

**Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference
September 9, 2003**

**Topic: What is the role of the primary care physician in the
EHD process and the medical home?**

TO: Ad Hoc Group for EHD
FROM: Danielle S. Ross
SUBJECT: Conference call information and agenda.
DATE: September 9, 2003

The next EHD teleconference will be on Tuesday, **September 9, 2003** from 2:00 to 3:00 pm **Eastern** time. To join in, call: **1-888-391-6570**. You will be greeted by an automated voice and asked to enter a Pass code. **PASSCODE: 50614 (plus the # key)**. Please call in 5 - 10 minutes before the conference starts so we can begin promptly at two. If you have any questions please contact Marcia Victor (*MVictor@cdc.gov / 404-498-3036*) or Marcus Gaffney (*MGaffney@cdc.gov / 404-498-3031*)

An internet based captioning service will be available at no charge during this teleconference. If you would like further information or to schedule use of this caption service, please inform Marcus Gaffney (*Mgaffney@cdc.gov / 404-498-3031*)

Agenda

I. Welcome

II. Dr. Patrick Brookhouser: "Introduction: The role of the primary care physician in the EHD process."

III. Dr. Albert Mehl: "The pediatricians' perspective on their role in the EHD process."

IV. Janet DesGeorges: "The parent's perspective on the role of the pediatrician and the medical home in the EHD process."

V. Dr. Fan Tait: "What is being done to involve, support and educate pediatricians about EHD?"

**CENTERS FOR DISEASE CONTROL AND PREVENTION
EARLY HEARING DETECTION AND INTERVENTION
AD HOC GROUP TELECONFERENCE
September 9, 2003 2:00pm (eastern)**

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>>**DANIELLE ROSS:** Good afternoon. This is Danielle Ross from CDC. I'd like to welcome all of you to this month's Early Hearing Detection and Intervention Ad Hoc conference call on the role of the primary physician in the EHDI process and the medical home. I'd like to remind you to please mute your microphones when you're not speaking to help reduce background noise. Also, please remember to say your name each time you speak. That will help the transcription service. Today's teleconference is being recorded and the transcripts will be available on our website in approximately two weeks. The title of today's call is "What is the role of the primary physician in the EHDI process and the medical home?"

Our speakers are: Dr. Pat Brookhouser who is the Director of Boys Town National Research Hospital and Immediate Past Chair of the Joint Committee on Infant Hearing. Dr. Brookhouser is going to outline for us the primary physician's role in the EHDI process and the Medical Home. Dr. Albert Mehl is Chairman of the Colorado Infant Hearing Advisory Committee, a member of the Clinical Faculty at the University of Colorado Health Sciences Center, and author of several published manuscripts on Newborn Hearing Screening. Dr. Mehl is going to discuss the pediatrician's perspective on their role in the EHDI process. Janet DesGeorges is the Executive Director of Colorado Families for Hands & Voices, and the parent consultant for the Marion Downs National Center. Janet DesGeorges is going to discuss the parent's perspective on the role of the pediatrician in the medical home and the EHDI process. And last, but not least, of course, is Dr. Tate, who is the bureau director of children with special health care needs of the Utah department of health. And Dr. Tate is going to discuss what is being done to involve support and educate pediatricians about EHDI.

Before we begin, does anybody have any announcements or comments or questions? Okay. Each speaker will have about 10 minutes for their presentation, and then after each speaker, there will be about 5 minutes for questions. Okay. So our first speaker, Dr. Brookhouser, as I said, will outline the primary physician's role in the EHDI process and the medical home. Welcome, Dr. Brookhouser.

>> **DR. PATRICK BROOKHOUSER:** Thank you very much Danielle. What I've set about to do here is to give a little background as to how the primary physician should fit into all this, but also to talk a little bit about the hurdles that those of us who have been working at this have found in terms of achieving the ultimate goal. The answer to what we want the primary physician to be is very easy. We want that primary physician to be the cornerstone of the child's medical home. We want them to be an informed and knowledgeable caregiver in the area of infant hearing problems. We want them to be a source of accurate and up-to-date information for the family and to support the family in the decision-making process, and to finally be an effective advocate for the child with the health care and educational providers that the child may need to contact.

There's been an amazing redirection of focus in the area of early identification of hearing loss, certainly in my professional lifetime. And a huge paradigm shift away from what we might call a failure based identification system in which the major indicators were provided by the family and others who noticed the child failing to develop normal communicative milestones to now a very proactive identification system. In the failure based system, the primary care physician many times came in for criticism for not having a high enough level of suspicion in response to the mom's or dad's concern regarding the child now the primary physician must play a key role in helping to find a way in which the family and others approach the results of hearing screening and

intervene with the child, if necessary. As the principal provider in the primary care physician has to deal with a lot of other I guess demands and priorities during this period. Instead of being at the 18 to 24 month age where most of the children were identified prior to the on-site of universal screening, we're now dealing with the first six months of life, during which priorities in the area of childhood nutrition, early immunizations and other types of priorities compete both with the parents and the primary care physician during visits to the physician's office. In addition to which, there is really not an effective way to achieve definitive follow-up in that primary physician's office for a child who has failed newborn screening. So all of a sudden, we have a primary care physician who, to a certain extent, feels powerless when it comes to gives responses immediately to the parents' concerns. We want the primary care physician to be a champion with a heavy dose of (inaudible) in helping the parents navigate through this process but what we really need to go back to is look at what they need to get there, and they need to be empowered where knowledge and they have to have trust in the reliability of the screening and evaluation results that they're presented with.

