrastructure for longer term follow up, and then finally the NBSTRN is collaborating very actively on a sickle cell project to gather some longitudinal data about sickle cell.

REDCap, people say, when you hear someone say, "Oh, it uses REDCap," and it's a little hard to know what that means unless you've actually used any of the systems. What REDCap is is an open source software setup. It is a programming tool that makes it very easy to create, essentially, surveys. It's like Survey Monkey on steroids is the simplest way of thinking of it. It makes it very easy to facilitate data collections and to take the information that's provided in that and export it into statistical software or to spreadsheets. It has some good things and some bad things about it, but it's very flexible and the price is totally right which is that it's free. REDCap has been a very powerful tool for research strategies. All the data that's been gathered in the LPDR is gathered on REDCap. People who are interested in accessing or using the LPDR for research or for other data collections can access the LPDR by application online. The intent is that they will add additional tools to make analysis more facile and more straightforward. When I come back to advantages and disadvantages, I'll tell you why that's important.

Next slide. The Inborn Errors of Metabolism Information System is the other data collection tool that many of you have heard about or be familiar with or have seen talks about. This is a very specific set of information that was put together by the Inborn Errors of Metabolism Collaborative. This includes data sets for all of the primary and secondary metabolic conditions on the recommended uniform screening panel, and data has been collected on 41 conditions. Not every disorder has any data collection because in some cases, even in the 29 centers and 14 states that have participated in the project, no one has seen a case of or entered that case in our data collection tool. We have some data on 41 conditions, if anybody sees a 2,4-Dienoyl-CoA reductase deficiency please let me know. We're waiting for that. Someday maybe it'll happen. We also use REDCap software for collections. Participation in the Inborn Errors of Metabolism information system is by request. This was an NIH funded project. We are currently working with support from and with some continuing support from some of the regional genetics collaboratives.

Next slide. What's really important to realize is that these are two halves of the same coin, at least with regard to the inherited metabolic diseases on the RUSP. When we created our original project we actually did data collection in a different data collection tool, and as the national desire to have a long-term follow up dataset emerged, we contributed our knowledge to an ongoing project that was going on as a joint effort between the NCC, the National Coordinating Center and long-term follow up committee, and the Clinical Centers Work Group of the NBSTRN. I'm very grateful, through the years, for all of the strong contributions from my clinical colleagues. What we basically did is sit down and hammer out what questions we hoped to answer from newborn

screening. I think people ended up seeing some of that effort move forward at the advisory committee in terms of some of the papers, but our datasets were designed to try and answer some of the questions that were elicited from those national conversations.

Those were confined in a set of REDCap data collection forms that, I'm just gonna call it out right now, of Jen Luttrell at now NBSTRN and Kristi Bentler who was working with me on this project on a long-term basis, spent months and months creating to have a dataset that would try and address those longitudinal questions. The data that is in the LPDR for inherited metabolic diseases on the RUSP is the data that's also in the Inborn Errors of Metabolism Collaborative. It's the same information. They're mirrored activities. The data collection tools are exactly the same. As I said, they're two halves of the same coin. LPDR is based out of the NBSTRN and our Inborn Errors of Metabolism Collaborative periodically ports that data in a de-identified fashion to LPDR.

New paragraph. Oh I'm dictating. Isn't that weird? Okay. So. You know how it is, when you're doing these things on the phone you start to see these automatisms and I just got a different automatic thing going on there. What kinds of things are in these datasets? I want to speak here a little bit about what we tried to do in terms of common data elements. The concept for both of these projects has been all along to create, essentially, a modular dataset where you will have general information that's captured about all elements for all newborn screens disorders irrespective of the sort of nature of the disorder, but we call them common datasets or common data elements. Examples of things that would be in that would be demographics, some socio-economic information about the families, some background about the family history, race, ethnicity, and so on. We think these are things that are common to all conditions. There is a subset of the data elements that are encompassed in newborn screening long-term follow up datasets that we're urging people to consider common data elements for.

