NewSTEPs

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Short Term Follow-Up Technical Assistance Webinar

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Using Advisory Committees for Newborn Screening Programs

Presentations: Rachael Montgomery from the Alabama NBS program

Kimberly Noble Piper from the Iowa NBS program

John Thompson from the Washington State NBS program

Luann Cartwright with a State Profile for Pennsylvania

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

Thalia Wood: Okay, so welcome everyone to the first webinar for short term followup in 2017. We're very excited to present to you another year I'm sure of very interesting webinars. Carol, you go ahead and do star seven and get us rolling. ... Carol, are you on the call? ...

Okay, I'm going to go ahead and start the call because Carol is having a little issue getting on, so she's ... I'm going to go ahead and get started here. Again, thank you for coming to the short term followup webinar for January. We're going to have a state profile from Pennsylvania. Luann, are you on the call? If you are, push star seven, please.

Okay, since I don't hear Luann on the call, we're going to go ahead and start with Rachael Montgomery from the Alabama newborn screening program. I'm going to find the first slide here real quickly.

Rachael, why don't you go ahead and start, do star seven to unmute yourself. Just let me know when you want me to advance the slide.

Rachael M: Okay, can you hear me okay?

Thalia Wood: I can, thank you, Rachael.

Rachael M: Okay, great. Thank you all, good afternoon everyone and Happy New Year. I wanted to thank APHL for giving Alabama this opportunity to share information regarding the Alabama newborn screening advisory committee. My name is

Rachael Montgomery. I am the newborn screening and birth defect program director for the Alabama Department of Public Health.

You can go ahead and forward to the next slide.

The purpose of the Alabama newborn screening advisory committee is to provide advice to the department of public health on technical and program issues that's related to newborn screening. Our advisory committee is an informal group that is appointed by our state health officer. We are not established by rule or statute. We are not authoritative.

Next slide.

This slide outlines some of the objectives of our advisory committee to include discussion of newborn screening needs of this state, advise on programs and policies for improving newborn screening services in Alabama, provide a channel for input from appropriate agencies, professionals and citizens in matters bearing on newborn screening services, and assisting and presenting information about newborn screenings to the public.

Next slide.

Membership consists of professionals and citizens who are knowledgeable in the area of newborn screening or have an interest in newborn screening services. It is not limited and our members serve as long as they wish. Currently, there is approximately 30 members of part of our advisory committee to include seven medical consultants, as well as representatives from various organizations, to include the AHP, the Alabama Hospital Association, as well as the Alabama Medicaid agency.

We're also fortunate in Alabama to have several parents of children affected newborn screening disorders on our advisory committee as well.

Next slide.

We have a minimum of two meetings per calendar year. Typically, we have one in the spring, and then, we have another meeting in the fall. All of our meetings are open to the public. Like I mentioned, we have one face-to-face meeting, at least one face-to-face meeting per year. Then, our other meetings may include video conferencing and our teleconferencing, depending on if our video conferencing sites, throughout our state, are available.

We do ask that a designee of similar standing be available to fulfill a member's role on the committee in discussions, if they are unavailable to participate. We do follow the guidelines of the open meeting act.

Next slide.

This slide outlines some of our agenda items that we discussed during our meetings. I have provided an example of our agenda from our last advisory committee meeting that was held on November 10th of last year. Some of the topics that we discussed include, we share updates of the program to include laboratory updates as well as followup staff updates.

We typically have a keynote topic. At our last meeting, we had someone speak about tele-medicine to our group. We also share national newborn screening news and updates. Anything that we receive from APHL or any other national organization, we do share with our committee members. Any information regarding education initiatives that we are planning, we typically have a stated-wide conference, and we share that with our committee members and get feedback on various education initiatives. We also share data, present data to our members to include aggregate data of confirmed diagnoses that we identify.

We have our families share their stories and testimonies. We also have our sub-committees report during our committee meetings.

Next slide.

We do have several sub-committees and they are designated to perform duties as may be deemed necessary. The list here is our current sub-committees which includes our endocrine, cystic fibrosis, our hemoglobin offices, metabolic, hearing as well as CCHD. [STED 00:06:55], which we will be implementing this year. We have a data sub-committee as well.