The starting point for those of you who are not physicians can be pretty minimal. There's very little stress on childhood hearing in the medical training that most of us receive. There are no mandatory (inaudible) otolaryngology or audiology through medical school, and there is not very much time spent during residency, either in pediatrics or family practice regarding this area. So all of a sudden you've got a significant information gap in the minds of many primary care physicians when they're presented with a potentially significantly hearing-impaired child and that's not totally in their area. None of us have really worked on a regular basis with children who we knew for sure were significantly hearing impaired within the few first weeks of life that we're now having referred to us. Apart from that, even the practitioners who have been in the field many years have not seen hearing loss of the significance that we're talking about here is a low prevalence disorder. Most of them have not seen very many children either, so we now have a need to bring together a knowledge base, along with the patients as they present themselves to the primary care physician. There has been an amazing change in the (inaudible) etiologies that we're confronted with as well during the professional lifetime of many of us on the call. We've seen a huge shift away from non-genetic hearing loss causes such as maternal rubella, measles, mumps, meningitis, all of which have been significantly impacted by immunization programs. (inaudible) remains a problem, but then you have this huge area of genetic hearing loss, much of which is non-syndromic and recessive in nature so the primary care physician is confronted with a real need to be aware, at least, that some of these types of losses can, in fact, be identified through screening of various kinds. Then beyond that, I think the physician needs to have some knowledge about screening and evaluation techniques. Most of us grew up thinking that kids were tested pretty much along the lines of visual reinforcement, audiometry or some type of a behavioral confrontational test.

Most physicians do not have a very good understanding of auditory brainstem testing and even less of an understanding of otoacoustic emission testing. They need to be informed about the strengths and weaknesses and limitations of these test methodologies because the next significant hurdle, I think, is overcome in the minds of both physicians and parents a mistrust of the results they're getting, based on the fact that there is a significant false-positive rate, even with the best test protocol. When you refer away 2% of the children that you're testing that you've screened for definitive testing and find out that only one out of those comes back with a positive test, you realize that -- that you really have a significant hurdle to overcome in the minds of many people regarding how many -- how many tests, in fact, a child has to have -- or how many children are, in fact, going to come back with positive results.

The pediatrician or the family practitioner begins to looking around for referral sources and they look for definitive testing sites and we're now finding that many audiological sites are not really prepared to test very young infants and also to provide early intervention in the forms of hearing aid prescription and fitting. I must say that (inaudible) is now beginning to work with the joint committee on infant hearing through a contract to try to develop a series of guidelines for making people knowledgeable consumers about audiologic services, to identify those basic abilities and capabilities that an audiologic center should have to be able to provide the kind of services that are necessary to confirm this type of hearing loss. So we need to give the primary care physician much more information about who to look for in terms of referral source and what kind of information they should expect back from these various referral sources as they provide information to them. It is very easy as they serve as an information source and support for the families during the decision-making to become embroiled in many of the present in the whole field of deafness for years. The issue referred the preferred communication modality (inaudible) regarding (inaudible) amplification versus cochlear implants, the care and

treatment of middle ear disease in young children with significant sensory neural hearing loss, all of these issues are going to come up very rapidly as the primary care physician begins to work to coordinate the medical home for this child. And so we have a significant knowledge gap. We have people that are very anxious to work at it. They're being presented with information very early in life about the child's hearing status, and then are confronted with a whole series of questions, both from other providers and from parents regarding the best way to intervene. So rather than say that we've met our goal, we've really just begun to identify our goal for the primary care physician as to what that individual should have. And I think just in time information has got to be the information. We've got a large number of people out there who are going to have to be given information regarding this, because remember, for every one of the kids that's identified as severe or profoundly hearing impaired, they're going to have a whole significant number of false positives that are going to raise the same degree of questions with the primary care physician as that person interacts with the family.

So at this point, I think that I would open it up for questions. My feeling at this point is that we're just beginning to scratch the surface as to what information needs to be put into the hands of our primary care physicians. The chapter champion system that's been developed by the academy of pediatrics is a wonderful step in the right direction. Very frankly, I can tell you both at that level and the joint commission on infant hearing, we're still not at the point where we've brought the family practice physicians on board to the extent we should and that's got to be a major goal, because like out here in Nebraska (inaudible) are actually compared to by family practice missionaries in and not by pediatricians (inaudible) of defense, so our first bulwark of intervention, but we need to consider how we're going to involve (inaudible) of providers, including nurses and newborn nurseries, who, of course, are looked at as a good source of advice by the young parents. So with that in mind, I am going to stop, open it up for questions, and I hope I have not run longer than 10 minutes.

>>**DANIELLE ROSS:** Okay. Does anybody have any questions for Dr. Brookhouser?

>>**DEBBIE BERINGER:** This is Debbie Beringer in Michigan. Lori Lang and I are working on the physician survey and we're trying to glean what is the best way to get information out to physicians? We've done a couple different things. We're looking at putting on a web page specifically for our doctors. We also have mailed out information to physicians. We've done some presentations, all with varying degrees of success, and what would be your suggestions on how we could work more efficiently with our physicians?

>>**DR. PATRICK BROOKHOUSER:** I think we'll talk about that a little bit later but I must say, if you want to contact somebody, Mary Pat Moeller at our facility here at Boys Town through BabyHearing.org has some ideas about it. Most of the studies that we've done here have shown that physicians don't necessarily respond to the same type of information transfer that some of the other providers do. Many of them look to grand rounds at their children's hospital as being a very important source of new information, and so you may not find that traditional mailings and even internet contacts may not be the best way to get to them. But I would say one thing. Repetition is not a bad thing, because as I mentioned, most of these individuals won't have an opportunity to implement this information that you're giving them on great numbers of cases, so constant repetition and updating them on the (inaudible) rates that they're going to see in certain environments and the false positives and how to deal with that issue can't be overstressed. But I think probably going through trusted others in their environment through such things as ground rounds, may, in fact, be your best approach to most of them.