There are also information, and most of those common data elements that are gathered at the time that the subject is enrolled in these research projects, the presentations includes, and we also then gather information that can include some condition or disease specific information. We collect information about initial care plans, and then when the kid comes back to see us we try and catch information about how they're doing, lab testing, emergency care, developmental evaluation, care coordination, pharmacotherapies and nutrition interventions. Those are, as general groups, things that are captured.

Next slide. Just to give you an idea of the scope of data collection, it sounds more intimidating than it really is. When you go through and enter data on a REDCap system you can add all sorts of nested logic, so it's not as overwhelming as it sounds, but there are nearly 7,300 unique data elements. Then there are some very specialized situations for which there are additional data elements including pregnancy transplants, dialysis as a special situation. A lot of potential

information to be gathered. At the time that we created this diagram, we had gathered more than half a million data fields.

Next slide. This is just, not to be mystifying, but what this does is show you the distribution of the cases we have gathered information about over the course of basically four years. This isn't all the data, we started before this, but makes an interesting story to see that a lot of our cases are PKU and MCAT. If you think about the demographics of the frequency of disorders and metabolic disorders in newborn screening, this reflects this to a large extent. The other three large groups that we've collected data on the significance are the LCAD, Biotinidase, and Galactosemia.

Next slide. Some details. We had about half males and about half females. we specifically allow people to enter data about a newborn screened disorder whether the person was newborn screened or not, so we do have ascertainment of adults. 64% of our cases at the time, we abstracted this, I just picked a slide that summarized some of the things, were ascertained by newborn screening only. You can pick more than one of these, so sometimes people were ascertained by more than one method, but the vast majority of our patients were ascertained by newborn screening. We also were recording more than one visit, and some of the subjects had more than ten visits recorded. Altogether at the time that we summarized this we had more than almost 2,000 person years of follow-up, and a lot of these patients actually have had genetic testing, which is kind of exciting. Of note, 44% of our patients have either MCAD or PKU, and those are conditions that occur more often in persons of Caucasian ethnic background, so the vast majority of our subjects enrolled were designated by NIH criteria as white. We regard this as a challenge that needs to be carefully assessed because we want to be as inclusive and representative as we possibly can.

New paragraph. Advantages and disadvantages. The LPDR is a tool set that's available by collaboration with the NBSTRN. Projects that have funded effort can access the tool and use it. If you want to use or collect data on things for which they already have datasets, you can basically take it off the shelf. If you have data collection that needs to take place beyond the common data elements or the existing datasets, you may end up having to do some REDCap programming. There's a broader mission scope for the LPDR than there is for the Inborn Errors of Metabolism system because NBSTRN is supposed to be a tool for all newborn screen disorders and even has a role in facilitating pilots. The Inborn Errors of Metabolism information system was created for a specific project.

Its origins are out of regional genetics collaboratives and it was used to develop the public health common data elements but it's specific to the recommended uniform screening panel metabolic conditions. It's an access by collaboration but it's volunteer driven. At this point there's no compensation for entering subjects, and so you have to basically want to participate and get in on it. The

scope of data collections, with regard to newborn screen disorders that are currently on the recommended uniform screening panel is focused most on the metabolic in both data systems, but options exist to create new ones. There are extant datasets, for example, in the NBSTRN for lysosomal diseases because there was a NIH funded project to study newborn screening and some of those disorders out of New York with Melissa Wasserstein. That's an additional set of data elements that are available in LPDR.

Next slide. All right. Well, the real challenge in all of this, of course, is that you have to have strong relationships between newborn screening programs at Departments of Health and clinicians. The data that we all want to realize the promise the newborn screening is really going to be available through collaboration and mutual support. All of us clinicians, Departments of Health, researchers, want the same information but there's only one place to get it and that's from the families who are willing to allow us to collect it. I'm going to make a pitch for all of you who I know love newborn screening and want to extend its ability to help children, which is that newborn screening without long-term follow up is only half done. We owe it to the families that we can realize the promise of newborn screening. With that, I will stop and let you go on with the rest of the agenda. Thank you.