Next slide.

That is pretty much it for the Alabama newborn screening advisory committee. I appreciate your time and attention. Thank you.

Thalia Wood: Thanks so much, Rachael. Carol, are you on the call now?

Carol Johnson: I am, I am now, yes. Thank you, Rachael. I appreciate that.

Thalia Wood: Yeah, thank you. That was very good information. Carol, we're going to go ahead and go through the advisory committee slide, so Kim will be next. We'll have the state profile from Pennsylvania last.

Carol Johnson: Okay, wonderful.

Thalia Wood: Thank you.

Carol Johnson: Next we're going to hear from Kim Piper, from the Iowa newborn screening program about Iowa's newborn screening advisory committee makeup. Kim, go ahead, please.

Kim Noble Piper: Thanks, can you hear me?

Carol Johnson: Yes.

Kim Noble Piper: Okay, great. It's always good when that works. We're going to talk about the Iowa congenital and inherited disorders advisory committee. We fondly refer to it as CIDAC here because it's just a mouth full to say that every time.

Next slide please.

The purpose of CIDAC. CIDAC represents the interests of the people of Iowa and a system of development of programs that ensure the availability of and access to quality genetic and genomic health care services by all residents of the state. The committee advises the director of the department of public health regarding issues related to genetics and hereditary and congenital disorders. As you can see, ours has a little bigger scope than Alabama's. Our advisory committee considers all congenital and inherited disorders, in addition or including newborn screening.

Next slide, please.

The duties of CIDAC are to make recommendations about the design and implementation of the center for congenital and inherited disorders program. This includes, but is not limited to, the Iowa newborn screening program, the regional genetics complications service, the maternal prenatal screening program, the neuro-muscular and related genetic disorders program and the Iowa registry for congenital and inherited disorders, which is our birth defects registry.

Next slide, please.

CIDAC is also charged with supporting the development of special projects and conferences regarding genetic and genomic healthcare services and issues surrounding genetic and genomic healthcare.

Then, they are also charged with advocating for quality genetic and genomic healthcare services for all residents in the state of Iowa.

Next slide.

Our membership. CIDAC membership includes representatives of professional groups, agencies, legislatures, parents, consumers, and professional healthcare providers. It's comprised of regular ex officio and honorary members. We have at least two parent representatives and two consumer representatives that serve as regular members of CIDAC. Our consumer representatives tend to be from the president or the current chair of the state laboratory managers

association and then we also have representation from the Midwest region Iowa heart association.

We have two honorary members that are one state senator and one state representative. If the director deems other honorary members appropriate, then he can certainly appoint other honorary members to the committee. The honorary members rarely, I think, they've attended maybe one meeting or participated in one phone call since I've been doing this for 10 years now. That's why they're honorary members.

We also have ex officio members that are nominated by virtue of their position held and the organizations that they represent. They're appointed by the director of the department of public health. These members provide expert information and consultation for the program.

We set it up so no more than 30% of the regular members shall be representatives of or employed by programs that are contractors of the Iowa department of public health and the center for congenital and inherited disorders. This is so it's not weighted for actually program staff. We try to make sure that there is cross cutting representation.

Next slide please.

This is a list of the types of organizations that we have memberships or members from. As you can see, we have probably a pretty extensive list. We work hard to get representation from each of these organizations or these areas. As far as parents and consumers and representatives from community based organizations, like the March of Dimes, the American Heart Association, Iowa Hemophilia Association, those types of things, that's an ongoing process to recruit those members in those categories.

If you want to go to the next slide, please.

It's really hard to retain and have the active participation of parents and consumers. A lot of them volunteer to serve, but they don't turn out for the meetings. They have their day jobs, so it's hard for them to get away for meetings during the day. If I contact them individually for feedback or opinion about an issue, they'll gladly reply. They're very interested in what CIDAC does and having a voice. It's just very hard for them to get away and find time to participate. When these presentations are done, I would love to hear from anybody else who has ideas as to how to empower parents and consumers to participate. I have asked if it would be easier for them to attend meetings held in evening hours or on a weekend, they said, "Probably not, because that is the time that they are with their family." That wasn't really an answer to the situation either.

