

MCH/CSHCN Director Webcast

Sickle Cell Disease

Newborn Screening Follow-Up Program

June 12, 2008

R. LORRAINE BROWN: Good afternoon. Welcome to the webcast in Baltimore, Maryland. The latest in a series of monthly interactive Internet webcasts. I am R. Lorraine Brown, project officer for the Sickle Cell Disease program. We have an interesting program today.

Before I introduce today's speakers, I would like to review some technical information about the webcast. Please note that in response to your suggestions, the speaker's power point presentation is available on the www.mchcom.com website.

The slides changes are synchronized with the speaker's presentations. Do not need to do anything to advance the slides. You may need to adjust the timing of the slides by matching the audio by using the slide delay control. We encourage you to ask the speakers questions at any time during the presentation. Type your question in the white message window on the right of the interface. Select questions for speaker from the dropdown menu and hit send. Include your state and organization on any message so we know where you are participating from. The questions will be relayed to the speakers periodically, throughout the broadcast. We encourage you to submit questions at any time during the broadcast.

On the left of the interface is the video window. You can adjust the volume of the audio using the volume control slider which can access by clicking on the loud speaker icon. Those of you who have selected accessibility features when you registered will see text

captioning underneath the video window. At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill an online evaluation. Take a couple of minutes to do so. The responses will help us plan future broadcasts in this series that includes our technical support. Today we will be presenting the follow-up program. We have two speakers with us. Sonja Ross from the National Center for Evaluating Center in Baltimore, Maryland, and also Ms. Callanan. I will present Sonja Ross, and she'll give you a brief introduction and continue on.

SONJA ROSS: Good afternoon, I'm Sonja Ross, I work with the Sickle Cell Disease association of America, and we have a cooperative agreement to be the national coordinating and evaluation follow-up program funded by HRSA.

I'll move forward with the next slide. The objectives of the presentation are provide an overview of Sickle Cell Disease and Sickle Cell Trait, evaluation and the newborn screening program and discuss the educational needs of parents and health care providers related to the training for Sickle Cell Disease and Sickle Cell Trait. And to describe the educational product. We have a Sickle Cell Trait tool kit and welcome kit. Sickle Cell Disease is called Sickle Cell Disease because many of the persons with the blood cells are shaped like a sickle, and it's a tool a farmer has used to cut their crops. These Sickle Cells can cause a log jam in the smaller capillaries that cause anemia and pain. The current life expectancy is 45 to 52 years depending and what kind of Sickle Cell Disease they have. It can affect every organ of the body. And this in-organ factor can lead to early death. Another complication found in children is stroke. And a stroke is a sudden and severe complication of Sickle Cell Disease. It affects from 6 to 8% of patients with the disease, especially between the ages of 2 to 10 years. A stroke may occur with a painful episode or infection, or may not be related to any illness.

Newborn screening identifies -- back up -- back -- back one slide, please. Thank you.

Approximately 10% of African American population has Sickle Cell Trait. And about 2% of the Hispanic, Italian and east Indian population. It's usually a mild condition and sometimes blood in the urine, pain or discomfort at high altitudes, and we are finding they have problems in hot and humid weather. One or more parents may also have a hemoglobin trait. It's important they know their status. If both parents have the genes, there is a possibility of having a baby with Sickle Cell Disease in the future. Historically newborn screening for Sickle Cell and other diseases have been a joint effort among the following, tertiary and comprehensive care center, primary care providers, among others. For over three decades the outcome of newborn screening has been a better understanding of the epidemiology of the disease, in newborns, the consequence, lifesaving consequently, lifesaving care protocol, provider of public education, and who is infected. Infection is the major cause of death in children with the Sickle Cell, and the bacteria is responsible for the deaths under three years of age, for most. Estimated that Sickle Cell under three years of age is more likely to get the bacteria. And we found something as simple as prophylactic treatment could reduce mortality and morbidity in the babies with psych -- Sickle Cell Disease. Aided in early identification and treatment.