Erin Darby: Thank you, Sue. Next we'll be hearing from Lisa Feuchtbaum. Lisa, if you will just press *7 to unmute yourself we'll go ahead and let you get started.

Lisa Feuchtbaum: Alrighty then. Can people hear me, first?

Erin Darby: Yes, we can hear you.

Lisa Feuchtbaum: Okay. Thanks to the NewSTEPs staff for arranging the webinar today and giving me this opportunity. I'll be talking about more of a theoretical presentation about moving from short-term follow up in a more traditional framework to long-term follow up, and some of the challenges and issues to consider when you're starting to think about the boundaries of how this is gonna work within your own state newborn screening program.

Next slide, please. We, I think, agree that a common goal for all state newborn screen programs is to provide high quality population-based newborn screening. As part of this, we really need to understand whether newborn screening is achieving this goal. As Sue just mentioned that the fundamental goal of newborn screening, are we achieving it, and this is going to require data to be collected to evaluate the impact and effectiveness of our screening program.

Next slide, please. Getting back to that fundamental goal of providing high quality population-based newborn screening, we want to know from a short-term follow up perspective, are we screening 100% of all births? That's one of the basic goals of newborn screening is to screen all births. We also want to know if we're referring all presumptive positives to specialty care follow-up

clinic for a timely diagnostic workup, and is treatment being initiated in a timely fashion. These are really kind of the first, I consider, the core questions that short-term follow up should be able to address from a public health perspective, and are we achieving this.

Next slide. This traditional model of short-term follow up is depicted in this diagram, and it reflects the way we do things in California, but it probably is very similar to a lot of the other state programs. The screen positive notification comes out of the laboratory, in most cases. California, we have clinical care coordinators who get those cases, it's their job to contact the primary care provider, who then is responsible for contacting the patient to arrange a referral and then our coordinators, kind of the first order of business that they provide for us is to make sure that the first follow up visit of the family occurs at the specialty care follow up center and that treatment is initiated.

Next slide, please. Just within this simple, most basic framework for short-term follow up we should be able to address issues about access to care. What were the percent of newborns, in fact, screened? What percent were getting that appropriate referral to a specialty care center? What percent were getting treatment? This also plays into some of those timeliness issues which NewSTEPs 360 has been addressing. The age when the specimen was received by the laboratory, age of the child when the laboratory reported out the positives, we needed just some examples of timeliness benchmarks. Age when the child was referred to a specialty care follow up center, etc., and age when treatment was initiated.

Next slide, please. Now everything shown with these red arrows is what I've just gone over, and I could call this the traditional framework for short-term follow up. Then some programs may be interested in moving into what I've heard the term referred to as extended short-term follow up. This goes beyond the first visit to the specialty care follow up center, but really goes into documenting the details about the diagnostic workup that was provided for the child and essentially all the details that can be documented through case resolution at certain point a decision is made. Does the child have a disorder or not, essentially, and that's depicted in these green arrows and that's the term that I'm using to refer to extended short-term follow up.

Next slide, please. If you are collecting data in this realm of extended short-term follow up, you may want to think about collecting information about, these are just examples, number of clinic encounters, the health status of the child at each encounter, types of services that were provided, types of healthcare professionals involved, tests ordered and the results, types of treatments initiated, and then at the point of the diagnostic decision, what was the age of the child, and who made the decision. In California, we have a data system that captures a lot of these data elements.

Next slide. These are just some public health questions that could be addressed through the types of data from this extended short-term follow up framework. You can find out things like how old was the child when follow up was initiated, was the child symptomatic when follow up was initiated, what percentage of children were lost to follow up. I'll just skip ahead. You may want to collect information on emergency room visits and hospitalizations that occurred at this time, etc.

Next slide. In California, we define long-term follow up as the period when it's after confirmatory testing is done, treatment is initiated, and basically you have a confirmed diagnosis. Our computer system is set up to flag those cases and move them into our long-term follow up system.