Next slide please.

We meet on a quarterly basis. We have two face-to-face meetings and then two conference calls or web meetings. Attendance actually is better for the face-to-face meetings. People, select a meeting site that is, kind of, midway travel time for most of the committee members. We have good attendance at our face-to-face meetings. Those are always preferred. They're a lot more productive than the conference calls or the web meeting.

Next slide please.

Sub-committees. Current sub-committees or recent sub-committees that we've had are informed consent sub-committee that had looked at the issue of informed consent for newborn screening. Not necessarily the screening program itself, but for use of residual newborn screening specimens. Then we've had and we still have management of the newborn screening panel sub-committee. This group of individuals looks at the addition or conditions that have been nominated or assigned to the RUS panel and how that would work out for Iowa. Then, we've had a residual newborn screening specimen sub-committee that looks at the storage conditions of the residual newborn screening specimen and the release of those specimens for research use. Then, we also will have ad hoc committees, as needed.

As you can see, most of these are newborn screening related. Newborn screening is our biggest program, of course, as everybody can understand. It tends to take up the majority of the work and the efforts that CIDAC does. Hopefully, we'll get to change that going forward.

Next slide, please.

Some of the issues that our CIDAC has addressed recently are a lot of the work that they do is a review of research proposals, researchers can send out proposals to the advisory committee for use of residual newborn screening or maternal prenatal screening specimens. Then, it is the responsibility of the advisory committee to make a recommendation to the department of public health as to whether to approve those research proposals or not. They also have input as to our administrative will process for the genetics programs across the state. They have recently heard work from the newborn screening management sub-committee about the addition of [Pompe 00:15:58], Iowa's newborn screening panel. There was a lot of discussion and thinking out of the box, for outside of the box, when we got to discussing the addition of [Pompe 00:16:11] to Iowa's newborn screening panel. Then, we've had another project that has come across our desk, as an outgrowth of the discussions through the advisory committee for that.

We also have an informed consent sub-committee, like I said. We looked at the issue of should we require informed consent prior to the release of any newborn screening blood spot specimens, as well as as any data. The decision for that has been, yes. We will no longer be releasing any residual, even

anonymized, residual newborn screening specimen, so researchers will have to obtain informed consent, going forward.

One thing I didn't address in my slides is that this is a mandated program. Chapter 136-A of the Iowa code and chapter 641.4 of the administrative code explain the process and the membership and the charge of the advisory committee. That's where I've taken a lot of this information here. It is a mandated advisory committee. It does provide advice to the department director of the Iowa department of public health.

The next slide.

That's all I have for you. Thank you.

Carol Johnson: Thank you, Piper. That was great. Even though, I'm in Iowa, I knew all that, but the way that you put it all together I always learn something new. That's great. Then, our final speaker on our advisory committee topic today is my co-chair of the short term followup work group and that's John Thompson, from the Washington State newborn screening program. John, would you like to go ahead? ...

Thalia Wood: John, don't forget the star seven to unmute yourself.

John Thompson: I tried before, but it didn't work. Did it work now?

Thalia Wood: Okay, yes. We can hear you, thanks.

John Thompson: I was already part way on my spiel. All right, so thanks for the opportunity to speak. I'm happy to share with you our experience in Washington state for how the advisory committee functions. It's different from the other two that we've heard today. I think if we open up the line to everybody, we would hear all sorts of different ways that our states go about this.

Please move to the next slide.

The newborn screening law in Washington gives statutory authority to the state board of health to adopt rules and regulations necessary to carry out our early detection and treatment of fetal ketonuria and other preventable ketone disorders, leading to developmental disabilities or physical defects.

Next slide.

The law also directs the department of health to require screening tests of all infants born in any setting to conduct screening tests as samples. To notify the infant's attending healthcare provider that the infant's screening test indicates the suspicion of abnormality that requires further diagnostic evaluation. To

offer the use of its services and facilities, designed to prevent intellectual disabilities or physical defects and many other things.

Next slide.

The revised code of Washington and neither the revised code of Washington nor the Washington administrative code has any mention anywhere of a newborn screening advisory committee.

Last slide.

