



NewSTEPS

A Program of the Association of Public Health Laboratories™

Short Term Follow-Up Technical Assistance Webinar

September 2016

Presentations: Lou Bartoshesky, MD on Newborn Screening Consultants

Sara Denniston, BS on Linkage to Care

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

- Thalia Wood: Welcome everyone to the September short-term follow-up technical systems webinar. I apologize if it says 2015 on the slide. I don't know what I was thinking this morning. Obviously, it's September 19, 2016. Our topic today is linkage to care communication and collaboration. I'm going to show the next slide which has our presenters on for today, the people that will be speaking today and we will take questions at the end. I'm going to go ahead and mute all the lines from my point of view here, so bear with me for that.
- Automated: The conference has been muted.
- Thalia Wood: The speakers will need to do "star 7" to unmute your line when it's your turn to talk. Carol, if you go "star 7" and introduce our first speaker.
- Carol Johnson: Hello there, everybody. This is Carol Johnson. We want to welcome you to our September Short-Term Follow-up webinar. Our speakers for today as you saw on the slide is Lou Bartoshesky from the Delaware Newborn Screening Program, he is a medical consultant there, and Sarah and Becky from the Oregon Newborn Screening program. Without further ado, we'll turn it over to our speakers for today. Thank you again.
- Thalia Wood: Do "star 7" and you're up first.
- Lou Bartoshesky: The members of our committee have kicked around the idea of these seminars and one thing that came up that we have not really talked about formally was how things work with referrals to specific consultants. What I'm hoping to do, if I can get my slides to work, was just talk about some general Vanilla ideas that came up as we talked about these things over the last weeks and months.

This is really, as I said, very Vanilla. It's just a list of different areas where we might want to get more detail on this as time goes by maybe have formal proposals to talk of these topics specifically. I don't have any slides up here.

Lou Bartoshesky: The first slide, I think, is to remind us, what Carol would remind us, that's timeliness, and any time we're dealing with consultants, timeliness is most important and we all know that. I only put it up there to remind all of us of that.

I think the next slide is a list of different kinds of definitions of what short-term follow-up is and we found that there are different definitions and you can see them on the slide. The commonest one, I think, is short-term follow-up ends after a diagnosis has been made by the consultant, but there are some states that stop sooner that they consider as short-term follow-up ending after the referral was made to the specialist and other programs somewhere in between. There is invariability from time to time or from place to place.

I have to ask what the next slide is. The different kinds of specialist is next, right? The different kinds of specialists that we deal with are listed on the slide and I think that's pretty universal, that we have gastroenterologists and pulmonary who share the CF, but otherwise, it's metabolic docs. The hematology, oncology, and the endocrinologist, and from time to time, our work group have discussed what makes a good referral, and one good referral topic is that things are done properly.

The other good referral factor is that things are done collaboratively and collaboration, of course, is a key finding that we all participate in. It's really important for all of us to make sure that our consultants are looking at things as collaborations. Here come the slides.

Thalia Wood: I'm on the slide "This is what makes life easy for consultants."

Lou Bartoshesky: All right. This came not from me. This came from Oregon friends and others that we talked about and it says here, "Good algorithms," and so, we don't live and die with algorithms, but they're certainly our first step, and a good algorithm will be something that the consultants will help us prepare.

Good communication pathways, and one thing that a consultant [inaudible 00:06:38] of this that programs, the after course is most important, and we as [inaudible 00:06:44] people understand that the entire newborn screening team not just the nurses the docs coordinators, but the other clerical people all have to keep communication pathways open.

Available programs, I have here email, phone, and mail, and some of us still use old-time mail [inaudible 00:07:02] lots of things. One thing that's come up is are things different in regional programs compared to state-only programs. They not really. The key issues remain. Timeliness, collaboration, they continue to be important no matter whether you have to cross state lines or not.

