Centers for Disease Control and Prevention
Early Hearing Detection and Intervention
Ad-Hoc Group

Agenda for September 3, 2002

Welcome

I. Genetics 101/ The basics
– Bronya Keats, PhD, Head, Department of Genetics and Director, Molecular and Human Genetics Center, Louisiana State University Health Sciences Center.

II. The genetics of hearing loss: What we know now and future steps in research
– Bronya Keats, PhD, Head, Department of Genetics and Director, Molecular and Human Genetics Center, Louisiana State University Health Sciences Center.

III. A visit to the genetics counselor and geneticist: What parents can expect

– Barbara Biesecker, Head, Genetic counseling unit, Medical genetics branch, Q and A

IV. Overview and update on medical home for special needs children
-Amy Gibson, Director, Division of Children with Special Needs, AAP

V. EHDI activities and screening in the medical home
-Sunnah Kim manager, Screening programs, Division of Children with Special Needs. AAP

Wrap-up

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JUNE HOLSTRUM: Hi. This is June Holstrum from CDC. I think we will get started. Hello everybody. I'm glad you all could join us again. I wanted to remind you all mute your phone when you are not talking. We are getting a lot of extra noise. Today's teleconference is being recorded and the transcript will be available on the Internet. Before we start I want to introduce you to a new member of our CDC EHDI staff, Dr. Krista Biernath is back. She is now back as our permanent (inaudible) and we are very pleased she is back with us. She has been the organizer of this session and will be our moderator. So with that, I'll turn it over to Krista.

KRISTA BIERNATH: Good afternoon, good morning, depending on where you are. Thank you very much for joining. I'm really excited about this afternoon. The presenters I think are going to have very interesting topics. I'm going to go ahead and get started, because we have quite a full agenda.The first speakers that we are going to have are Amy Gibson and Sunnah Kim, and they are from the American Academy of Pediatrics. Amy will be speaking first. She is the director of the division of children with special needs at the American Academy of Pediatrics and she is also the director of the National Center of Medical Home Initiatives for children with special needs. She will talk about federal home concepts. And she will be followed by Sunnah Kim, who is the manager of the screening initiatives in the division of children with special needs. And she will talk about how activities and screening in general can be better integrated into the medical home.

With that, go ahead, Amy. Amy, are you on yet? Okay. What I'm going to do then is I'll skip over and go ahead with our next speaker, we will come back to Amy and Sunnah at the end. The next speaker is Dr. Bronya Keats. Bronya, are you on?

Dr. BROYNA KEATS: Yes.

KRISTA BIERNATH: She is the director of the molecular and human genetics center at the Louisiana State University Health Sciences Center. She is interested in identifying and characterizing genes that cause hearing loss. She will speak on basic genetics and then she will talk a bit about genetics of hearing loss. Go ahead, Bronya.

Dr. BRONYA KEATS: Thanks very much, Krista. I'll spend the first ten minutes or so giving an overview of some basic genetics, and after that I'll focus specifically on hearing loss.

Genetic disorders used to be considered rare. They were disorders such as Down syndrome, Turner syndrome, cystic fibrosis and others, which were very important to families and individuals, obviously, who had these disorders. But in general, genetics played a relatively small role in health care.

Now we know that genetics is extremely important in all areas of health care, and that genetic factors contribute to the etiology of the majority of the common disorders that directly or indirectly affect almost all of us. These are disorders such as Alzheimer's, heart disease, diabetes, cancer, and of course hearing loss. Much of our new knowledge about these diseases is a result of the human genome project that I'm sure you've all heard about.

The basic genetic material is DNA, which is found in the nucleus of cells. It has a double helical structure, and consists of four bases, adenine (A), thymine (T), guanine (G), and cytosine (C). The T's pair with A's, and the G's pair with C's to form the double helix. One goal of the human genome project was to obtain the sequence of all the bases in human DNA. It sounded like a tall order, but how great was it? Well, we have three billion of these bases in our genome. To get an idea of the size of that number, suppose you are sitting at a computer keyboard and typing at a speed of 300 letters a minute for 10 hours a day and 360 days a year. It would take you more than 40 years to type in all of those three billion A's, C's, T's and G's.