In 2001, when I was a lowly graduate student, looking for a practicum project for my masters degree in public health genetics, I had the opportunity to meet with our former office director here, Mike Glass. He had a project that he needed help with to review the literature and develop the medical model for cost benefit analysis for adding [npad 00:20:57] deficiencies to the mandatory screening program.

It was a project to inform the newborn screening advisory committee in some decisions that they would be making in the next couple of years. This project seemed interesting to me, and so I accepted it. As a part of that, he invited me to attend a series of five advisory committee meetings, starting in August of 2001 and ending in April of 2002.

The ad hoc committee was convened, jointly by the board of health and the department of health and was co-chaired by a board of health member and the state health officer, who is a department of health employee. The multi-disciplinary team included clinical experts, several parents, representatives from insurance, including Medicaid, advocacy organizations, and both the hospital and nursing associations in Washington.

After the first meeting, the committee recognized that there were some people who weren't at the table that should be. They added a couple of members and rounded out at 20 members for the final meetings. At that time, in 2001, Washington state was screening for PKU, hypothyroidism, adrenal hypoplasia, and the hemoglobin disorders. We were definitely on the low end of the number of disorders tested when compared with other states in the United States.

The board and department wanted to establish a rigorous way to evaluate ketones newborn screening conditions. The advisory committee spent two meetings developing a series of five criteria for ketones conditions.

They're on the next slide.

The criteria are that early identification benefits the newborn. That there's treatment available. That the need for the condition justifies population based

screening, rather than just risk based screening. A good screening test exists with good sensitivity and specificity and that the benefits justify the cost of screening.

Next slide.

Continuing on, the advisory committee was tasked to apply those criteria that they just developed in the previous meetings to nine different conditions tested for in dry blood that were being screened for in other programs. Then also, hearing screening. The committee also had a discussion about using tandem mass spectrometry in a limited versus a broad fashion. The committee's role was to review the evidence and make recommendations to the board of health, based on their findings.

From the blood spot side, the end result was five conditions were recommended to the board for mandatory screening. Three did not meet those five criteria on the previous slide. Then, the committee thought that cystic fibrosis was close to meeting the criteria, so they recommended revisiting it within a couple of years. Hearing screening was recommended being added for a couple of different reasons. It was not added to the newborn screening log primarily because all the hospitals were either screening, offering screening, or were nearly offering that mandatorily. That didn't get part of the log. Next slide, oh sorry, just kidding, don't go to the next slide. Oh thanks, sorry about that.

2004 is when we did this, our first major expansion. We added those five conditions, which include three new lab techniques. Two enzyme activity assays, and then tandem mass spectrometry using the multiple reaction monitoring process.

Now next slide, please, thanks.

Over the next 10 years, the advisory committee was convened, on that ad hoc basis, to reconsider cystic fibrosis in 2002. Then, to evaluate and expand its screening, using tandem mass spectrometry. There was a technical sub-committee that met first, then followed by a full committee. Then, in 2012, the committee was convened to consider screening for severe combined immuno deficiency. Based on feedback, the committee makeup has changed, slightly. The core group is still the same, but notably adding a bioethicist to the core membership.

In 2012, advisory committee was convened to carefully review the original criteria from 2002 in the context of advances in technology and the push to screen for more conditions, including some that have late onset phenotypes.

The criteria were evaluated, both individually and in a whole, by the committee. They stood the test of time. The committee kept those five criteria. They added a few points clarification and established a qualifying assumption for a

preliminary analysis per ketone conditions. That updated criteria can be found in the newborn screening section of the Washington state board of health's web page.

Next slide please.

The advisory committee did not need to make unanimous decisions. This fact is highlighted by the experience of the advisory committee in 2014 when they used the revamped criteria to consider screening for X-linked adrenoleukodystrophy.

Next slide.

As you can see, the advisory committee voted unanimously that screening boys for ALD met each of the five criteria. The advisory committee was not unified in their feelings about screening for girls.

Next slide.

These recommendations were given to the board and the decision was to add ... The board's decision was to add ADL screenings for all babies, which we are currently preparing to do.

Next slide. Thanks.

The board has received inquiries recently about screening for lysosomal storage conditions, so we anticipate that the committee will be reconvened in the near future.