Before our process, it varies from state to state. There are a couple patterns. Some programs, the newborn screening lab sends results directly to the consultants. Some programs, the newborn screening labs send their results to newborn screening follow-up team, and some it's directly to the primary care provider, and some [inaudible 00:07:44].

Actually, nobody has any specific right answer to this [inaudible]. Everybody works up things the way they can. We don't have a national newborn screening program. Each state has its own decisions to make and we've found as we asked around the different processes work better in different places.

We asked a couple of our consultants what the barriers are and although it's a cliché, communication certainly can be a barrier, and that involves the consultants, having someone available at all times. When our labs were open and when our newborn screening programs are working, we need to be sure that a consultant is available as soon as it could possibly happen.

Complex cases. Our consultants [inaudible 00:08:34] need special care and that's obvious as well. Our consultants are often busy. Some state have to deal with time zone differences, some of the regional programs also have to deal with different states having different approaches to the program.

A consultant lab in Pennsylvania might, my work with Delaware residents and New Jersey residents, and Delaware Newborn Screening Program, New Jersey Newborn Screening Program, and the [inaudible 00:09:01] Newborn Screening Program, so it's important in situations like that that there's clarity and the pathways be open. [inaudible 00:09:11] that some of our consultants have said was that they're concerning about primary care of understanding and we hear anecdotes about a primary doc saying we'll, I'm not that worried about this thyroid.

I think my [inaudible 00:09:20] always been those mostly anecdotes and that for the most part, our primary care docs are really invested in the benefits of newborn screening. The AP and the AAFP both assure them there are members that newborn screening is an important program and I think that's a big deal really.

Quality assurance. Everybody has quality assurance programs. We all have our report cards. We all have our own way of doing it. Again, collaboration is important here. Some places have newborn screening programs. Some newborn

screening programs have their quality assurance specifically just follow up, others have specifically addressed in the lab.

The labs, of course, have their own requirements that the labs have to have, but it's been most people's experience that when a newborn screening program is a program, that the quality assurance will overlap, that there will be good projects that involve the newborn screening program, the lab, and the follow-up people, and part of that will be the consultant sub-specialist. We all know that we talk to our labs regularly, but most places have a regular program where they [inaudible 00:10:28] the consultants as well.

The next slide talks about consultants and meetings. It seems like these things should occur, meetings face to face. Some [inaudible 00:10:37] too big to do it face to face and they get people who know how to operate computers not like me to have teleconferences and so forth. Whether they should be held quarterly or semi-annually, I think, each state has to work out its own way of doing that, but certainly consultants face-to-face meetings or at least regularly scheduled teleconferences with the consultants are something that we need to keep in mind.

Advisory committees are essential, I think. There are some states where the advisory committee tends to be just a technical committee, not just but technical committee working around with the consultants providing medical feedback. I think our discussions have said that the advisory committee has the opportunity to really serve a great purpose to the follow-up team and to the families. Advisory committees again are written into law in some states and other states that it's up to the people working to do it, but our recommendations had been that the advisory committee should include the consultants themselves.

We learned also that there are different types of agreements that take place between and among the consultants and the newborn screening programs. Some places have memorandum of understanding, some people just do it on a gentleman's agreement, and some places have specific contracts with specific centers. For example, in Delaware, we have specific contracts with the Children's Hospital of Philadelphia regarding our metabolic and these contracts are carefully written and probably a good way to do things, but there are other ways that things can be done collaboratively without contracts, and a memorandum of understanding is one way, and there are a few states in which things are pretty much operated by we really get along well with our consultants. We don't think we need any specific written agreement and I think that's going to become less and less the case.

Financial agreements can be very complex. Money often changes hands. There are some programs that consider continued financial support for the families into the specialist appointment. The specialist like that. Some places have one visit to the specialist. Some places have no visits paid for, but acknowledgement of the specialist centers that we're here to serve their families and to work well

with the newborn screening programs. There are different way that these financial agreements can be worked out and I don't think we have any way of saying at this point which one is the best and which one is the worst. Each state has to work at its own.