Today, most of the human genome sequence is available in public databases. In addition to obtaining the sequence, analyses of this enormous set of data have provided new knowledge. For example, we now know that we have about 35,000 genes in our genome, considerably fewer than the 100,000 we thought we had. We also learned that only about 1 to 2 percent of our genome is, in fact, coding sequence. That is, only about 1 to 2 percent is the actual sequence that encodes proteins. And we also found out that we are approximately 99.9 percent genetically identical. This means that on average, two human genomes differ at about 3 million bases. Most of these differences explain normal variation, but some may be deleterious mutations that are associated with serious disorders.

DNA is packaged into chromosomes within the nucleus. Humans have 46 chromosomes, 23 inherited from one parent and 23 from the other. And the genes are simply segments of these chromosomes. So, in general, we have pairs of chromosomes and pairs of genes. Chromosomes 1 through 22 are called autosomes, and there are two sex chromosomes, X and Y. Females are XX and males are XY.

Geneticists are generally interested in relating the phenotype of a disorder to the genotype. The first step is to determine the likely pattern of inheritance of the disorder by obtaining a family history. I'll mention some of these patterns (in each case, I'll use N to designate a normal form of the gene and D for an abnormal form):

Autosomal dominant: Individuals with the ND (or DD) genotype have the disorder. So if you inherit an N from one parent and a D from the other, then you are affected. Typically with an autosomal dominant pattern of inheritance, males and females are equally likely to be affected and some individuals in each generation are affected.

Autosomal recessive: Only individuals with the DD genotype have the disorder. Thus, an affected individual would have inherited a D from both parents. Individuals who have the ND genotype are

unaffected. Typically, the parents of an affected individual both have the ND genotype, and with each pregnancy there is a 25 percent chance of having an affected child; that is, of having a child who inherits a D from both parents and therefore has the DD genotype.

Often with an autosomal recessive disorder, there is no history of the disorder in the family. The D gene may be passed on from one generation to the next, but it's only when two individuals who both have the ND genotype (carriers) have a child that there is a chance of the child being affected. Thus, just because there is only one affected child and there is no family history, it doesn't mean that the problem is not genetic.

X-linked recessive: Females have two X chromosomes, but males only have one, which is inherited from their mother. So for a gene on the X chromosome, a male who inherits the D will be affected. However, his unaffected mother would be a carrier with the ND genotype. In general with X-linked recessive inheritance, you'll see only affected males. Thus, if the family history information indicates that everybody who is affected in the family is male, then this suggests an X-linked recessive pattern of inheritance.

Finally, I'll mention mitochondrial inheritance. Within our cells we have organelles called mitochondria with their own DNA (mtDNA). The mitochondrial genome is much smaller, with only about 16,000 bases, but mutations in the mtDNA can also lead to disorders. We inherit all of our mtDNA from our mothers. So (without going into the complexities of mitochondrial inheritance), in a family where there is a mutation in the mtDNA, we would expect to find that all the children of an affected mother are affected, but none of the children of an affected father are affected.

At this point, I'll stop talking about genetics in general, and ask for questions on that part of my presentation before going on to talking specifically about hearing loss.

KRISTA BIERNATH: There are no questions at this point. Why don't you go on and we will see if there are any questions afterwards.

BRONYA KEATS: Okay, I'll do that. So far I've talked about DNA and various patterns of inheritance that may be inferred from an extensive family history. As far as genetic hearing loss is concerned, about 65 percent is inherited in an autosomal recessive fashion and about 30 percent is autosomal dominant. The remainder is either X-linked or mitochondrial.