The last slide.

In summary, the Washington state newborn screening advisory committee is convened jointly by the state board and the department of health on an ad hoc basis. Each one of those entities provides a co-chair for the committee. Membership is multidisciplinary and is adjusted slightly, depending on the task at hand. Voting does not need to be unanimous. While this committee is not required by law, the public process for considering changes to the mandatory newborn screening panel is considered rigorous and helpful from both a public health and a medical standpoint. Thank you.

Carol Johnson: Thank you, John. That was a very good summary of what happens in Washington. Now, I'm going to talk a little bit about what we're going to do next. First of all, I wanted to say that the reason that we wanted to do this presentation today about advisory committees is that the short term follow up work group has been receiving more and more questions about this. I think as more and more issues come up in newborn screening programs, it does seem that advisory committees are becoming more and more important to that

process. We know that some states don't have an advisory committee at all and are interested in developing one. We've heard that some states have an advisory committee but aren't satisfied with the structure and function of their committee. We hope that today's presentations have given you some helpful information and ideas, either to help you form a committee, if you don't have one or to make changes to your existing committee if that's possible for you, so that it can better meet your needs.

Then, what we're going to do next is we're going to hear the state profile from Pennsylvania. Then, after that, we're going to open it up to questions and discussion about advisory committees, then also, if you have any questions about the state profile as well.

Our next presenter today is Luann Cartwright from the Pennsylvania newborn screening program. Luann, if you would like to go ahead and tell us about how newborn screening works in Pennsylvania, that would be wonderful, thank you.

Luann C: Thank you and I apologize for my technical difficulties earlier.

We can go on to the next slide.

The first slide that I'm showing basically is just a map of our state and the various counties. Much, probably, like other states, we have a situation where we have some very rural areas, and then, some very urban areas. What I would point out is, the department of health is located in Dawson County, which is in one of the pink areas. It says "Dawson." Our lab is actually located at an Allegheny County, which I have highlighted in red, and that is Pittsburgh. As you can see then, Pittsburgh and Philadelphia, being at the opposite ends of the state, and then, the actual department of health where the capitol is in Dawson County.

I would say some of the issues that we have, again, just like other states, when we are against the border, both New York, Ohio, New Jersey, Maryland, Delaware, and from West Virginia here, that sometimes poses challenges to us because we have people living in different states across the borders. Then they're born in Pennsylvania and vice-versa. One of the things that Thalia wanted me to talk about was the issues we have with having two labs. As of last year, we no longer had two labs. We have had PerkinElmer genetics, and then, we also had a contract with UMass. When we talked about bringing on LSD, UMass didn't think they would be able to continue that in their contract. They did not re-sign with us.

Some of the challenges that we were having when we had a two state lab was a baby born in one hospital may have had their initial specimen done by UMass, then if they had been transferred to another hospital, the repeat would have been done by the other lab. We weren't able to link the filter papers and that

sometimes caused some issues for the program and then the hospital doing the followup.

Next slide.

These are some of our statistics. This is 2015 data and I will say that it's very difficult for us to quantify our data because we, up until last year, had two different systems. One that housed hearing and one that housed metabolic, and it was very difficult to get good data, to get the data to match. As you can see here, the births are reported to our bureau of statistics are 140,139. Then the eligible for screening are about 127,000. One of the challenges that we know we have here also that our newborn screening is not linked with our bureau of health statistics and birth certificates. That's something that down the road, I think, the administration is really looking to do so that we have better data. That we also know we're not missing babies when we are screening. We had 248 who unfortunately expired without the screening. 120 refused screening and then 1,408 were unknown or lost to followup. Then, we have no ability to capture some of these.

Go on to the next slide, please.

In Pennsylvania, we have seven conditions on our mandated panel. Then, probably another 22 or 23 on our supplemental panel that would also include hearing and CCHD. These are what are outcomes have been for 2015 and the different conditions. One of the things that we are doing here is very much trying to mirror our screening program to what the RUF has always recommended. That's a challenge because we do have a legislature that really is not really attuned to what the newborn screening program truly is. They often try to add things through legislation, new conditions through legislation, that there isn't science to substantiate it, why we should be screening for that. Or there are things that we already know hospitals are doing and I would give the example of the CCHD screening. We knew hospitals were doing that, but in 2012, we then asked hospitals to begin reporting that.