One thing we learned talking to some different centers is, is there consumer feedback? Many places have consumers on their advisory committees, but it's specific consumer feedback regarding how things worked at the consultant's center are not common, but something that may want to think about that sampling our families how do things go when you went to the big medical center in the sky and how ... Not the sky, the big medical center in the big city and [inaudible 00:13:54] about how we might set up some kind of feedback like that; should it happen, how can it happen, and who should sponsor it?

One thing we keep talking about in newborn screening short-term follow-up is closing loops and there are lots of loops involve. The newborn screening lab with the consultant, the newborn screening short-term follow-up team with the newborn screening lab, the follow-up team with the consultants. Loops also often may difficult to close when they're state line's involved, so loops are closed. We'd learn that consultants like to hear back from the screening programs about how things went. We also know that this newborn screening programs like to hear what happened to their patient when it went off to the medical center, and sometimes, that's not done as well as it might be. One thing we might want to emphasize with the consultants is to help us close loops.

Publications is something not everybody thinks about, but we generate the important information on newborn screening programs and publications can be done just by the center. Some centers are very good about getting back to these programs and saying "We're doing a paper on this baby with unusual metabolic disease. You help us a lot. Maybe we'll put your name on the paper," and sometimes that doesn't happen. One of the topics you might want to think about in the future is should there be more clarity about what happens in publications.

That's a very Vanilla presentation of just some general areas that we and our sub-committee have talked about and we're a little anxious, I think, in the future to do some more formal presentations and more formal studies with the different consultants around the different states.

Thalia Wood:

Thank you, Lou. That was a good segue way into talking about Oregon in the northwest regional programs, so I don't know who's going to go first, Sara or Becky, or Cary, but "star 7" to unmute your line, and I will advance the slides for you.

Sara Denniston: Can you hear me? This is Sara.

Thalia Wood: Yes, Sarah. Go ahead.

Sara Denniston: Go ahead to the next slide. Just to give you a brief overview, I'm the follow-up coordinator in Oregon. We have about 45,000 births a year and we are two-screen states, we're also the regional programs for all of these other locations listed, so we're pretty busy. We had never until about 2014, they broke apart and they do their own screening now, so this isn't pretty consistent numbers, but when you add the second screening there, we're usually up to about 300,000 screens a year. Slide.

Just last year, we had 262 confirmed cases after going through follow ups. That's not counting [inaudible 00:16:50] that we pick up in Alaska which is special, but you can see there, last year, we had about 186 babies we picked up just using [inaudible 00:16:58], but we have started DNAs for that. All Alaska babies now are screened for the DNA for the [inaudible 00:17:06] and we've already had 152 homozygous since July 1st alone.

It's been very busy here trying to figure out how are processing those and getting the information to Alaska, but 262 also includes things we're looking at like [inaudible 00:17:22] carries. We do our primary T4 assay with a reflex to TSH, but we're still picking up secondary hypothyroidism and TBG deficiency, so we continue with follow up and work with our endocrinologist on getting full serum panels on babies.

Our follow up is here at the lab which is really great. The lab often just walks things over to me and gives me a heads up especially if it's a Friday and they know they need to retest something to confirm. If it's something like a galactosemia or MCAD, they'll give me the head up on a Friday so we find the baby and get a hold of them before the long weekends.

feel like even though we have a large program here, we're not really closing that relationship with our consultants. My endocrinologist emails me every Monday her schedule for the week, so I know if he is out of the office or not and would have call as backups. Our metabolic docs give me their own schedule as well, so I'm always aware of where people are.

For me, here, the short-term follow-ups, my definition is it ends when we get diagnostic testing facts and we've communicated that with the primary care and the specialist, and everyone's aware of the results, and then, a referral's made, where treatment is started, I guess that's still a gray area. Things with hypothyroidism, we know a serum comes back really fast and there's treatment recommended, but do I track if mom actually picks up a prescription and starts the baby on Synthroid? No, that's out of my realm of what I consider short-term follow-up here. Next slide.