The hearing loss phenotype may be nonsyndromic, meaning that the child has no other obvious anomalies. Or the hearing loss may be associated with other problems, such as eye disorders. An example of that is Usher Syndrome where the child has hearing loss at birth and then later on develops visual problems due to retinal degeneration. Other examples are Pendred's syndrome (hearing loss with thyroid problems), Jervell and Lange-Nielsen syndrome (hearing loss with a cardiac disorder), Waardenburg's syndrome (hearing loss and pigmentary abnormalities), and Alport's syndrome (hearing loss with renal anomalies).

Usher Syndrome is an autosomal recessive disease. The child is born with sensorineural hearing loss and develops retinal degeneration (retinitis pigmentosa) in the teenage years or later. This syndrome accounts for more than 50 percent of the deaf/blind population, and 3 to 6 percent of children born with severe to profound hearing loss may, in fact, have Usher Syndrome. There are three clinical types of Usher Syndrome. In Type I the hearing loss is profound, whereas in Type II it's in the severe range.

The onset of the retinal degeneration is earlier in Type I than Type II. For Type III, the hearing loss tends to be progressive, and the age of onset of the retinal degeneration is quite variable. We now know there are mutations in at least 11 different genes that cause Usher Syndrome. Of those 11, seven are Type I, three are Type II, and one is Type III. And the proteins encoded by four Type I genes, one Type II gene, and one Type III gene have been identified.

With Pendred's syndrome, the inheritance pattern is also autosomal recessive. In this case, affected individuals, in addition to the hearing loss, will develop a goiter or enlarged thyroid. As many as 20 percent of children with severe to profound hearing loss may have this syndrome.

The cardiac abnormality associated with Jervell and Lange-Nielsen syndrome can lead to fainting spells and to sudden death. Thus, it's a serious disorder if it's not diagnosed early. Although it's rare (probably only one or maybe less than one in every 100 infants born with profound hearing loss has this syndrome), it's critical that it be identified and treated.

All three of these syndromes (Usher, Pendred, Jervell and Lange-Nielsen) are autosomal recessive, and in each case it's important to try to make the diagnosis as early as possible.

Waardenburg's syndrome is an autosomal dominant disorder in which hearing loss is associated with pigmentary anomalies such as different colors eyes, a white forelock, or early graying. It's important to pick up families that have Waardenburg's, to provide them with the counseling that they need. In many cases an individual with Waardenburg's may present with only hearing loss, and it's only by taking a careful family history that it becomes clear that the individual, in fact, has Wardenburg's syndrome and not an autosomal dominant nonsyndromic hearing loss.

An X-linked form of hearing loss is Alport syndrome, which is caused by mutations in certain forms of collagen. In addition to hearing loss, the affected males usually have severe renal problems.

And finally I'll mention a couple of syndromes that caused by mutations in mtDNA. You may have heard of MERRF and MELAS. These are acronyms for syndromes, in which hearing loss is one of the clinical findings.

I'll now discuss nonsyndromic hearing loss for which a very large number of genes have now been localized and some have been identified. We know that there are more than 70 genes that cause nonsyndromic hearing loss. In some cases, the inheritance pattern is dominant, in others, recessive. Most of these genes are on the autosomes, but there are also some X-linked and mitochondrial forms of nonsyndromic hearing loss. So far, 25 of these genes have actually been identified; that is, we know the proteins encoded by these genes. Sometimes the same gene may have different mutations, some of which cause autosomal dominant hearing loss, while others cause an autosomal recessive form of hearing loss.

One form of X-linked nonsyndromic hearing loss is of particular concern. The auditory findings are early onset of a mixed loss that is caused by stapedial fixation. However, corrective surgery is attempted, the result is a perilymphatic gusher and the child is worse off than before the surgery. Thus it's important to diagnose this particular disorder, and that can be done easily with a CT scan. There is a very distinctive bony abnormality of the cochlea that is found in this disorder, and if this is seen on CT scan then surgery should not be done.