>>**CHRISTINE ROSENWASSER:** I am a pediatrician in New Hampshire and a new chapter champion. I am still learning a lot about this. We're struggling with this same issue of how best to get to family practitioners and pediatricians in our area. We're probably going to start with a mailing, and perhaps have representatives go to hospital or practice meetings, and the other thing I thought of was an on-line CME where we could perhaps put all the relevant information that we want -- we would want our practitioners to know in a succinct manner.

>>**DR. ALBERT MEHL:** Danielle, this is Albert Mehl in Colorado. I'm wondering if I might proceed and some of these questions might -- we might hold till the end, only because we might touch on some of the information.

>>**DANIELLE ROSS:** Yes, that would be great. Dr. Albert Mehl is going to provide us with the pediatrician's perspective on their role in the EHDI process.

>> **DR. ALBERT MEHL:** Thank you, Danielle. Forgive me for that interruption, but I am realizing that some of the things I am about to say may at least touch on the questions that you're raising right now. I'm charged with telling you about pediatricians and/or the primary care physician/family practitioner but at first I need we need to realize that into context of 50 different states with 50 different systems and 50 different EHDI programs, and I am so intrigued that the newborn screening program for hearing will probably never be the equivalent of newborn screening for metabolic disease such as PKU. In my state, if I am not particularly knowledgeable about PKU, somebody literally barges through my door and helps me figure it out when a child has an abnormal PKU test and they do it within about 48 hours and I can't help but provide the right care to that patient because of that system.

I think in hearing detection, we've come a long ways, but we don't have blood samples that go to a state lab and I don't think we will ever, then, have the same kind of statewide system to respond. We will be much more dependent on hospital-based systems that do screening, that do follow-up, and if the states can provide an adjunct to that, so much the better. But I think very much we need to continue to look at the challenge being in a hospital system world rather than a state EHDI program world. The more we can do to tie up the loose ends at the state level to find out who didn't get and why, to then bring back those names and get people timely follow-up, I think we will succeed even better but I think we have to emphasize the hospital systems.

Well, when I think of 50 states, I am guessing we're talking about something like 5,000 hospital systems, and all of different size, all with different audiology capabilities, screening capabilities, different staff made up of pediatricians and/or family practitioners, and all of the variables about how that screening happens. And so my first piece of encouragement is to sort of continue to carry that torch at the hospital-based level, to -- to do the kind of job that makes the physician's job easier in terms of the importance of follow-up, making sure that babies who -- that babies get screened before they leave the hospital or have a plan for screening if they haven't been, that they get very complete follow-up and that we keep the physician tied into that loop. That's not only information for the physician, but every one of those contacts is an educational phenomenon as well.

Well, if I think of 5,000 hospital systems, now I want to speak on behalf of how many pediatricians across the country. I pulled off the -- I pulled my American Academy of Pediatrics directory off my shelf and counted 200 pages of three columns each with a hundred names in each column, so I am thinking we're on the order of 60,000 pediatricians. And let's double that with family practitioners, and imagine that we're talking about a hundred thousand plus physicians.

I'm so impressed with the idea that those physicians have variable knowledge level, and I have had the great pleasure of being involved with newborn hearing screening and have given talks in -- on an assortment of continents and when I show up, people sort of refer to me as an expert in the field and I am chagrined to say that about 18 months before I was an expert in the field, I knew nothing about this field. And so I am intrigued that physicians out there taking care of these children mostly fall into that category. They're learning in a very sporadic way about what is -- is this actually important and what am I supposed to know about it and how am I supposed to be part of the process? And I'm -- and Pat's comments, I have to echo, about some of the just in time information. That assumes that the knowledge level will be at a variable level, and rather than provide information at a time when perhaps I don't have any babies in my practice who recently failed the screening or have been diagnosed as hearing loss, how do we provide information that -- that accompanies the baby who has the problem so that we can provide the education instantaneously?

Now, all of those hundred thousand physicians have various sources of information in their current lives. I think of the following ideas when a physician says, "well, maybe I need to know more about that." First they go to their bookshelf and they pull out a text. And on my bookshelf, the texts are a few years old and I bet I couldn't find a textbook on my shelf that talks about newborn hearing screening. Some will go to their peers who then will share their own faulty level of information with them, and feel reassured that they both have the same imperfect information. I have to be quite frank that there's a very steep educational curve for our consultants, for our otolaryngology specialists, and so even the information we usually seek out from a consultant may, in fact, not at all be as timely or as perfect as we'd like it to be in this evolving, rapidly evolving information era.

Physicians get information from drug manufacturers or in this case, equipment manufacturers, which may be not bad and more than they've had before, but certainly introduces bias and certainly not complete, for them.

And then as you look at journals and CME programs and the things we're doing now, which I am so intrigued about the power of repetition and the importance of continuing to put that information in front of people, but I am also intrigued by the natural response of myself and other people when we see something brand-new that wasn't in our training. Many of us -- and maybe yourself included -- we tend to seek information that supports our old world view of maybe this isn't important, maybe this will just go away, maybe I really don't have to learn about this or do it. And I think because of that natural instinct, we've had our bumps in the road with the -- with Jack Paradise's editorials that allowed for people to sort of say, "I think we won't play right now" or the more recent preventive services task force that become questions we have to answer for those physicians who might have a natural tendency to stay in an old world, rather than move into a new world.

Years ago, I was giving a talk and I said to an audience of largely audiologists, that "I used to think if we did a really good job educating physicians, eventually they would all understand this, but I am starting to think maybe the goal is to just educate them enough to get them out of the way." Now, that is not -- I don't think that's the right approach anymore. We've come a long way since the day of that talk, and I do think that we have to move physicians from the phase of being obstructive to perhaps being open or out of the way to eventually being an ally and an advocate for what we need to accomplish.