We have very specific algorithms and flow charts that's established, but there's often times this being a pretty common example, on the right, you'll see our listed analyte from this baby we picked up, and it was several elevations all over the place, nothing specific, and what I would do before even contacting the consultant? I called the doctor and the nurse, talked to the clinic, verify if they'd see the baby. They had seen the baby at 2-day check up. She was healthy. Then, I'll send just this basic information to a metabolic consultant that's on call for the day and we'll go over do you wanted full work up, should we draft you a second screen? We both agreed let's just get the number two specimens that are waiting for the typical 14-day age range. Let's get it fast and just watch for that.

I called the doctor on day four of life. They got this second routine newborn screening on day five of life which ended up coming back completely normal. That's something I use my consultants with a lot, usually a couple of times a week. I'll send then emails like this just asking them to review and give me their opinion, and we'll make a decision on what kind of work up to do. Slide.

Here's stats that we have and are normal we're coming out. I will track down the baby in the primary care, talk to their clinic, get all the information I need. I will fax them our results, the instructions, and their fact sheet about the disorder we're looking at, any contact information. I give them a heads up that there's a consultants that's going to be calling, do they have any questions, and after that's all done, I will then email out our group we've got set up with, any state contacts if it's not an Oregon baby, and anyone associated with that specific disorder. We've got some of dietary nutritionists that see our metabolic emails to stay on top of abnormal that we call out.

After that, our consultants will then do their reach out and they will contact the primary care. I try to get them direct phone numbers or cell phones to doctors because they really don't like to go through the phone tree of clinics. The consultants will answer any questions, give their instructions. If it's something that looks like the babies are already not doing well, they'll coordinate which hospital will have them admitted to if needed.

We only have one metabolic center here in Oregon. It's in the Portland area. A lot of times, babies are going to be seen at that same hospital and it's our consultants then that have been them within a few hours if they're here at the ER.

Some mild conditions of things we see really often. If the primary care is fine on talking to me, our consultant may not even make a phone call and there's just kind of available on-call to be paged if that doctor has more specific questions they want to talk to the specialist about. Slide.

As far as our diagnostic process for workups, we've turned it now to where a lot of the labs can be done wherever their network facility sends them out to, but we do recommend certain places that we know will get labs done faster,

especially like MCADS, PKU callouts. Just in the Portland area, we can get them done here at our location and get those amino acids done faster. We send all of or VLCAD, [inaudible 00:23:02], and DNA to one specific lab, and so that's for the whole region [inaudible 00:23:08] disorders we try to keep centralized. Slide.

When we close a case, we'll just track the results and any diagnostic testing to come back. I'll review it. I send it to the consultants to review. We report back to the primary care and make sure they understand and they see the results. We'll do a closure process, send the final email out to the group, and make sure that the doctors are aware that they need to do a referral. Slide. That leads me to my next slide.

Our CS center, there's just in Portland here, so they try to coordinate if there's something coming in for [inaudible 00:23:52] testing. They'll try to schedule them the same day in the CF clinic to be seen right away, especially when that looks like it's probably going to be a positive.

Our dietary treatment is personalized for metabolic disorders. They're usually on stand-by. We had a recent PKU that was four hours away, so they're watching and assuming those amino acids will come back positive and they are on alert that they know they need to coordinate getting formula out that far away because in terms of the hardship for families to be seen right away.

I think another reason our close relationship with our consultants pays off, there was a baby recently in Idaho that got diagnosed with PKU and our metabolic doc, Dr. Harding, was already headed that way for clinics, and so they were able to coordinate and get the baby seen really fast and get lined up with specialty clinic just because we all communicate so well. Slide.