I think the next slide, if you want to go ahead, just continues on to some other conditions that we have captured as a result of our blood spot screening.

Then, the next slide.

This is an image of our filter paper, which we recently updated, just last year. We included pulse ox information on the filter paper to make reporting a little easier. We were actually doing some manual gathering of this data, asking our 99 birthing facilities to report monthly the numbers they screen and the numbers that failed, so we could get a pretty good idea of making sure that everybody was getting a pulse ox screening who was born in Pennsylvania.

Again, from going to the conference in Orlando and then in Bethesda, I don't think Pennsylvania is immune to the same things other states are. We have facilities who don't thoroughly complete this, requiring our staff here, the department of health, to do some followup. It makes linking filter papers difficult. Then also, a lot of times, the PCP information is not correct. We're doing a lot of tracking down of that information, so that we can make sure the babies are getting good care and followup from their PCP.

Next slide.

Something that's been very exciting for us, in Pennsylvania, is that on July 11th, we implemented a new data system. This data system is contracted through Mavis. We call it ICMS. One of the great things about this is that it enables the dry blood spot screening lab, who at this time is PerkinElmer, to transmit through an HL7 message into ICMS. That gives us our blood spot results and our pulse ox results. Then, our staff can begin case management. We've broken down our assignments. I have five community health nurses who do followup. We have assigned specific hospitals to specific nurses so that there can be true case management. Where the nurse is actually following the baby for their metabolic, their hearing and their CCHD results.

Currently, right now, only the lab and our internal department of health staff can use the system. Next year, we're going to go into what we call phase two where our hospitals, midwives, and birthing centers can manually enter data. Then we're going to also have the hearing screening data be uploaded directly from the hearing screening machine. This will also allow our treatment centers to have access to our system. They're the ones who get the referrals for those metabolic conditions when the results are presumptive positive. Then, in phase three, which will be sometime in 2018, our physicians and audiologists and other professionals who may be giving care to newborns will also have access to ICMS. That will be specific for the patients that they're assigned to. It will allow them to see in-patient, out-patient diagnostic tests and provide followup activities.

The next slide is just our contact information.

The director of our program is Kelly Holland and then myself. I've been the manager for about four years in the program. That's everything from Pennsylvania today.

Carol Johnson: Thank you, Luann. That was very informative. I enjoyed that and congratulations on your new data system.

Luann C: Thank you.

Carol Johnson: That's great. That is a huge hurdle to shuffle so good for you. Now what we're going to do. Let's first open it up for questions for any of our four speakers. Does anybody have any questions?

Thalia Wood: Carol, this is Thalia, there was one question in the chat box. Thank you, Luann, I enjoyed that, too. Especially hearing the last about your data system.

Luann C: Sure.

Thalia Wood: The question in the chat box is a general question for presenters. Do you consider the discussions during committee meetings to be confidential. If so, do you ask members not to share the information unless it is final and becomes part of the official minutes?

Luann C: I know, in Pennsylvania, we have an advisory board. Our meetings are what we call "sunshine." They're public meetings; therefore, anybody can attend. Obviously get out of those meetings anything that they want; however, you have to be on the agenda to speak. Somebody from the public would have to have been given approval to speak. They're not closed meetings, and we do publish the minutes then on our website. Ours are not closed. That was Luann in Pennsylvania, I'm sorry.

Kim Noble Piper: Hi, Kim Piper in Iowa. It's the same. These are public meetings. They're open to anybody. We don't have any secret meetings or confidential meetings. ...

Thalia Wood: John or Rachael, you want to chime in?

Rachael M: Yeah, can you hear me?

Thalia Wood: We can, thank you.

Rachael M: Our meetings are also open to the public. We don't typically discuss any confidential information during our meetings. Now, we do have our sub-committee and they can meet after our advisory committee meetings. Sometimes that discussion is closed, but not typically during our advisory committee meetings. That information, we do keep meeting minutes. Our discussion, from our advisory committee meeting is captured in our meeting minutes.