Next slide, please. Populations that are affected, African American, Italian, Greek, Portuguese. Populations that are typically targeted for the disease and the population that have emerged, causations, Hispanic and Latino. This is a map of African American in black and what are considered non-Hispanic in this country. There are 40.2 million black residents in the United States, including those of more than one race. They make up about 13.4% of the total U.S. population. The projected single race black population of the United States as of July 1, 2050, 64.1 million, and at that time blacks would constitute 14.6

of the nation's total population. Okay. The percent of the Latino population is, is delineated in this map the. And we have information that as of July 1, 2006, 44.3 million Hispanics, and they made up 14.8% of the total population of that, 299 million at that time. And the Hispanic research center projects the population will soar to 438 million by 2050, and the Hispanic population will triple. Between 2000 and 2006, Hispanics accounted for one-half the nation's growth. 24.3% growth rate, more than 3 times of the total population, which is 6.1%. The rapid growth rate of Hispanic population is being attributed to the immigration and higher birth rates. Despite HRSA funded pilot projects, concerns exist for parent, provider, education, contacting and counseling parents of infants with the carriers, follow-up efforts have remained problematic and very little of it has been documented about the effectiveness of efforts to improve follow-up in newborn screening. To give you a little information about the national coordinating and evaluation center now.

Next slide, please. The purpose of the program for Sickle Cell Disease is funded by HRSA, increase the capacity of HRSA-funded Sickle Cell Disease newborn screening community based programs, and increase the capacity of the 17 funded community-based programs and the new cycle began on the first of June, through the development of network. And also to provide model education, counseling and follow-up services to families whose babies have been identified with Sickle Cell Disease or Sickle Cell Trait, or any other hemoglobinopathies. These are the outcomes of the national coordinating and evaluating center, increase the knowledge of the families of babies identified with Sickle Cell Disease, or the carriers, Sickle Cell Disease or other diseases, by the community-based programs funded by HRSA. Strengthen partnership between the community-based programs, for Sickle Cell Disease, the state newborn screening program comprehensive Sickle Cell Disease centers, primary care providers and Title V programs. And the third outcome is to improve the newborn screening for carrier follow-up communities, and then

to develop, assess and disseminate essential educational materials for providers, families, and individuals in plain language. Now I'm going to introduce Nancy Callanan and she is going to talk to you about the materials we have developed.

Okay. She'll tell you a little about herself.

NANCY CALLANAN: My name is Nancy Callanan, and I am a member of the MCEC and today I would like to introduce you to what we have done with the MCEC in terms of educational materials.

Next slide, please. So, prior to developing any new educational materials, the MCEC conducted a preliminary needs assessment, so that we could learn more about materials and target our efforts in material development. What we did was we included a very detailed review of both print and web-based materials that were currently being used, and by our MCEC grantees, as well as others. This included an assessment of the overall breathability of the materials, general material, as well as the consent. A series of focus groups were conducted with the target population, and in this case it would be parents of infants identified by newborn screening to have Sickle Cell Disease or Sickle Cell Trait. And we gave a lot of information about what their informational needs were, and how they wanted to receive information.

Next slide, please. So, our goal was to develop materials that would be accurate, and include relevant content, but key to this was that it would be in a reader-friendly format. To do that, we followed a series of principles which you'll introduce briefly in a moment. Develop the content, have the content reviewed, then, by experts in the field, but then at each step or several times along the way, we did field testing with the target population. So it was an ongoing development process of develop, review, field test, and evaluation.

And later in this presentation I'm going to hit on some of the key lessons that we learned by this process.

Next slide, please. So briefly I would like to introduce you to the, some of the things that we kept in mind, as we attempted to develop reader-friendly materials. You can see these include some basic things, like size of the font, and using simple fonts, avoiding caps, etcetera. Also some formatting issues, such as using white space, a lot of ample white space, and limiting the density of the text. So rules for eliminating the number of lines on the page, and you can do this by using formatting strategically. So bullets, and boxing, and bolding, formatting the things to get your message across in a way that's reader friendly.