However, some of the weak points that we deal with, sometimes the primary care to the patient communication is weak. A lot of times, patients are coming in to see the specialist and they've had misinformation given to them. Sometimes our consultants need to give a push to the primary cares because they don't think it's so urgent and everyone thinks things are false positive. We've had a couple of instances where our consultants really have to make a second phone call or make a push to let them understand this is really serious.

We still hear use of the phrase "PKU test." That's very common and we're still always educating "Please don't say that anymore." Then, we have issues with our time zones since our original program; Guam, Saipan. We do several military bases over in Japan. Those are usually just email communication because there's a huge time zone difference.

With communication, this was just fresh this morning that happened. I had a call from our metabolic doc. A baby walked into the ER this morning. Mom was really upset and concerned. She thought baby had sepsis. We looked it up. It was back up September 7th. I had talked to the primary care. It looks like a Duarte variant

galactosemia. There was plenty of enzyme activity. Doctors said baby looks fine, no issues, growing healthy, so we're doing optional confirmatory testing and they said they'd get it ordered. I haven't seen anything come back yet and then 12 days later, Mom shows up in the ER really freaked out about her baby. I don't know the full story of what happened, but there's probably some kind of communication breakdown between her and probably her primary care that will be interesting to hear the final results about. Slide.

We do face-to-face contact with our consultants. We have program meetings here in Oregon every other month with our consultants in the lab and the follow-up staff. We try to do them in person, but sometimes we just do a conference call. We alternate whether they're at Oregon Health and Science University or whether they're here at the lab. We also do an annual regional meeting here at the lab and that's representatives from all the states we screen for, our maternal child health people at the states, all the consultants for all the specialties, the follow-up and the lab people all gather for a two-day meeting, and everyone involved, just thinks it's worth the cost and the time because it's really a valuable time [inaudible 00:27:38] together at one room, and over the years, I think some of my favorite conversations have come out of those, just having all those heads in the room to compare stories and talk. Slide.

That's me. I'm Sara and I don't know if Becky has slides also after me. She is our education and quality assurance coordinator.

Thalia Wood: This is Thalia. Becky didn't send me a slide, but Becky, maybe you could talk about what you do and Cary having you here on the phone. You could talk a little bit about what it's like to run the regional program and reaching out to doctors in other states. It's "star 7" to unmute your line.

Cary Harding: This is Cary. I don't know. I was waiting to see if Becky came on.

Thalia Wood: I don't even see if she's listed on the list of attendees, so Cary, why don't you talk a little bit about how it is to work with the regional doctors, regional programs and to doctors in other states and so forth, how that works for you?

Cary Harding: I think in general, it works pretty well, just that we have similar issues that Sara already went over. It's not really different from one state to the next in terms of getting them to understand the urgency and most of them are very responsive, don't have many issues. I think our biggest impediment being a large geographic program is getting confirmatory testing sent from some remote labs to places where it needs to go and we have this ... Sara said that we recommend specific diagnostic laboratories for specific disorders but we have no legal leverage over that, so they often get sent to other places, and then, we're left with kind of track down the information at some point.

That's probably, from my standpoint, logistically, our biggest issue is staying on top of the confirmatory information. Then, it depends on where the patient's at

in terms of where they would end up going to see a specialist so that we obviously have a system of knowing where they're going to end up going to, but that's probably our second biggest impediments, I will guess.

Thalia Wood: Thank you. Does anybody have any questions? You can do "star 7" an unmute your phone or you can type a question to the chat box if you have a question for any of the presenters today.

Lou Bartoshesky: Hi. This is Lou. Am I on?

Thalia Wood: Yeah. Go ahead, Lou.

Lou Bartoshesky: My question has to do with what I thought all of a sudden anecdotes about our primary care doc not doing the job we'd like to have her do. Do we have a feeling that's a common occurrence or is it uncommon?

Cary Harding: I guess I don't have it. It depends on what your definition of common [crosstalk 00:30:57]-

Lou Bartoshesky: Common is, yeah.