John Thompson: Our meetings in Washington are held at the public health laboratory and they're public meetings. We have had members of the public come or interested physicians are invited to be part of the committee, have come to listen in and provide feedback, in some instances, when appropriate.

Carol Johnson: Any other questions?

Thalia Wood: Carol, while we're waiting, there's another question in the chat box, it's actually for Luann. Does Pennsylvania routinely screen for galactosemia caused by epimerase enzymes. I'm not sure I'm saying that right, epimerase enzymes.

Luann C: I don't think so. I would say that no, the galactosemia, no. It would just be off of the regular newborn screen.

Thalia Wood: Okay, thank you.

Carol Johnson: Any other questions for any of our speakers?

Thalia Wood: Does anybody else want to share how your own advisory committee works in your state?

Carol Johnson: Right, so now, I think we'll open it up for discussion if anybody would like to share. ...

Kim Noble Piper: This is Kim Piper. Does anybody else, have you had successes with getting parents, or affected individuals, or consumers engaged with your advisory committee activity?

John Thompson: We have in Washington, and since we're holding ad hoc advisory committees, the commitment for the family members has not been as extensive as what you would have in Iowa. We do have a member who represents "Save babies through screenings" who's a grandmother. She has been on every single advisory committee that we've had since I've been involved in 2001. She's just really passionate about this. She's a good resource for us because she's been involved for so many years.

Luann C: In Pennsylvania, I know our hearing advisory committee, the way the Act was written, requires a parent advocate. On the metabolic side, we don't have a parent representing anybody. Obviously, when a parent feels strongly that a condition should be added, they come to the meeting. I can honestly say, most recently, this would have been with the situation with [Crybase 00:45:05] disease. There is a mother right here in Dawson County in Harrisburg and their baby did pass away recently. She was only a few months old when she succumbed to that. She has made several attempts, and successful attempts actually, to attend those advisory committee meetings and try and be persuasive with regard to what we should be screening for. Again, I think, a lot of our issue is is that being those advisory meetings being in the central part of the state, in Harrisburg. It's not necessarily worth their time to travel to those advisory meetings.

Thalia Wood: Okay thank you, sounds like we have parents who will attend, or consumers who will attend if they know the topic that is very near and dear to their hearts is on the agenda. They will ask for it to be put on the agenda. Then, they kind of fade away, once that issue has been addressed or discussed to their satisfaction.

Maybe, I need to expand the reach a little bit to grandparents and things like that. Maybe start recruiting some interested folks who would have a little more flexibility in their schedule to attend the meetings. Okay, thank you.

Cindy: Hi, this is Cindy in Vermont. Can you hear me?

Thalia Wood: Yes.

Cindy: Good, hi. We've had some pretty good luck recruiting parents of children with screening disorders. Mainly because, for many years, I was both running the newborn screening program and the metabolic clinics. I got to know the parents really well and could invite those that I thought would be a good addition. Since I've stopped doing that, our metabolic clinic will also do that reach out to parents. What has made a difference is not having too many meetings. We also will pay for mileage and babysitting, if that's what's necessary for them to come to the meeting. In fact, I have a meeting tomorrow with a parent of a child with glutaric aciduria. Once we kind of have gotten to know each other a little better, we'll talk about if there's a role for her on the advisory committee. I think it's the personal touch that bears fruit. They have been absolutely wonderful additions to the committee. ...

Thalia Wood: Good to hear, thank you.

Carol Johnson: Any other questions or comments? ... No more questions in the chatbox, Thalia?

Thalia Wood: No, there's a technical question, but I will send it directly on to the laboratory.

Carol Johnson: Sure, sure. We'll wait one more minute, see if anybody else has any questions. ... All right, so hearing nothing else, I guess we'll wrap it up for today. I would like to thank all of our presenters for your great job. Thanks to all of you on the call for joining us for our first short term followup webinar of 2017. We would want to remind you to join us for our next webinar, which is on March 13, 2017, at the same time. I wish you all good tidings for 2017 in your newborn screening programs. Thank you.

Thalia Wood: Yes, thanks everyone, Happy New Year.

Carol Johnson: Yes, happy new year. Thank you all.