Next slide, please. As shown here, it's important to choose illustrations carefully. You want to make sure that these are clear and realistic. And that they are likely to be understood by the reader. And they should always have a purpose, not just to pretty up the page, but to really drive home a message as well. Stating key messages and action messages in a very clear and unambiguous manner throughout the document is also really critical.

Next slide, please. I'll comment reader-friendly materials have to have an amount of content that is manageable. You may need to break it into smaller packages. Rather than have a big document, you might opt to have several shorter brochures or pamphlets. Other things that you can do is to be sure that you are making your content clear by using shorter words, shorter sentences, making the information very personal, speaking to the consumer or to the reader in a conversationable tone, and getting back to not overwhelming with topics. With content, limiting the messages. So, you know, having a set number of key messages for each educational brochure, so that you can really stay

targeted. And finally, we think it's a good idea to limit the use of graphics or statistics in preparing reader-friendly materials.

Next slide, please. So noted on this slide, there are really several factors that contribute to the need to develop relevant and useful materials about Sickle Cell Disease and Sickle Cell Trait, not only for family, but also for health care providers. It's especially important that primary care providers and emergency providers have access to good information, because these are settings frequently used by family. So, the overarching goals of materials development for the MCEC are shown on this slide. For a health care providers, our goal was to include accurate and relevant information about the condition, including treatment protocol, and to provide guidance, guidelines for effective ways to offer information to families. And as noted previously, our goals for the patient family materials were that they be reader friendly, accurate, and provide useful, clear information, and action messages.

Next slide, please. So, there are actually three major materials that I'm going to introduce you to. The first is a Sickle Cell Trait tool kit, and that is just the cover sheet for that.

Next slide. Included in this tool kit are materials that are to be used by providers, by health care providers, to enhance their effectiveness in giving this information to patients. So, keep in mind that the end audience for this tool kit was health care providers. And so included in the tool kit are things such as a checklist of five things parents want to know, so in a sense we are saying here is the model content. This is the information that you should be covering with parents, families, who have a newborn identified with Sickle Cell Trait. We also included in the tool kit a checklist and guide for creating reader-friendly materials. Similar to what I just showed you a moment ago. Also in the tool kit are

materials that the providers can use in providing their educational compliance, a few brochures and other educational tools are there, so the he said audience for the brochures, of course, are the families, but they are included in the tool kit. Something providers can use and also as models for types of materials they need to be developing, and I'll briefly introduce you to some of the materials in the tool kit.

Next slide, please. So there are two brochures in this tool kit. And again, they are model brochures. The first one, shown here on the screen, it says your new baby has Sickle Cell Disease. Sickle Cell Trait. I hope that's what it says. I don't think I can see the slides. And you know, as shown here, the purpose is to provide parents of newborns with Sickle Cell Trait with information that they might not otherwise get. And included in this brochure are five key points for parents, and I don't think they'll surprise anyone that is listening to this webcast, but key points like at least one of the baby's parents has a Sickle Cell gene. Very important. Your baby does not have Sickle Cell Disease.

Another message in the brochure. You could possibly have a baby with Sickle Cell Disease in the future. And the S gene could affect your children's children in the future. And that's why it's important to talk about it. So encouragement to learn more and talk about it in families. Finally, this brochure introduces the concept of Sickle Cell Trait as a condition, and so talks about the fact that although this is not Sickle Cell Disease, in rare cases Sickle Cell Trait can cause a few problems, and miss Ross outlined what those were. Five things you can do, and basically says learn more about these things, learn more about what this is, why to get tested, where to get tested, how to get reliable information. So again, in a very reader-friendly way, covering a manageable amount of content, we hope, with the key messages.