Next slide, please. We currently follow up most cases through age five in California. We do this to be able to address these issues, the availability of ongoing care and management. We want to track clinical outcomes and whether appropriate developmental assessments are being done. We also want to look at this impact on healthcare utilization in terms of what the intensity of services being providers, what additional laboratory tests may have been ordered, treatments change, and of course the health status of the child throughout this period of five years.

Next slide. These are the types of public health questions that the long-term follow up framework can address. Did newborn screening make a difference? That's really the fundamental thing we want to know. Was death and disability prevented? For asymptomatic newborns, was ongoing disease management available and used by the family? Now with late onset disorders, we want to know whether appropriate disease monitoring is being provided at the appropriate interval. Were preventative treatments eventually provided? Again, getting back to documenting the health status of the child following preventive treatments.

Next slide, please. Just these are some of the issues and challenges, just really food for thought about as states think about moving into this realm of long-term follow up. When is the data going to be collected? Is it a yearly patient assessment as part of a program evaluation, which is the model we use in California, or as Susan just described this encounter based as part of a research protocol. There are kind of different ways of approaching how you'd go about justifying and framing the work in long-term follow up. Who provides the data? Important question. Is it coming from a specialty care follow up center? Is it coming from a primary care provider or perhaps even the families themselves? There's been a move to engage families more in data collection and so, again, these are just some thoughts to consider.

Next slide. How long do you collect long-term follow up data? We traditionally have been collecting for five years in California, but should you go to 18 years? 21 years? Over the lifespan, ideally, but there's going to be costs associated with

what approach you take. Who pays for the data collection? The newborn screening? Funds? The funds you collect to conduct newborn screening, is it a research grant or perhaps industry needs to get involved in terms of, perhaps, the pharmaceutical companies. I'm just throwing these out as some ideas. Then who evaluates the data?

Next slide, and my last slide, trying to be very brief. These are really just some ideas to consider as you think about how to incorporate follow up. I don't have all the answers. I gave you an example in a very broad sense of how we go about this in California and I just want to say thank you for your time and interest.

Erin Darby: Thank you, Lisa. Our final presentation will be from Nancy Vanderburg and Kristi Bentler. Nancy, if you want to go ahead and press *7 to unmute yourself, you can go ahead and get started. Nancy, if you're on the line, or Kristi, press *7 to unmute yourself. If you're speaking, we can't hear you yet.

Nancy V.: Sorry. Can you hear me now?

Erin Darby: Yes. Hello.

Nancy V.: Sorry. Hi. This is Nancy. Thank you for this opportunity to talk about the Minnesota Blood Spot long-term follow up program. We were asked to talk about two aspects of our program, the care coordination and the family support. I want to talk about our long-term follow up strategies that we've implemented and why we think that they're effective.

Next slide. Most of you are very familiar with the Minnesota Newborn Screening program from the Public Health Lab and testing through short-term follow up. When that process is completed and the infant has been diagnosed, the baby's information is transferred to long-term follow up. We're part of the Minnesota Department of Health, yet we're in different buildings and different divisions than the Public Health Lab and the short-term follow up. We're located in the Community and Family Health and we are staffed within the Children and Youth with Special Health Needs program. Before the long-term follow up program began in 2008. The two divisions had already been working closely together to ensure the early hearing detection and intervention, the EHDI program was supported and functioning smoothly.

Next slide. We are two public health nurses, and we conduct periodic individualized family nursing assessments. The first two are phone interviews, usually with the baby's mother, and the first one is soon after the baby's diagnosed. The second one comes about a year later. The third assessment which we are adding this year will be when the child's about four years of age. That assessment, we plan to use an online survey tool for parental responses. At these assessment interviews, we address any concerns the family has, and we ask them a set of questions on how the baby and family are doing such as what

services are they currently using. We tell them about other resources that are available and may be of benefit. We explain the concept of medical home, and through a series of questions we determine if they are receiving the components of a medical home through their primary care provider.