I thought I would just spend one last minute speaking about the educational spectrum by describing my own journey through this process over the last 10 years, with my background as a pediatrician. I have never been a specialist in hearing or otolaryngology and I was approached about a grant where our hospital here in Boulder, Colorado, was -- had a possible grant to screen newborn hearing. And since I was the chair of our little baby department, I nodded yes and said, "sure, okay, sounds interesting." Well, I had no knowledge about this -- that this might actually be important, but already I was the head of about 60,000 physicians who would say if it's new, it must be a bad idea." I very gradually learned about the real frequency of hearing loss. You know, much more frequent than the other diseases that we screen newborns for in terms of metabolic screening, and the importance of universal screening and started thinking about missed screenings at the hospital or home births. I gradually realized the importance of making sure that follow-up actually happened, that people didn't go home and never come back for their retesting, and the importance of catching the one baby in that group who really does have the hearing loss, even though there are some false-positives.

The time -- the importance of the timeliness of follow-up. In fact, it struck -- the counterintuitive idea that it's easier to screen a 2 month old or 3 month-to-date who falls asleep during the test than a 6-year-old who doesn't fall asleep during the test took me a long time that there was an extra reason for getting babies back in quickly. And then glad gradually I learned about amplified babies and that you really could do that, and what the skill and training was for that professional that hadn't been amplifying babies before might involve. I learned about the role of the physician for reinforcing hearing aid use when it -- if a child does require a hearing aid. I learned so much about how early intervention is more than hearing aids, and I will be interested to hear Janet speak in a minute about the parents' role and perspective about that as well.

I learned even recently about the importance of an adjunct evaluation by ophthalmology for other associated defects and about genetics to counsel families about recurrence risk or other potential problems. I learned that when we started universal screening, we couldn't throw away the idea that risk factors still existed and children still had acquired hearing loss and came from families with risk factors, and that we couldn't stop thinking about that group just because we were doing universal hearing screening. I'm learning even today about unilateral hearing loss and what are we supposed to do with babies with unilateral hearing loss? If nothing else, it is a risk factor that they could have acquired hearing loss in the other ear. But in fact, do they need intervention? Might they need a hearing aid? Is it worse in the right ear than the left if you have unilateral hearing loss? And in the very tiny group of kids who go on to have cochlear implant, to learn about that process. And finally with Janet, the idea of being an ally and empowering parents as opposed to just sort of getting out of the way, that we can really have a mutual support about getting the best outcome for these children.

So having expressed that spectrum of education that I have gone through, my challenge to each of you is to imagine that every physician who you deal with is somewhere different on that spectrum and what is it that we need to do to provide that one person a step up the ladder, but also universally help everyone come along that path. Thanks very much.

>> **DANIELLE ROSS:** Thank you, Dr. Mehl. Does anybody have some questions? Okay, we will move on to Janet DesGeorges who will provide us with the parents' perspective on the role of the pediatrician in the medical home and in the EHDI process. Welcome, Janet.

>> **JANET DESGEORGES:** Hello, thank you. I want to thank CDC for this opportunity to speak with you today. It's great to hear, as everybody comes on, that there's people represented from all over the country. If Dr. Mehl was feeling the pressure of speaking on behalf of the perspective of a hundred thousand physicians, you can probably imagine my stress level at trying to represent the perspectives of millions of families who go through the newborn hearing system. Nevertheless, I will try my best. I want to assure all of you that even though this is a teleconference, I am appropriately dressed in my two-piece black business suit. I am not sitting here in my sweat pants and bunny slippers.-- okay. So now that you have a good visual going....

Mark Twain once said "life is just one thing after another," That would probably be a great tag line for the establishment of universal newborn hearing systems....from screening to identification to early intervention with all the stakeholders, and their different roles that they play. I'm really happy today to be talking about the pediatrician's role. I think it is like looking at it as a piece of the giant puzzle and each piece within itself is very complex, and so in looking at the pediatrician's role within the context of the overall system is -- is a really good thing to do.

I wanted to approach the parent perspective from the concept of the medical home. I have to tell you when I first started hearing about the medical home, there was some cynicism that kind of crept into me as a parent of a child who is deaf as I began to look at some of the bullet points and the goals that the medical community was going for. But, hey, this looks great. You know, who doesn't want an accessible family centered, comprehensive, continuous, coordinated, compassionate, culturally competent system? You know, I am sure all parents do, and I would actually like to approach my presentation today from the position of believing that the medical home concept is being implemented, and will actually be implemented in its finest form. With that being said, what that would this look like in context to families who have deaf and hard-of-hearing children? I think that even if the medical home concept is brought to fruition, we must look at this experience of having a child who is deaf or hard-of-hearing and how it fits in, really, to the medical home, the medical community, or another way to say it is really as a "medical condition."

The reality for families is that deafness soon takes a departure from the typical medical model of a "condition" that we as families would come to our pediatricians or our physicians to. I mean, when you look at the deaf experience, there's a culture, a community wrapped around it, in context to the decisions and the questions that come for families about this process. Are we really asking and saying that we expect or want, really, our physicians to be the main center core of resources and information in this journey?

When we look at the universal newborn hearing systems, and all the pieces of the puzzle, we begin to understand that the information that family needs comes from a variety of places, and rightly so. When you look at the kinds of questions that families face and the decisions they face in this unique experience, obviously you can begin to differentiate the places and the times where families need these questions answered. For instance, some of the physical causes of the hearing loss, the etiology of hearing loss, families have questions about the medical diagnosis, the implications of the degree of hearing loss their child has, amplification options, what other communication choices, what are the educational implications, what's the emotional process families are going through, what is the information families need to know about deaf community and deaf culture, what are our funding issues, sibling issues, language development issues... The list goes on, and right away, you begin to see that I don't think parents expect to have those questions answered from one place.