A form of deafness referred to as familial aminoglycoside-induced deafness is due to a mtDNA mutation known as A1555G. Individuals who have this mutation are likely to become deaf if they are given even

small amounts of aminoglycosides. Thus, it's important to identify these individuals early and make sure that aminoglycosides are not prescribed.

Now let's talk about connexin 26, which is probably the gene that you've heard most about. Mutations in this gene are thought to explain perhaps as much as 50 percent of congenital deafness. Usually, the onset is prelingual and the hearing loss is symmetric, but the severity may be quite variable. The audiogram tends to be flat or descending, and there are no associated anomalies; that is, it's a nonsyndromic hearing loss.

There are some common mutations that our found in this gene. For example, there is the 35delG mutation, which means that at the 35th position in the sequence, a "G" is missing. Another relatively common mutation, especially in Ashkenazi Jewish communities, is the 167delT, which means that a "T" is missing at the 167th position. And when a base such as a "G" or a "T" is missing in the coding sequence, the protein is either extremely abnormal or not formed at all.

We know there are many mutations found in the connexin 26 gene, and the problem right now is that interpreting the test results is quite often not straightforward. Some individuals with hearing loss who have a connexin 26 test done may be found to have known mutations in both copies of the gene. In these cases the individuals have inherited an abnormal form of the gene from both parents, and then the cause of the hearing loss is fairly clear. However, often a mutation is found in only one copy of the gene, and interpreting the results is not obvious. Also, it is important to realize that finding no mutations in connexin 26 doesn't mean that the etiology is not genetic. There are many other genes that may explain the hearing loss.

There is still a lot that we don't understand about connexin 26 and the many other genes associated with hearing loss. But there is no doubt that genetic medicine plays a critical role in health care.

We have a whole new field called pharmacogenetics. Drugs may be designed for individuals based on their genetic makeup. Gene therapy is becoming feasible for some disorders. Of course, these advances in genetics also raise concerns. For example, genes run in families meaning that confidentiality is a critical issue. There is also the real possibility of discrimination as far as employment and insurance are concerned.

But as we look to the future, in particular for hearing loss, let's suppose that we know there are a thousand genetic variations that strongly predispose to hearing loss. And let's say another thousand or so are also associated with hearing loss but to a lesser extent. We are looking towards having what's called a chip based test that can be used to determine if an individual has any of these variants in their DNA. Based on the results, an effective, individualized therapy may be available for the hearing loss. This is still a way in the future, but it is one of the directions in which research is going.

To summarize, we now know that: (1) Mutations in more than 70 genes cause nonsyndromic hearing loss and many others are associated with syndromic hearing loss; (2) Medical and family histories are extremely important for diagnosis and management; (3) A negative family history does not imply that the etiology is not genetic; and (4) A genetic evaluation and testing will allow for early detection of syndromes such as Usher, Pendred, Jervell and Lange-Nielsen.

So let's see, I'd better stop before we run out of time. Any questions?

HAILLIE MORROW:This is Hallie Morrow from California. If I were to send a child today for genetic

testing, what exactly would be tested for and what would that cost? Do they routinely test for the syndromic genes or only for Connexin 26?

BRONYA KEATS: I don't think the College has recommended that at this point. The recommendation is to make referrals for genetic testing in an informed manner and make sure that a geneticist is part of the team involved in the child's care.
HALLIE MORROW: So even though this has come out from the American College of Medical Genetics as a recommendation to test pretty much everybody who has hearing loss, there is no standard out there for that testing?

BRONYA KEATS: I don't think the American Society has recommended that at this point. The recommendation is more be very cautious about it. There is still a lot we don't know. I think we are still a ways from providing this as a routine test.

AILEEN KENNESON (CDC): I'd like to add to that a bit. Generally, what happens is like the American College suggests that any child with a hearing loss should be referred to medical geneticists and an MD doctor that is interested in genetics who will do what Bronya Keats was talking about. See if it's syndrome versus not syndrome. And Connexin 26 testing is available. It costs a few hundred dollars to have it done. But you want to go through a medical geneticist to have that done. You don't want anybody else to order that test.