The second brochure in this tool kit is called getting tested for genes that can cause Sickle Cell Disease. So again, the last brochure in the tool kit, the first one, was very informational just about what it is, and this is really targeted towards some action messages, you know. Why would you get tested, there are points in this brochure that, that talk about the reasons why you might get tested, to plan for future children, and to be sure that previous tests were accurate. The brochure points out that not only people are African descent are affected. There are also three very clear messages about how to get tested, and it includes information that distinguishes the more useful detailed tests that are recommended for identifying Sickle Cell Trait conditions. And again, following our own guidelines for reader-friendly material, we limit the number of key messages. And so the format is, here are five things you need to know, here are five things you need to do.

Next slide, please. Another item in the Sickle Cell Trait tool kit is a future babies card, I'll show you in a moment. This is specifically a tool that is intended not to just be handed to a family, but to be used interactively by a counselor or other health care provider in explaining genetic risks to people. The tool can be used to clarify misconceptions about probabilities, and to hopefully as a way to translate this whole issue of numbers into a common link, which the people can understand.

And you can have a look at this tool, in the next slide. So you can see that on one side, I hope you can see this better than I can, an educator can work through the different possibilities for the couple shown there, where each has AS, and then on the other side of the card, you can write in the gene of types of the family you are counseling and actually work with them, the possibilities for outcomes in their future children. Another item that's included in this tool kit is an advice at a glance book mark, and this is intended to be given to teens or adults who have Sickle Cell Trait, and it notes five things to know.

Advance to the next slide, you can see these. So the five things to know are you have one Sickle Cell gene, it is usually a mild condition, it's not Sickle Cell Disease. Problems with Sickle Cell Trait are rare, but here is what they are. Very specific information about the problems that can occur. The S gene runs in families and not just a certain ethnic group, not just in African American families. And, a key message that you can have a baby with Sickle Cell Disease in the future. And that is the way to know more about that, to find out your partner's status. So again, this is a tool, it's a model with some very developed with reader-friendly principles and hopefully with some very clear messages for the targeted audience.

Okay. Next slide, please. So, what I've just presented is a Sickle Cell Trait tool kit. We have a parallel product that is in development which is a Sickle Cell Disease tool kit. So again, the principles are much the same in which the intended audience are health care providers, but the tool kit contains specific items that can be used to enhance their education with families. So once again, this tool kit will continue a checklist of important information to cover in context with families, with newborns with Sickle Cell Disease. And under development will be some tips for explaining risk information. One of the things that keeps coming up in this process, not surprisingly, is how challenging it can be to explain genetic risk information in ways that can be understood by most. So, we are hoping to put together some written guidelines based on some lessons that we have learned in pilot testing and field testing our materials. Again, in this tool kit, there will be some sample notification letters, and then two brochures about Sickle Cell Disease, and I'll show you those in a minute. The what if future baby cards, the educational tool, will also be a part of this tool kit.

Next slide, please. So there are two brochures, the first is called caring for your baby with Sickle Cell Disease, and this is intended to provide a very initial description of Sickle Cell Disease for parents of babies identified by newborn screening. So, our thought here was that it doesn't -- it's not the only information they need, it's not all the information they need. But it's some of the information that we think parents need up front, and as you can see from the list there, we really wanted to give them some important action messages for taking care of their child, which include how important it is to keep all appointments, even when the baby is well. It introduces the need for Penicillin protocol. It introduces the concept of treating fever as a medical emergency. And, and other times when you need to be on high alert and call your doctor or bring your baby in, if they show signs of illness, and encourages parents to ask questions. It also includes some very clear messages of encouragement. It says it's a challenge, but you can do this. And there are lots of people who can help. So again, in our format, not everything that a parent would ever need to know, but some -- but a very tight educational agenda, you know, having just a couple key messages in mind so that we can use our reader-friendly techniques for getting those messages across.