We need systems that are put together well, so that where and when we need our questions answered, there will be somebody in front of us who can answer those questions. So, to answer the question: "What do parents want from pediatricians?" Here it is in three simple answers. I am sure there's probably many other things families could step forward and say that this is what we hope for from the medical community, from physicians, but I can't really begin to answer those questions until we understand, I think, and acknowledge the reality of parent experiences in the past. And I think both the doctors before acknowledged that. I wonder if I am just focusing here on 'sour grapes', but when I have had the opportunity over six years to talk to hundreds of

families, I would say particularly for families of late-identified kids who almost always have a story of sitting across from a doctor, bringing their concerns about their child's hearing loss, and basically being told, "don't worry about it," the feeling from families that they are not being listened to. I completely understand the defensible argument that physicians don't typically see deaf and hard-of-hearing kids, and it's true that kids do develop that at different rates. But I just want to acknowledge the reality of those parent experiences over the past years, as we're looking forward, into a new era, that those are acknowledged and that parent stories are heard in order to really create an effective system. And I have to tell you, I have been really heartened by many stories from families who are beginning to have a different experience than that what was typically seen before. I think the education of physicians is beginning. Hopefully There's a different story being told now by a lot of families.

But anyway, the answer to the question, "what do parents want from their physicians?" Number one, we want physicians to understand the basics. It's not okay for a physician to tell a family who has just come from failing a screen, to say, "don't worry about it, forget about it." That was the answer to a family's question last week in one of the states on this call today, and so it is still a concern, I think, for parents. Again, we want physicians to understand the basics. We want physicians to be able to tell parents, "yes, there is a test that can reliably assess your child's hearing," rather than hearing, "oh, you might as well wait for six or eight months" or even for a child who is identified with a hearing loss, for the physician to say, "oh, there's nothing you can really do about it. You know, for eight months or a year, I wouldn't worry about it." We want physicians to understand the basics, both technologically and medically. We depend and rely upon our doctors for the 'medical condition' part of this experience. If our child has an ear infection, how does that relate to our child's ability to hear? Different things like that. I know I am just skimming the surface here, but I think the AAP guidelines are a really good step for physicians to understand those basics.

Number two, what families want from their physicians and pediatricians, is a sensitivity to the complexity of the decisions that parents have to make. I don't think parents are hoping that physicians will someday be able to sit down and tell a family the difference between auditory-verbal therapy and auditory-oral therapy or total communication and American Sign Language. I think what we want, though, is for physicians to understand that this is, by nature, a complex process for families to get through, and what Dr. Mehl said is so right, that they would actually empower families through learning ways to approach the methodology issue with sensitivity. When physicians make comments to families like, "well, don't worry about it, a cochlear implant will cure it," or, you know, "your child -- you should do this method or that method," it just kind of takes away from the ability -- for families, really, to make an effective decision. And so what families want is a sensitivity to that process. I'm throwing in here a few quotes from families that I have heard. You know, they said, "for a physician, you know, to sit across from a family and say 'your child will never live alone, be able to live alone,'" you know, that's obviously a lack of sensitivity to the deaf experience. And so that is something that we would hope physicians would develop, as well as understanding the basics of -- of this process for families that they go through.

I am going to get to number three in a second, but in Colorado, we have been trying to come up with a way to use one approach to help physicians learn about this 'sensitivity' to the process. What we have realized, and I know Dr. Brookhouser talked about this regarding pre-training. Physicians don't get a lot of training about hearing loss. We have found is that once families are identified and they're sitting across from their physician and that doctor has a baby or a small child in his office with hearing aids on, those physicians tend to become extremely interested in this process. Because all of a sudden, it's right across from them, it's there in front of them. And so what we're developing is an idea to actually use families to help educate physicians. I have heard from many families that once their children were identified, their doctors really came on board really quickly and became an advocate for them, were really interested. Here in Colorado we're trying to figure out a way to get information and resources to doctors through the family. So for instance having our families get two copies of a resource guide and giving that resource guide to their physician, who now has a child in their practice. The interest level completely increases the moment the physician actually has a child in their office, so that's one way we're looking at kind of being able to increase physicians' awareness.

Number three, what families want from their pediatricians is for the medical community to understand their own place in this system. That there is a connection between their understanding of the screening, identification and diagnostic and entry into early intervention at a very basic level that they at least understand their role

established through each state's guidelines or committees; that they would understand their role in a concrete way to say, "we understand that every time a family walks into our practice, we're going to find out where each family is in the -- in the screening system. Has this family been screened, are they -- have they moved on to rescreening. Have they been identified with hearing loss."

These are ways that families feel physicians and pediatricians can really be a meaningful, realistic, part of this experience in our families' lives. I want to close by saying; I know it's my role as the parent of a child who's deaf to prepare my daughter Sara for life's road ahead. I am passionate about creating systems for families, because I think we as a system have the opportunity to actually prepare the road for families who are on a journey with their kids. Thank you for this opportunity of sharing this.

>>**DANIELLE ROSS:** Thank you very much. Are there any questions for Janet Desgeorges?

>>**DR. PATRICK BROOKHOUSER:** I just have one comment and I really appreciate the input regarding the parents' experiences in the past. We had some focus groups as part of a research program we had in setting up this website and we had a group of pediatricians that we -- and we thought that Mary Pat Moeller was involved in it. I think al may have even been there. That we were going to be stressing to them the importance of early identification by showing them some of the sort of horror stories of the past where kids were missed and the pediatrician didn't have a high enough level of suspicion or index of suspicion. It turned out that that was a negative kind of thing to present to the pediatricians to motivate them. They became very defensive and sort of threw up a wall about fear of liability. So it's an interesting phenomenon. It has definitely happened. There's no question about it. But stressing it sort of throws up a wall of fear of liability for missing diagnoses and sort of puts them in a different mind-set, so i think as you begin to approach individual physicians stressing the positive aspects of now you're going to have information in your hands that will help you by the family rather than showing the horror stories of late identification might be a more effective way to get their support.