Cary Harding: I think most of them are pretty responsive.

Lou Bartoshesky: No. It takes one bad story to spoil everybody's day, but [crosstalk 00:31:12]-

Cary Harding: [inaudible 00:31:12] and then go to the family. That doesn't happen very often, and the PCP is ... Some of them, I think, would prefer ... I get this feeling that sometimes they just wish we would just deal with everything and they wouldn't have to deal with any of it. Maybe let them know later what happened, but obviously, we don't agree with that model in terms of the-

Lou Bartoshesky: AAP doesn't like that model either. The AAP says a lot of results probably should go to the primary care [inaudible 00:31:41].

Cary Harding: It's all around the family centered care which I completely agree with, but to maintain that is sometimes difficult, but that's the symptom of the long issue, too. If the patient ends up truly being positive for something and come in to metabolic clinic trying to keep the primary care person engaged in the treatment of their specific disease when it's really our job to do that. It's hard, but that's a constant issue and that's also variable from one place to the next.

The one place I find a little bit interesting is that you might think that some of the followup is harder in rural areas, but actually, I find it opposite that the docs having the community out in the rural areas, [inaudible 00:32:29] and they know it, and they're really good about staying on top of things, and it seems like, to me, that in large places where there's multiple docs taking call for each other, etc, etc, that's harder to keep people focused and keep them on top of making

sure that the confirmatory results get back, and every time you call you have to talk to different physician who is on call that day. I think that's more problematic than some of our smaller practices.

Debbie: This is Debbie [inaudible 00:32:58]. I have a question for Sara or just a more general comment. We work with five specialty groups between metabolic hematology, immunology, pulmonology, and probably neurology coming on board fairly soonest where things get [inaudible 00:33:12], but the burden to the program to do 20 conferences a year is huge. There's a lot of effort that goes into each of their ad hoc committee. We meet with them yearly and there's a ton of effort that goes into each of these meetings. We will talk with them on conference calls if something comes up in between.

Then, for a large state also, we have also 50 specialty groups that we're working with throughout the state. Coordinating everyone, obviously, we coordinated by condition, but it gets to be really kind of [inaudible 00:33:54] sometimes in trying to get all 50 specialty groups which means that we're probably somewhere around 200 specialty physicians because a lot of the groups have multiple members and we have multiple centers around the state. It gets a little bit harder in terms of centralizing everything.

Then, also, we found that our specialist, in terms of publications, prefer to work with the state because this sense that the state is [inaudible 00:34:26] and sometimes we have two centers that are not collaborating well, we have problems and they feel that it would be neutral to come through the state.

Then also, my other question was when we report out what we detect per year, we only include those that are out on the actual panel. We certainly report our DTs, but we don't include that in our numbers of how many we detect per year, and so it's interesting to hear that things are just a little bit different around the country. I don't know. Does anybody want to comment on the burden to the program of doing quarterly meetings with everybody?

Lou Bartoshesky: States vary now that it's a lot easier for a small state to do that than it is for big state like you guys, but-

Sara Denniston: We have a pretty small group. There's only about 15 people when you get everyone together and as much as we try to do it every other month, not everyone makes it. There's always people absent.

Cary Harding: This is Cary. I think, for instance, there's quite a few pulmonologist, but there's only two of them that have really been assigned to deal with a newborn screening site, not that the others don't know about it and the same is true for endocrinologist, so we keep the group pretty small in terms of it's not the entire endocrine department that is part of the consultant committee. They may have to deal with staff occasional on call, but for the most part, it's a smaller restrictive group.

Lou Bartoshesky: This is Lou. The thing that's impressed me is how there are even, from one state to another, differences, that we all have our own way of doing things. There are common things that we all abide by, but specific steps taken can really be variable.