A follow-up brochure, next slide, please. Is called what you need to know about Sickle Cell Disease. So this takes it up a notch. It's a slightly longer brochure at the moment, although it may be revised further. But it contains just a bit more detail. Now we are starting to go by major symptoms, and give a little bit more detail about the features and the management of Sickle Cell Disease. Again, including messages of encouragement and very clear action messages, as shown on this slide, for example, learn what you can do to keep your child healthy. Keep appointments. Learn how to tell if your baby is getting sick. Treating fever as a medical emergency, etcetera. Five things to know, five things to do, system. Those are the tools, the two tool kits. The final material that I'd like to introduce

you to is something that we have called a welcome kit. The welcome kit contains a lot more information in a very different format. I don't know if you can see this, but the welcome kit is, I'm holding this up, is actually a small planner sized, three-ring binder, tabs, and lots of pocket folders and business card holders and so forth. So this is meant to become a very useful tool that we can put in the hands of parents who have a baby with Sickle Cell Disease. And as noted on the slide, the purpose is to provide a little more detailed information about symptoms in management, but furthermore, to give people a tool that we can use to help navigate the health care system in which their child will be managed. So, it outlines what people need to know and where they can find out more, and includes very practical information such as advice on records that should be kept and how to record information, and finally, it includes information for child care providers and teachers as well.

Next slide, please. So in the introduction to this binder, encourage people to use the kit, and we give them ideas for how to get the most out of the kit. And as you can see here, we encourage people to ask questions about material that they read in the book. And to use it to keep track of things, like doctor's visits, and I'll say a bit more about that in a minute. We encourage people to keep it on hand, keep the book with them and to take it with them when they bring their child in to see any doctor. To ask doctors to make brief notes about the visit in the book, because this is a way to informally have, help doctors, various doctors who might be seeing the child, communicate with each other. And we include some useful things, like pocket folders and zipper folders and business card holders to help people keep track of information.

Next slide, please. Section one of the book is called about your child, and gives parents an opportunity to record important information about their child. Space for recording health insurance information, calendar and other note pages to keep track of appointments.

Next slide, please. The second section is people who care for your child. In this section we introduce the concept of the medical home, and we provide very brief descriptions of the different health care professionals that might be involved, and who they are, and what they do, what role they play. From a practical level, there's a space to write down all that contact information for all these providers and again, a business card holder in this section.

The very next section, next slide, please. When to call the doctor or go to the emergency room, and as suggested in the title, this is very, very clear action messages, how to tell if your child is sick and when you need to take action and what that action should be. The practical navigation side of the section has a place for the parents to write down the preferred emergency room, encourages them to talk with your primary care doctor and their hematologist, people who have offered to help with transportation, 911, and what to do if your child gets sick while you are away from home. And again, the key message here is treat fever as a medical emergency and other symptoms that need to be treated as an emergency. And, to make sure that every doctor, any doctor that sees your child knows that your child has Sickle Cell Disease, and this is a key message that is repeated, we hope strategically in different places within this document.

Next slide, please. There's a whole section just for doctors to record notes. And this was actually added as a specific recommendation from our focus group. It is not intended to be an official medical record, not intended to be comprehensive, but our health care providers

and our parents talked about how useful it would be for a very brief dated note with the major reason that the child was seen in a pediatrician's office, a specialist in an emergency room and what happened. And so if the book travels with the child, then that's the way to informally share information among the various health care providers.

Next slide, please. We have a whole section on what to know if you have a young child with Sickle Cell Disease. And, this includes some more detailed information about the major features and management. So, it also includes some very general information about good health care, including checklists, so the parents can have some guidance about what care they should expect at different ages and can check things off the list as they go. And again, our idea is this tool be used very interactively, that the parent will have it as a visit that the health care providers can use it in their education, they can make notes about it, they can clear up misconceptions along the way.

Next slide, please. But also in this section, as you can see, we have an opportunity to provide more information about some of the major features of Sickle Cell Disease in young children, in that what you need to know, what you need to do format.