KRISTA BIERNATH: We should be moving on. Our next speaker actually is going to talk about going to a genetics counselor. Barbara Beisecker will talk about -- she is the head of the genetics counselling unit of the medical genetics branch, the National Human Genome Research Institute at NIH, and she will talk about this to us.

BARBARA BIESECKER: Genetic counseling, provided by master's level trained genetic counselors, medical geneticists, genetics nurses and others who work together in teams, deals with both the educational and the psychological aspects of the genetic science that Dr. Keats so nicely summarized. Genetic counselors are interested in issues of adaptation and coping, especially when a child is born with problems like hearing loss and/or other problems that are unexpected. We also facilitate our clients' decision-making about how to use that information either for future reproductive decisions or in seeking help and resources for their affected child.

So we have the formidable task of communicating complicated technical information about genetics to families in a way that they can glean from it what they need to know both to cope with and ultimately to adapt to the diagnosis. Understanding cause is an important aspect of adaptation and can facilitate clients' ability to use the information. So a couple who comes to a counselor with a child suspected of having hearing loss, who is picked up by newborn screening or otherwise, are asking questions about why this happened and whether or not it's ever going to happen again. Their concerns extend from the affected child, when that child becomes an adult, and to their future as parents, whether a subsequent child of theirs may also be affected.

Parents do not necessarily share our scientific worldview. While they seek information and meaning, their explanations of cause may not complement those of the professionals. And if you really listen to their questions, it's not just why did this happen in a numerical sense, but it's why did this happen to my child? Why did this happen to us? These are metaphysical questions that don't have direct answers but are an important part of their attempt to accept and adjust to what's happened to their child. Genetic counseling addresses parents' causal attributions and their need to gain feelings of control over their

circumstances.

Genetic counselors seek to understand what families believe happened and then try to use that understanding to help work with them to assimilate genetics information, assuming that there is a mode of inheritance to which we can attribute the hearing loss and thereby predict the recurrence risks. As health care providers we also help families learn about available resources. If parents just learned that their child may have hearing loss, they probably have many questions about where to turn and how to get their child's developmental needs addressed. While it may seem premature when a baby is an infant, having that knowledge is critical to the adaptation process. All of us want to see affected children get promptly tapped into resources, both medical and educational.

Overall genetic counselors strive to provide psychological counseling and genetics information, but not direct reproductive advice to clients. Preserving the personal nature of reproductive decision-making is an important mantra of genetic counseling. None of us knows what is right for a family in terms of having additional children. There are many aspects to reproductive decisions beyond understanding genetic risks. If a couple has had a child with severe hearing loss and has concerns about having a subsequent child, it would not be appropriate for genetic counseling to assume that they wouldn't want to take a 25 percent risk and perhaps have another affected child. Our job is to understand what risks clients are willing to take, how much they want another child, and how big an issue or burden they consider the hearing loss.

In the arena of hearing loss, the issue of whether or not hearing loss is a burden is controversial. Hearing parents who unexpectedly have a child with hearing loss likely interpret the circumstances as unfortunate and face quite an adjustment in their expectations for their child's life. They expected to have a child who was hearing. They are both hearing themselves. The adjustment involves learning what to do for the child in order to maximize his/her learning and use of available resources. The child may be capable of accomplishing significant life successes, but the means to reach his/her potential will be different.

However if you counsel two adults who are deaf themselves and are part of the Deaf community, they may be strong advocates of not viewing deafness as a burden or as a problem to be fixed. Deaf adults may seek out a genetic counselor to understand what the chances are that they would have Deaf children harboring a preference for raising Deaf children. It's not surprising that two Deaf parents might have an easier time raising a Deaf child than two hearing parents. This circumstance serves as an example of why genetic counseling cannot start with the bias that hearing loss is a problem to be avoided and fixed. For some parents, it may be, but for others, it may not be. It is the counselor's job is to understand how the couple views hearing loss and to help them make decisions consistent with their own life experiences and values.