Debbie: Yeah, and for us, since we're so large when do have our ad hoc meetings, I would say generally, we have 10 to 15 people from the program, both follow up and lab, in the room as well, and there are team leads and a whole variety of things. It's not just a specialist who's in the program itself. There are a large number of staff that are pulled in with the various reporting aspects and the various issues that are being discussed. I don't know if that's a problem for other programs as well.

Lou Bartoshesky: I think that the specialist still select. A group of eight pulmonologist [inaudible 00:37:26] that may really like newborn screening and so they often push those to be the delicate. Do you find that in the big states?

Debbie: As I said, we have over 50 groups not just physicians, so yes, very frequently, there is one or two people within a group that will be their representative for a newborn screening, but we also find the specialist, the endocrinologist, there tends to be a lot of turnover and from year to year, it'll be somebody different. It's kind of a moving target for us.

Sara Denniston: Maybe that is unique and how we are more of a small close-knit community [inaudible 00:38:09] with endocrine and hemoglobin. We have one main consultant that's really involved in the newborn screening process and then they've got a backup for on-call people, and they've got younger folks coming up behind them, but they're grooming one specific person. We know in the future, when they retire, that's probably just going to come in and take their spot, so when we have those meetings every other month that we try to have, it really is, it's not a huge group. It's not everyone involved in the specialty centers. It's just you people that have really come in to this newborn screening community.

Lou Bartoshesky: Do you think it's so under attended that it's futile? Are you still convinced that it's valuable?

Debbie: Is that to me, Lou?

Lou Bartoshesky: Yeah.

Debbie: This is Debbie. I think it's absolutely valuable and I think it's very critical, and I think that the engagement in the continuing ... We have close relationships with all of our centers and the folks in there, but we're spread a little bit more in that we have nurses who do the follow up and most of their nurses are assigned to a particular specialty. The metabolic nurse will be speaking to all the metabolic centers and they'll know everybody's schedule and all the rest of it, and when

people are on vacation, and all that kind of things. We're just spread a little bit more, but I think when we bring everybody together, I think that it's extremely valuable.

We just had a pulmonology meeting last week and the comments that we got which is one of newer groups, and the comments we got back is we know our little part of it, but we didn't see the whole overall picture and it was extremely valuable for them as well. I think that there's a lot of buy and I think it's valuable.

On the other hand, our endocrinology group which has the most turnover is everybody comes voluntarily on their own time. We seem to have different people every year and it's like we'll have a meeting, people suggest something, we'll implement it, and then the endocrinologist will be different endocrinologist from [inaudible 00:40:24] and they'll say "Why did you do that? We don't want that. We want this." It is a plus or minus, but there's, I think, keeping them engaged in the programs and keeping them a part of the overarching issues I think is extraordinarily helpful, but I just can't see us doing it four times a year for each group.

Cary Harding: You said something about I thought that was key there is that I think is crucial for us is that we do have a contract between OHSU and the state to provide this consultant services, so it pretty much identifies by name, I think, that individuals that are responsible for those activities, and we don't have to travel far, but I know that for the regional meeting, expenses are paid for the people that come from the other states to be involved. If you're depending upon physicians in particular to stay engaged and pay their own way, I could see where that might not go very well.

Debbie: Actually, Cary, surprisingly, people do do that, but we tend to get people from the larger academic centers as opposed to ... From metabolics, we don't have any practices out there that aren't affiliated with academic centers, but the folks we get tend to be the academic medical centers, and I'm always amazed they show up.

Female: Hi this is [inaudible 00:41:56]. I just have a quick question for Cary.

Cary Harding: Yeah.

Female: You mentioned that you have relationships you recommend for in labs that people use for follow-up testing. Are you able to get the results directly from those labs or do you have to go back to the specialist or the primary care doctor to get the results>

Cary Harding: For most them have a lot of metabolic stuff is our lab here at OSHU, so they come to us. I have the data, but like our VLCAD screening, we don't, and that they usually alert when they get the results as well. You're absolutely right. It's a problem when the data go to some other laboratory and if we aren't listed as

ordering people which we do sometimes ask them to do, put us on the list, then we have to depend on getting the data through the primary care and that just adds more delays.