Next slide, please. There is another section that says what do you need to do, if you have a child with Sickle Cell Disease? And this section includes lots of advice for taking care of your baby, from very, advice that's very specific for Sickle Cell Disease, things that I've already mentioned like Penicillin and looking for symptoms that require immediate attention, making sure immunizations are up to date, and also general and specific advice on nutrition, on adequate hydration, making sure children avoid temperature extremes and get rests and that kind of thing. We used to have a section in the book that said here is a list of questions you might ask, and based on the focus groups we changed it to here are

some things you should know the answers to. This section in a sense, almost acts like a review. By age interval, 6-month period, we listed some of the common issues that parents should be thinking about and talking with their health care team about. Things that have been covered in the book. But it gives them an opportunity to look down and say yeah, I do know about that, and it gives you a place to write additional questions they have, and lots of encouragement to ask those questions during their visit.

Next slide, please. We have a whole section about what records to keep. It includes advice about the type of records that are important to keep and some pocket folders, but it also includes three important sections. These are log-type pages in the notebook for recording, keeping track of lab results. There's one for keeping track of medicine, dose, when started, who ordered, etcetera, and then finally a section just for helping parents to keep track of their child's pain episodes. And again, they were difficult to show on the slides, but they have been formulated with a lot of advice from both our focus groups and health care providers and our parents focus groups.

Next slide, please. We also have a whole section on information for child care providers, and teachers.

Next slide. And these are really the key messages for child care providers. We, you know, our messages for providers are that, you know, you can and should, you know, there are things you need to know when you are taking care of a baby or young child with Sickle Cell Disease. And there's similar, you need to know if the child is getting sick, what to do if you see fever, other symptoms, and you need to know who to contact and how to contact. So in the tool kit there are two ways we handle this. One is there's a single sheet, double sided document meant for child care providers, baby-sitters, daycare centers, etcetera,

and it really does just specifically run through the danger symptoms, what to do, and make sure there is a place for, how to contact the parent today, and our intention is this can be something multiple copies, maybe even a tear-off sheet that parents can use when they go out, or a child care provider changes. For teachers, we have come up with a, you know, one single sheet, four sided booklet that does contain some basic information about Sickle Cell Disease, that same important information about what to do if the child gets sick. But also introduces the concept of individualized health care, provides a link to the Head Start program, information on individualized health care planning for teachers.

Next slide, please. And finally, there's a resource section and as you can see here, we give some general information about where to call Sickle Cell Disease Association of America, Comprehensive -- a place to write in the closest comprehensive Sickle Cell care center. I'm Reading problems, I have to switch. Here are good sites for information and there's some sites that are not as accurate, and we are going to tell you what a few really preferred sites are and you should always come -- talk with your provider about other information you see on the Internet. We wanted to give the warning that not all information on the Internet is accurate.

Next slide, please. And again, just an overview of developing the welcome kit, this is meant to be easy to read content in a very useful format. Our parents tell us that some kind of three-ring binder personal planner type size is going to be, work for them. Lots of action messages. Tools to help people navigate, and this is the educational piece that is likely to be part of other items, you know, of, packaged with other useful tools such as a tote bag. We got a lot of input along the way from focus groups with parents of young children, physicians and other health care providers.

Next slide, please. To finish up, I just only have a few minutes to very quickly tell you about some of the lessons we learned along the way in terms of terminology, and as you can see here on this slide, this gives some examples of things that we ran across, and some decisions were made about how to present information, and then once we made a decision, we tried to make sure we were using that consistently throughout all of our educational material. So, for example, concept of a detailed test result or useful test, we said that's a good way to say I and people understand, then we use that consistently.

Next slide. In terms of main messages, we needed to think about what to say and when to say it. So, for example, one of the things we learned early on in our focus groups was a lot of information for especially for Trait notification, don't worry. Your baby doesn't have Sickle Cell. The parents said you know what, when you told us not to worry, we quit listening. And so they wanted, they wanted to know the difference between Sickle Cell Trait and Disease and they wanted to know not to worry about Disease, but what were the important implications of having a child with Sickle Cell Trait. Other things we learned in terms of main messages are introducing the concept of Sickle Cell Trait as a condition. Based on what we know and in spite of the need not to alarm people. Wanting to be able to describe Sickle Cell Disease in a way that helps people understand what they may need to worry about if they have a child with this condition. And, the need to give people very specific information about how to get tested, and about the fact that not all tests are created equally. So the fact there are some tests that are more useful than others.