In the interview assessment, we hear from the family's perspective about the services that are used and needed and the medical management of the condition. The challenges they face, the impact on the family, emotions associated with adjusting to life when your child has a chronic condition. We listen as they share the emotional aspects of decision making, the challenges they are facing, and the emotional toll that may take on them as well as hearing about the joy of their child being alive and in the best possible health due to newborn screening and medical management. Finally, we have improved our program and services through talking with families and hearing their questions and needs. We've made changes such as developing new parent guidebooks for families on some of the conditions because parents ask for survival information written in a way that was easy to understand. Or they told us that they had to search for some materials and information, so we added those things to the resource binder we send to each child's family.

Next slide. In early childhood work, the phrase Two-Generation Approach is frequently heard. We use this approach on the whole family knowing that families and children do not come in pieces. By that, I mean we focus equally and intentionally on services and opportunities for the parent and the child. Our aim is to provide opportunities for and meet the needs of parents and their children together. We care deeply that children are under the care of medical specialists and receive the best evidence-based clinical management, but we also want to be sure the family has access to and is able to maintain health insurance coverage, that families have information and resources about post-partum anxiety and depression, families have financial resources to cover food for the family as well as medically prescribed foods and formula, that children are in high-quality childcare settings, and families receive the social and emotional support they need to parent their children with special healthcare needs.

Next slide. Part of our efforts on care coordination and family support includes our collaborative work with clinicians. We have numerous connections with specialty medical centers and their multidisciplinary teams. We have and continue to work on joint projects related to care planning and particularly emergency care plans. We stress with families the need to be well-connected with their medical specialists for evidence-based and best practice medical management which includes the children with congenital hyperthyroidism and the need for follow up by pediatric endocrinology. We offer clinicians and medical centers technical assistance such as efforts to ensure care coordinators are part of their team and information and support for efforts to successfully transition use from pediatric to adult service systems and they offer us technical assistance with input into their knowledge of the needs of these children.

We're tapping into the strength and resources of both the healthcare systems and the public health system to create healthier children and families. There are conversations between us that have led to strategic coordination or integration of public health and healthcare on research efforts and ways for both systems to improve our programs and services. These joint efforts allows us to be as efficient and effective as we can be in trying to improve the health of our population. It's been very energizing to have so much common interest between public health and healthcare systems around these infants and children who are found through newborn screening.

Next slide. Some of these direct and indirect means of family support have been mentioned before. There are a few that I want to elaborate on a bit. We have direct support through phone contact with families and some face-to-face meetings and events. Another way we provide support is through our ongoing availability via phone contact with families who are seeking support in particular situations. We have developed trusting family professional partnerships with our children and youth with special health needs parent advisory group. This allows us to hear the family's perspective and incorporate them in our work. Through our mutual cooperation, we strive for the best interests of the child and family as we work on specific goals.

About a year after we started the long-term follow up program, we stopped cold calling families when they were transferred to long-term follow up. We began sending families a letter of introduction and information on our upcoming phone contact, and recently we added to that letter a link to an online survey that allows families to share with us their preferences on the best ways and times to reach out to them. I've already mentioned the condition-specific parent guidebooks we have developed as a support to the families. We also wrote a children's book about congenital adrenal hyperplasia at the request of parents and the CAH clinic team. There was no children's book on CAH which parents could use to explain the condition to their children in a developmentally appropriate manner. A gifted artist and our staff did beautiful illustrations to complete the book. One other very positive part of where we work within the community and family health division is that we find many more ways to support our families through connections with our maternal and child health, woman, infant, children, and the family home visiting colleague. It was through them that we've added to our family resource binder information on back to sleep, tummy time, emergency preparedness, maternal well-being plan, and we have learned of other opportunities for our families to participate in focus groups. That's just to name a few.