Female: You have an MD who gets list as the ordering or they'll list it as someone just the newborn screening can get the results because [crosstalk 00:43:03]-

Cary Harding: [crosstalk 00:43:03] that they put my name on there and then they send us the bill. That's shocking.

Sara Denniston: This is Sara. A lot of the times, I'm listed as a person to get the results as well as the primary care doctor. They come to us at the peak time and then, I'll forward them on to whoever needs to see them.

Thalia Wood: In a large state where our follow-up list [inaudible 00:43:34] driven by their insurance and there's no one lab across the state that everyone can utilize. Even it's commercial level, whatever, it's all driven by who their insurance is contracted with.

Cary Harding: Right, and we don't have any bigger [inaudible 00:43:53] than you do. The only [inaudible 00:43:56] that we have is that as a [inaudible 00:43:59], especially if the family had no insurance and we as the screening program, we're going to pay for their testing, but that would have to come through our ... We won't pay for it unless it comes to the labs that we recommend, but you're absolutely right. In terms of if it's their insurance dictating where it goes otherwise, then that's where we have more problems. About all we can do, as Sara has suggested, is try to get ourselves listed as being people that the data should return to, but Sara ends up spending a lot of time on the phone tracking the data [inaudible 00:44:33] I think.

Female: At what point in the process do you tell them to list you? When you make the initial referral you request to be listed to get the results or do you do that [crosstalk 00:44:45]-

Sara Denniston: It varies. VLCADs, we send to the same lab and I'm listed on the requisition forms, and they know to send us a copy. Things like hypothyroidism and we're just looking for a free T4 TSH, a lot of times, I'm not getting a copy of those or I have to call the primary care. Sometimes they'll voluntarily send me things, but-

Cary Harding: You probably have a harder time closing out your thyroid cases I would guess.

Sara Denniston: Yeah, we just do a verbal. Our endocrine specialist don't need to see the actual labs. If they've talked to the primary care, we've got verbal information. We know baby is started on treatments.

Lou Bartoshesky: I'm sorry. Does that mean the primary care docs in some cases handle everything for the hypothyroid? They don't send the kids to consultants at all?

Sara Denniston: It depends. I think there's in the community that some docs are okay managing those babies and other docs prefer to send them to specialists, and that's the same here in Oregon.

Cary Harding: It depends on geographic locations.

Lou Bartoshesky: Right. If you live 300 miles away from everywhere, you're going to have to handle it.

Thalia Wood: This is Thalia. This has been a great discussion. Does anyone else have any questions? It's great to have all these medical consultants I know that they [inaudible 00:46:19] talk about your individual program.

Lou Bartoshesky: Are there any typed in questions we missed?

Thalia Wood: No. Nothing in the chat box. Carol, there's no more questions? Lou, did you have something?

Lou Bartoshesky: I just want to apologize for my technological failing at the beginning, but-

Thalia Wood: That's all right. That's okay. We got it then, so-

Lou Bartoshesky: You're used to it by now.

Thalia Wood: Carol, would you like to say our fond farewell?

Carol Johnson: Thank you. I thought this was a great webinar, great discussion. I have some notes that I took that I also am part of a regional program and it gave me some ideas, so thank you for that. Thank you to Lou and Sara, and Becky, and Dr. Harding for their input. It's nice to be able to have some of our consultants on the calls with us as well.

This does conclude our September webinar. Stay with us for our November webinar. Thalia will be sending out information about that. Thank you for your time and have a great rest of your week.

Thalia Wood: Thank you. Our next webinar is November 14 and you will all get an email.

Lou Bartoshesky: Thanks everybody.

Thalia Wood: Thank you.

Sara Denniston: Thank you.