>>**DANIELLE ROSS:** Thank you for that comment. Are there any other questions? Or comments? Before we move on/

>>**BETTY VOHR:** I have a comment. Al mentioned the mechanism by which families are -- or that primary care physician is notified when a child fails the metabolic screen. We actually have a committee right now made up of representatives from metabolic screening and newborn hearing screening in Rhode Island, and one of the things that we're considering right now is to have a similar phone call to each pediatrician when a child is identified with a hearing loss, to make sure that he's -- he has all of the materials that have been sent out by the EHDI coordinator and whether he has any questions that need to be answered, and making it as important as if it's a metabolic screen fail. So I just wanted to react to Al's comment in that regard.

>> **DR. ALBERT MEHL:** Betty, thank you for that comment and I know that in Colorado we are similarly looking for babies that they can't find a record that they ever completed their follow-up and we are also looking to make an outreach to both the physician and the parent of that group as a double safe method of somehow making sure those babies get checked. I do think there are opportunities and i don't think we should be complacent about that, but I do think its interesting how dependent we are on hospital-based systems as opposed to a state laboratory blood system, so the job is tougher. But that doesn't mean it's less important.

>>**PAT RICE:** Are you saying that you followed up only on the positive confirmed hearing loss or those babies that didn't pass screening?

>>**BETTY VOHR:** At the moment, we are debating which way to go. If it's -- the rescreens who fail who then are referred for the diagnostic, or whether we should just go once they've failed the diagnostic. We can easily go in either direction with our current statewide fail rate of just under 2%. So we do have a medical home task force which is working on that in terms of developing the materials that are going to go out to each physician each time he has a child identified that will be sort of personalized towards that individual child. But we're trying to add to that the phone call and we haven't made the final decision yet when the phone call would be made.

>>**LILAH KATCHER:** This is Lilah Katcher in Wisconsin, and I actually have a question for you. We also use the blood spot card and we are finding that at the point of screening, when we have information about babies who

have not passed their screening, we actually do not have information -- accurate information at that point about the (inaudible)

>>**UNKNOWN SPEAKER:** well, yes, it really boils down to what your data management system is for identifying these, you know, is variables, and getting that information sort of coordinated. I can't really comment on your system without knowing how the data management works, but certainly there has to be a link between the hearing screening and the metabolic screening.

>> **DR. ALBERT MEHL:** I will comment that if you already have a link with the metabolic screening database, you are one step ahead. In Colorado, we linked with the birth certificate database and so we are identifying the mother's doctor, rather than the baby's doctor, in that database, and so we're having to do extra work to try to reconnect with the baby's physician, even though, as you say, sometimes that information is not accurate.

>>**LILAH KATCHER:** What we found is we actually did not collect the physician's contact information that's written on the blood card. We could do that, but we made a decision, based on (inaudible) input that the physician recorded on the blood card is 60% of the time not accurate (inaudible). We do have (inaudible) infant to --

>>**DR. ALBERT MEHL:** Lilah, while we're waiting, I will mention that having a name of a physician who cares for children in your -- in that database is still helpful, even if 60% of the time it is wrong. There is a physician who may be hospital based, for example, who might have some sense that they are exposed to liability if they don't follow up on an abnormal screening test, and their name is attached to that baby while the baby's in the hospital. So I think it does give you a potential ally, if only to have the physician also looking to contact a primary care physician. And so I wouldn't assume that that name is useless. I think it still has value to be able to track down if that is not the -- the responsible physician, who will be, and can that physician be an assistant in that process.

>>**DANIELLE ROSS:** Dr. Fan Tate is our next speaker and she is going to discuss what is being done to involve support and educate pediatricians about EHDI. Dr. Tate?

>>**DR. FAN TAIT:** First of all I want to thank CDC for the opportunity of being involved in this teleconference and I really enjoyed the three presentations. For the next few minutes, I will talk about the efforts at the national and state levels to actually support and educate the pediatricians, and hopefully talk a little bit about at least the beginnings of what we're trying to do through the American Academy of Pediatrics (AAP) and many others to understand the basics and to fill that information gap that's been talked about today. I think when we think about all that needs to be taught and done, it can threats initially be somewhat overwhelming, but we've started looking at the issues -- some of the issues that have been identified today, and so I will talk a little bit about that.

The AAP -- in collaboration with the Maternal Child Health Bureau and CDC almost two years ago established a task force to improve the effectiveness of newborn hearing screening diagnosis and intervention, and today you've actually heard from three of its members, Dr. Brookhouser, Dr. Mehl, and Dr. Betty Vohr who was just talking. It's been a real privilege for me to work with them and with other experts on this task force for the last two years, as I mentioned.

Just for the next few minutes, I am going to talk a little bit about the chapter champion program, some about the guidelines, some about what's already established from a continuing medical education perspective, and then finish up with information about legislative packets that the different states can use. So going back to the chapter champions -- and I know there was at least one, there may be other chapter champions on the call. Through the task force and particularly through a wonderful AAP project coordinator whose name is Michelle Esquivel, the AAP chapters in each state identified what we call chapter champions. Hopefully, most of you know these chapter champions and have worked with them. They are wonderful pediatricians who are active in the states, and we actually asked them to do a lot of things in addition to their normal jobs and families, et cetera. Many of these chapter champions have attended the last two annual EHDI conferences, and in addition, the members of the task force have been -- so everyone on our task force has been assigned to work as a mentor to these chapter champions in a designated maternal child health region. And usually the mentors and the chapter champions meet periodically via conference calls, as well as exchanges of e-mail communications, and often on these conference calls, there will be the whole group of chapter champions in that region. Sometimes

the EHDI coordinators are involved. They're certainly welcome to be involved in these activities. In addition, all chapter champions have been asked to submit a work plan for the year, and were sent out a template in June of this year for its completion, and these work plan activities actually focused on the next two years' activities with the AAP and with the grant. And task force members then will discuss specific chapter champion work plans and related activities with their assigned groups in the fall.