An important issue of concern to new parents is securing education for their child. While there are promising outcomes for deaf adults in our community today that didn't exist in the near past, there remains a serious issue about whether or not parents live close to sufficient educational resources. In the Washington, D.C. area Gallaudet University offers preschool, elementary, high school, undergraduate and graduate education for those with hearing loss. But for families who do not live near such a specialized school, parents are likely ultimately to face a decision whether or not to send their child away to school. At young ages, this may be a harrowing decision.

Another issue new parents may consider is the option of cochlear implants. Parents need access to research outcomes, specialists and consumers who can help them make the decision about whether or not to pursue surgical options. These are not simple choices. The Deaf community does not

universally support the option of cochlear implants. Genetic counselors alert parents to this controversy so that they do not walk into it naively.

When parents see a genetic counselor, the counselor negotiates with the couple their needs from a medical genetics consultation. Family history information is gathered as an important step in assessing the mode of inheritance. The medical geneticist performs a thorough physical exam of the affected child to differentiate between syndromic and nonsyndromic hearing loss. The source of the hearing loss predicts medical prognosis and guides the team in decisions about what genetic tests might need to be performed in order to determine recurrence risks. Studies into underlying genetic causes of hearing loss may also be offered to the family.

No genetics education can occur without a careful history and examination by a medical geneticist as the outcome determines the accuracy of the information that will be conveyed. In research settings such as at the NIH and at Gallaudet University, deaf adults who participate in research studies are increasingly learning whether or not they have Connexin 26 mutations or other underlying molecular causes of hearing loss and what that may mean in terms of having an affected child.

Children with syndromic hearing loss will be put in touch with support groups for families with similarly affected children. Referrals to individuals in the Deaf community and the deaf education community are also made to help parents make decisions about when to begin teaching American Sign Language as well as to experts for careful evaluations for the option of cochlear implants.

Families adjust well over time and make good use of resources available. Genetic counseling early in the process can help ease families into the health care system and can address some of the more emotional aspects of adjusting to the unexpected finding that a child is deaf. For Deaf adults, genetic counseling can provide answers to inquiries about the chances for having deaf children. All families are supported in the personal nature of their reproductive decision-making and in making the best adjustment possible to parenting a deaf child.

KRISTA BIERNATH: Thank you, Barbara. Any questions? Okay. If not, I want to thank both Bronya and Barbara for the great outline basically of genetics of hearing loss. I think that was a real nice, comprehensive set of information. I do want to see, are Amy and Sunnah on now?

AMY GIBSON: We apologize for the technical difficulties I think maybe it's even more appropriate to talk about medical home as kind of a wrap-up, because we really believe that if we can link children with special healthcare needs to a medical home, they will have better access to a lot of the resources that you just heard about and better interpretation of test results and visits with specialists and genetic counselors and so on. But just so that we are all on the same page, I'd like to start off with reviewing the definition of medical homes. As most of you know, medical home is not a building or a house, but an approach to providing high quality comprehensive healthcare services coordinated in partnership with families.

In 1992, the Academy published a formal definition of medical home and a policy statement, and the policy statement just begins by stating that "The American Academy of Pediatrics believes that the medical care of infants, children and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family, and should be able to develop a partnership of mutual responsibility and trust with them."

As you can see, that is a global definition of what we think of medical home. What the academy decided to do this past July is they revised that policy statement. It was published in the July issue of Pediatrics. And within that definition they really expanded upon this definition and made it more concrete, really set forth an operational definition of medical home. And gave a better idea to those broader concepts, some practical things that physicians can think about doing in their practices.