Next slide. We've been doing blood spot long-term follow up since 2008, and it's been a very satisfying experience to develop our own program and our own approach, however we do maintain an awareness of national efforts related to long-term follow up for newborn screening, and we strive to incorporate those visions in our program's work. We particularly enjoy hearing about other models of long-term follow up practice. Of course, there's a huge challenge of limited

funding and resources. I should mention our funding for the two public health nurse positions within blood spot long-term follow up comes from the newborn screening fee dollars. We're excited about the work that is being done to develop a uniform core set of data elements to be collected for public health across all the newborn screened conditions, and also the work on condition-specific data elements. Minnesota has received one of APHL's new disorders implementation awards and through that grant we have the opportunity to partner with a variety of stakeholders on their work of developing and evaluating follow up protocols and processes for X-ALD, Pompe disease, and MST1.

Last slide. Thank you. It was a pleasure to talk with you about the family support and care coordination aspects of the Minnesota long-term follow up program.

Erin Darby: Thank you, Nancy. Thank you to all of our speakers. At this time, I'm going to hand it back over to John. I think we have a few minutes for questions or comments, so John, if you want to jump in, press *7 to unmute yourself and we'll wrap things up.

John: Great. First of all, thank you to all of the speakers for putting the effort in to sharing with us your experiences. Are there questions that were typed into the chat box?

Erin Darby: No questions yet. If you do have questions, go ahead and type them into the chat box in the bottom left hand corner of your screen or press *7 to unmute yourself and ask a question.

John: Great. We're open for questions now.

Erin Darby: We have a question from Tony, "Lisa, how are your care coordinators paid for? Title five or newborn screening fees?"

Lisa Feuchtbaum: Can you hear me?

Erin Darby: Yes.

Lisa Feuchtbaum: Okay. I'm sorry. I wasn't sure if I was on mute. This is Lisa. All of our services, including the long-term follow up, are paid for from our newborn screening fees. We have something called the Genetic Disease Testing Fund and all of the fees that we collect get put into ... Doesn't go into general fund dollars within California, it does into our bank account if you want to think of it as that, and then we fund all of the services we provide through those fees that are collected.

John: Hey, Lisa. As a follow up question, how many FTEs do you have in California that are devoted to the long-term follow up effort?

Lisa Feuchtbaum: A lot of the initial work was really computer development work, because our system is a computer-based system. The annual patient summaries come up at the designated clinics for designated patients, and so in order to get the long-term follow up program going it was a lot of computer development work essentially with our web-based system, and then it's up to the clinics to go in each year and provide the data. It's essentially like a survey, an annual patient survey. There's, to a certain extent, a lot of people within California are giving us that data. In terms of staff here at the Genetic Disease Screening program, we have on the newborn screen side we have about five staff that are engaged in different levels of evaluating the data. Once the system is created to collect the data, the work of the FTE on our side is to evaluate the data. I don't know if that's the kind of answer somebody is looking for, but I would think you'd need to have a team of at least a couple of people to develop whatever the system is going to be and then to do the ongoing monitoring and evaluation of the information you get through the system.

Erin Darby: I have another follow up question in the chat box. I apologize if you did answer this already but, "Are the care coordinators state or clinical?"

Lisa Feuchtbaum: This is Lisa. I guess I can. The care coordinators are out in the field. We have several sites, six or seven locations throughout California, because we're such a big state, and they're primarily in the major medical centers. It's really a public private partnership. The state newborn screening program reimburses our coordinators for the time that they put into providing the follow up services. They're not sitting in the same location. Again, they're out in the field, responsible for following up newborns in their region of the state.

Erin Darby: "Are your staff epidemiologists?"

Lisa Feuchtbaum: Our program evaluation staff are very much in the epidemiology genre, we have also a biostatistician on board, but yes, epidemiology I'd say is the common educational background of the staff that do the program evaluation work.

Erin Darby: Are there any other questions? Go ahead and type in the chat box or unmute yourself with *7. All right. If there are no more questions, we'll go ahead and wrap up. If you do have any questions or comments or suggestions for future webinar topics you can email them to me at Erin.Darby@aphl.org. Thank you again to all of our speakers, and we hope to have you all participate at our next short-term follow up webinar. Thank you.

Speaker 7: Thank you.