Furthermore, Michelle, who is our coordinator, actually sends out a monthly or bimonthly EHDI e-mail express, it's called, to all the chapter champions, and this keeps them updated on information and activities. Just to give you a quick example, the June e-mail express contained information on characteristics of newborn screening programs nationally, availability of videos from the key sessions of the national 2003 conference, availability of 2004 planning grant funding, and the AAP bright futures activity. So it's a -- each month, it's to try to keep all the chapter champions up to date on activities that are occurring nationally. The guidelines, as you know, the task force also developed the universal newborn hearing screening diagnosis and intervention guidelines. Chapter champions and EHDI coordinators were recently informed of the availability of quantities of this flowchart for broader dissemination to pediatricians, family physicians, and other pediatric health care providers, at the state levels. We are pleased to say that nearly 50,000 copies of this flowchart have been produced, and to date the majority of them have been disseminated. The guidelines are also available to AAP members and others via the AAP website, and will also be promoted to members in an announcement, an upcoming announcement in the national AAP news. Maybe you know this, and certainly we can put it out to all of you but there is a link that you can obtain an electronic copy of the guidelines: <http://www.medicalhomeinfo.org/screening/hearing.html>.

When we were talking a little bit earlier about different states looking at the whole continuing medical education piece of this, let me tell you what's happening from a national level, and this is only part of what's going on nationally. With respect to CME teleconferences, something like we're doing today, the AAP committee on CME has actually approved two what we call hot topic EHDI CME teleconferences for primary care pediatricians. And the teleconferences will feature very knowledgeable and respected faculty including Dr. Vohr, Dr. Mehl, Mary Pat Moeller, and Judy Gravel. The conferences have been designed to be marketed as a series but you can register for one of the two, or both of them. The first call will actually be held on October the 15th at noon central time, and wait till you hear what all will be talked about during that conference. It will focus on genetic and environmental causes of congenital hearing loss, new technologies, the physician's medical workup, amplification choices, and parental concerns. The second call will be on November the 12th at noon central time, and it will focus a little bit more on the flowchart and guidelines that have been mentioned, referrals, role of early intervention, family advocacy, cost reimbursement issues, and national resources.

A very strong evaluation component has been designed to complement these programs. Promotion of the programs will begin as soon as the official final approval has been received from the AAP, and that should be within -- we hope within the next week. The EHDI coordinators who are on the call today who want to promote this teleconference series to primary care pediatricians in your state can obtain the program brochure via the AAP website that I mentioned earlier. If you'd like, you can call the AAP customer service center at 866-843-2271. Limited quantities of the brochures are really available, so if you get them electronically, that would probably be the best approach.

Let me tell you about three other CME activities. Grand Rounds -- one has to do with visiting professorships and grand rounds. Grand rounds and other professorship type teaching awards were made available to the chapter champions over the last several months, and of course through our grant, we funded travel expenses and an honorarium. And the way we decide order this, and we'll probably be looking at this in the next year also, the criteria for the presentations were that they had -- needed to be held at academic institutions that actually have residency programs. And in addition to the grand rounds opportunity, other educational opportunities had to be arranged as well. For example, specific one on one sessions with pediatric and family practice residents meeting with key leaders in the institutions and things like that. These presentations have already occurred in Delaware, Louisiana, and Ohio. The fourth one is to occur in Ia on September the 17th through the 19th.

I think someone mentioned earlier the interest in CME activities in the state. Those pediatricians who are on-line will -- will know about Pedialink modules, they're called. One of the CME activities of the academy is called Pedialink and it's where physicians can go on-line, review a module, and receive CME credit. Pedialink module on EHDI has been funded and approved and is being developed and will likely be pilot tested at the

national AAP meeting in New Orleans this fall. When we're thinking in terms of what's happening in each state, I wanted to let you know about state-specific resource pages. Part of what we're doing as a medical home grant here in Utah with the University of Utah and children with special health care needs is the development of a medical home website with resources, general information, and disease-specific modules. One of the modules that we've developed is on newborn hearing. Over this next year, we'll be working with the AAP and chapter champions and EHDl coordinators in the states to see if we can work out a way to develop state-specific resource pages that can link to the module that we have on newborn hearing. And part of what our goal has been with that module -- and again, some of the people on-line today have been involved in helping us develop the module, but what we want is for pediatricians to go there and be able to download usable information quickly when they see someone in their office, with a child who has -- and family who are dealing with newborn hearing.

Finally, the legislative packet. The AAP provides that state chapter's information on many, many, many legislative issues. The legislative packet, which focuses on universal newborn hearing screening, was finalized in May of this year, and has been disseminated to chapter presidents, vice presidents, executive directors, as well as some of the chapter champions, some of the EHDl coordinators, legislative contacts, and select chapter advocacy people. Just so you know, this packet includes the universal newborn hearing screening advocacy resource update, which serves as a supplement to the AAP model bill. The advocacy update provides a variety of approaches for state chapters to use by providing actually point by point options given the different political considerations in each state.

So I hope that's been a little bit helpful in very quickly reviewing some of the activities that are going on currently. We look forward to working with everyone in making these activities continue to happen, and I would be glad to answer any questions. Thanks.

>>**PAT RICE:** I just had a comment. When you talked about referring, having states put on your website, just about every state now has their website. Would it not be better to refer the physician to the website in the state?

>>**DR. FAN TAIT:** Yes, we've talked a lot about that, and absolutely. We're working on referring from the perspective of resources to the state. The question is whether every state wants to do its own module, which actually takes a lot of funding and a lot of effort, and since we've already been funded to do that through maternal child health, if the states wanted to use that as an example rather than developing their own, that's why we're offering that. But the resources would be very much state specific. That's just to keep every state from having to -- having to reinvent the wheel. And the funding came through for this module through CDC and maternal child health, so states can certainly decide if it's what they want to look at or use. Irene, who is on the call, was very helpful in helping us get that going.