Next slide, please. I do need to gloss over this a little bit, but as I'm sure most people in this audience know, there are some misconceptions that we have known about Sickle Cell Disease and the way it's passed through families and inherited, so we work very hard also to make sure that we were trying to design materials that could clear up some of these

misconceptions as well. A few more misconceptions, which are probably familiar to many people in this audience. The need to stress the S gene can be present in people from many different populations, and the need to stress no fault involved, both parents of a child passed the gene on.

Next slide, please. So where we are going next is to continue to obtain feedback from multiple stakeholders. We want to do some more intensive field testing in the community, specifically with the welcome kit. Because we really want an opportunity to find out if and how that welcome kit tool is used by patients and their providers and if there are ways we can improve it and make any revision before the welcome kit is disseminated more broadly. We have been disseminating the materials to the community-based programs, to Title V programs, this is in progress. To other member organizations, current and former MCEC grantees, and ultimately, we are very motivated to make these materials accessible, broadly, and I think one of the best ways to do that, is to have electronic versions available, both on the HRSA, Sickle Cell Disease website which is under development, as well as the MCEC and other websites. And just to end with some acknowledgements, which I think I will turn back over to our moderator.

>> Thank you. We really are thankful to having a number of programs involved with this, MCEC staff, psych -- Sickle Cell Disease Association Of America, consumers, parents, and grantees. It's very helpful, very thankful for everybody who has given input into having these materials developed. So, this is our contact information, and I know that we have a number of questions that came in. Most of the questions that have come in all ask pretty much the same question, which is when will these materials be available, what is the timeline to make them available on the website, how can you gain access, kind of summarizing all the different questions. Will there be a downloadable version, and are

they available for purchase. They would not be available for purchase, they would be free to grantees, and I think that was the basic questions, so Sonja, would you like to --

>> Well, first of all, we would like to send them to all Title V individuals and anyone else who would like to provide another review process. We needed to, this was recommended to us by HRSA, that we send it out to the Title V programs. And, and others for another review process of the Sickle Cell Trait tool kit. That's the one that is probably in the most finite state at this point, having been reviewed several times, having had four focus group reviews at this time. We have not finalized our timeline with regard to when we expect to have the other documents out for review, but we would have that done very shortly as we are on a, we have a very large project ahead of us, because we want to make sure that all of this information also gets translated to Spanish. So, if you are interested in reviewing this document, we would gladly send you the tool kit, the Trait tool kit. We have one of those, it is about this size, if you can see that, it's a standard size notebook, and we'll send those documents to you for any comments and we have a letter that we have ready to go and we'll be able to do that.

>> Okay. There was an additional question to find out, do any of the materials speak to Trait in detail?

>> In the interest of time I did not go through all of that. But yes, the two brochures included in the Sickle Cell Trait tool kit, one is specifically about testing, but the other really does describe what Trait is, what it talks about -- I guess that's the question. It does, yes, provides very detailed information about what Trait is and what the implications are, and includes the concept of Trait as a condition.

>> One additional question from sandy Condition. condition.

>> Sandy in Ohio. [Inaudible]

>> Great question.

>> Great question. That's why -- this is why multiple reviews are important. We'll certainly go back and look at that. It's a great point.

>> Okay. We don't have any other questions at this time. So, I'm going to give my closing remarks which thank you very much for participating in this webcast, and like to thank the contractor, University of Illinois in Chicago, school of public health for making this technology work, but it is technology. And today's webcast as with all the webcasts will be archived and available in a couple days on the website at www.mchcom.com. We encourage you to let your colleagues know about the website, and hope that they will find it useful. We would like to make these www.mchcom.com webcasts responsive to your needs as possible. If you have suggestions on topics, or have comments in general, please email them to us at [info at www.mchcom.com](mailto:info@www.mchcom.com). Thank you, and we look forward to your participation again next month.