I don't have time to go over all 37 components, but just to give you a bit of an idea of what we're talking about, when we say accessible, we are talking about care that is provided in the child or use community. Family centered, that the family is recognized as the principal caregiver, and center of strength and support for the child. That coordinated care, a plan of care is developed by a physician and the family and shared with other providers, agencies, and organizations that are involved in the care of the patient And then culturally effective. We mean that the child or youth and family's cultural background, including their beliefs, rituals and customs, are recognized and incorporated into the care plan when possible.

Here at the academy our division of children with special needs, our mission is really to improve the system of care for children with special needs by connecting them to medical homes. Within our division, we actually have several grants that we manage to help us fulfill that mission. The maternity child health bureau provided us funding through a cooperative agreement that funds the national center of medical home initiatives for children with special needs. The Centers for Disease Control and prevention have funded another cooperative agreement that is funneled through our division that is really working to better integrate screening programs and activities through medical homes.

We have three major components within our division. We have training and education. We have technical assistance, and we have screening initiatives. And just in the essence of time, I'll skip over a more detailed description of our division activities. And turn it right over to Sunnah so she can give you a better idea of what our screening initiatives are all about.

SUNNAH KIM: Okay. Thanks again for inviting us. As Amy described, the medical home is really important when caring for a child with special healthcare needs. But because screening is often the first step in identifying which children have special needs and which don't, it's important to make sure that the screening system has appropriate linkages to the medical home. Ideally, it's the medical home who refers the child for additional evaluation, treatment and services.

Basically, knowing that we don't have much time left here, just quickly, to go over a survey that we conducted, we actually conducted this on a newborn screening program and we got responses from all 51 programs. But I think that there are some important parallels to be drawn from this survey that we did. And what the survey was about is -- related to communication between the public health screening system and the private care system and the link to the home. And what we found is out of the 51 programs, there was only about 12 states actually had a procedure for linking all prospective parents with a pediatric primary care physician for the purpose of assuring a medical home. And this was an interesting finding compared to the fact that 50 out of 51 respondents notified the medical home about abnormal screenings and the need for a repeat specimen. In fact, many times the primary care physician was responsible for making sure there was retesting.

So you can imagine the extra work and frustration that occurs if the primary care physician was not correctly identified with the test results (inaudible.) So that's just one thing that I think could be improved on in the newborn screening system and also in the other hearing systems. Anyway, the

medical home then needs to insure that appropriate follow-up takes place. And another barrier for effectively linking the systems and the medical home is that some medical home physicians lack knowledge of the EHDI programs. If the physician is to provide a medical home for a child identified with hearing loss, they have to be aware of the EHDI system as well as the resources that exist in the state and community. So the academy has been working on this through the Department of Chapter and state affairs, through the Chapter Champion Initiative, which I believe you heard about in previous teleconferences. But we are working to educate these chapter champions and other pediatricians in the various AAP chapters, and share resources and information with them. And they are working to build partnerships with the state EHDI coordinators, et cetera.

To conclude, I wanted to go over a few resources that we have available. First, you can access the -- our new medical home policy statement on line. And you can access it actually on our academy's website. The actual URL, if you are interested, quickly, is: Www.aap.org/policy/060016.html. We also have a website that outlines a lot of our activities, including some medical home state plans. That can be accessed at http://www.medicalhomeinfo.org./

We have medical home training programs. One that is notable is we will be having one as a preconference session to the academy's annual meeting in October. That will be held in Boston. But at that preconference, we are actually going to be pilot testing a screening and surveillance component that will cover some of the issues that we are talking about today. And if you have specific technical assistance requests or would need additional information, you can also contact us and our information is all found on the website, medicalinfo.org. And I think that's it.

KRISTA BIERNATH: Any questions? Okay. Well, I wanted to thank all the of speakers today. It was a great teleconference. I want to thank you all, too, for joining in to listen. Our next teleconference will be the first Tuesday in November. So go ahead and check our website for the transcript and the upcoming agenda and transcript. Thanks.