>>**BEPPIE SHAPIRO:** I was wondering, you mentioned the teaching awards that you had. You said there were three states and one state upcoming. Is that competition for those awards finished and they've all been awarded and this is like you're reporting on something in the past or is that still an opportunity for your states?

>>**DR. FAN TAIT:** yes, it's actually been awarded and it was a competition for this year. It's been awarded but we may very well be looking at that at the beginning of 2004, and so we'll certainly get all of that information out to all the states through the chapter champions.

>>**MICHELLE ESQUIVEL:** Just to interject here. Interestingly, there was one last-minute cancellation on the visiting professorships and so the chapter champion from Hawaii actually contacted me this week and she is interested in the opportunity. We are working out the details on that. But so Hawaii is actually going to be represented.

>>**BEPPIE SHAPIRO:** Super. That's great. I'll call Lynn. Yes, she's just back from a leave, so that's great.\

>>**MICHELLE ESQUIVEL:** Yes. And it looks like it's going to be in March 2004 is when it actually will happen, so it's going to be a little while from now, but -- but that is one of the places.

>>**PAT RICE:** I understood that the conference last spring that those guidelines were sort of a draft and they

were going to be redone but now they've printed 50,000. I don't guess that they changed them. Is that correct?

>>**MICHELLE ESQUIVEL:** That is correct. We have thought that we might make some changes. However, the suggestions that were provided to us by the EHDI coordinators and by some of the chapter champions and even some of our own task force members were insignificant to the extent that we didn't feel that we wanted to do another draft, mainly so people wouldn't be confused about which was the final version, since they were so new. The task force is going to be revisiting that issue at their meeting in November.

>>**UNKNOWN SPEAKER:** we just had some questions here in our state about the -- you know, the validity of having the physician have like a name of an interpreter or some of those things that, you know, might be in the hands of -- better in the hands of someone else in a different professional level.

>>**MICHELLE ESQUIVEL:** we'll be looking at all of those issues when we revisit it, too. Thanks.

>>**HALLIE MORROW:** This is Hallie Morrow in California. How can we get a hold of you, Dr. Tate, to talk about how we can collaborate and, you know, have links with websites?

>> **DR. FAN TAIT:** Sure. My e-mail is ftait@utah.gov and let me give you my phone number too. Area code 801-584-8239. I'd be happy to talk to anyone.

>> **MICHELLE ESQUIVEL:** and same goes for me. This is Michelle again. I'd love to hear people's initial ideas or thoughts about that. I'd encourage you to take a look at the university of Utah website on newborn hearing screening, the section in intervention and help me creatively think through what would make the most sense. Whether it's linking to the state websites or just -- or we're really going to be talking a lot about this at the November task force meeting as well, so I'd like to be an informed person going into that meeting, so we could make some good decisions in this regard. And I think pretty much all the EHDI coordinators know my e-mail address or phone number and how to get in touch with me.

>>**HALLIE MORROW:** One of the things that we're trying to struggle with, because we have Karl White coming out here to la, is how we can try and get that presentation accessible to more physicians, and one of the things that we are hoping to do but I'm not sure it will work is to videotape it, digitize it and offer it for CME on a website, although it turns out there's lots of people who have been doing that, and what would be really nice would be if there was some national newborn hearing screening CME website where places that offer, you know, those kinds of grand round programs, those could be posted on that website and someone could manage that CME.

>> **MICHELLE ESQUIVEL:** I think the Pedialink module that fan referred to that is currently being developed and very soon will be pilot tested on EHDI issues will sort of serve the purpose of exactly what you're talking about. And then Mary Pat Moeller, from Boystown, as many of you know, also been working on a grand rounds presentation on CD-ROM that she's been farming out to a lot of physicians around the country to get input and feedback on it before she actually finalizes it. So i think both of those things in combination will probably accomplish that goal. It's just a matter of moving to that step, and we're not quite there yet.

>> **HALLIE MORROW:** Okay. That sounds good.

>>**DEBBIE BEHRINGER:** This is Debbie Behringer and Lori Lang from Michigan. Michelle, do you have the conference call schedule for the chapter champions or know where we could access that, so the coordinators could listen in as well?

>>**MICHELLE ESQUIVEL:** Which conference call are you referring to? Are you referring to the regional conference calls that the task force members hold with their chapter champions or are you referring to the CME teleconference series? For the regional call -- actually, for you guys, I am actually planning it out for Dr. Mehl for your region so I will send you, Debbie, the e-mail. And that gives you a selection of dates and times and asks you about your availability, and I am sure that they would love to have you all participate on that call.

Just for our other EHDI coordinators on the call. Basically what happens is i ask the task force member to give

me three or four or five dates in time when they might be available and then i poll their chapter champions and then we go with what the majority -- with the majority for when the majority of people are available, and they are not meant to be exclusive in any way. However, in the past, they primarily have only involved the chapter champions, the task force member who is sort of mentoring them, and on occasion, the (inaudible) network audiologist, and that's just sort of starting up, too.

>> **DANIELLE ROSS:** This is Danielle from CDC. I hate to cut short such a great discussion, but we're going to have to close up now. I'd like to thank all of our wonderful speakers for agreeing to present on this call, and for doing such a great job. And I hope everybody found this teleconference as informative as I did. There will be a transcript available of this call on the CDC EHDI website, probably by the end of the month: <http://www.cdc.gov/ncbddd/ehdi/ddtele.htm> **The next ad hoc call will be on November 4th**, and an announcement with some information about the topic will be sent out closer to the date. And thank you, once again, for calling in and also to our speakers and good-bye for today.