

MCHB/DHSPS OCTOBER 2004 WEBCAST

Partnership to Reduce the Risk of Sudden Infant Death Syndrome (SIDS)

BENITA BAKER: Good afternoon. Welcome to the Maternal and Child Health Bureau Division of healthy start in perinatal services webcast. I'm Benita Baker. The title today is partnership to reduce the risk of Sudden Infant Death Syndrome. Before I introduce the speaker I have some general instructions. Flags -- slides will appear in the central window. They're synchronized with the speaker's presentation. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window. We encourage you to ask the speaker questions at any time during the presentation. Simply type your questions in the white message window on the right of the interface. Select question for speaker from the dropdown menu and hit send. Please include your state or organization in your message so that we know where you are participating from. The questions will be relayed onto the speakers periodically throughout this broadcast. If we don't have the opportunity to respond to your questions during the broadcast, we will email you afterwards.

Again, 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 you can access by clicking on the loudspeaker icon. Those of you who 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 out an online evaluation. Please take

a couple of minutes to do so. Your responses will help us to plan future broadcasting in the series and improve our technical support. At this time I would like to present this afternoon's speaker. She currently serves as the deputy director for the National Institute of Child Health and Human Development located within the National Institutes of Health. Her name is Dr. Yvonne Maddox.

DR. YVONNE MADDOX: Good afternoon. Thank you very much. I would also like to take this moment before we begin our webcast today to personally express my appreciation to the health resources service administration, particularly the Maternal and Child Health Bureau and the Division of healthy start and perinatal services for arranging this webcast. It is not only appropriate at the NIH and partners with HRSA come together in this forum but specifically to come together to speak a project that we all have been actively involved in for many years, reducing the risk of "By My Side: Taking -- Sudden Infant Death Syndrome. I'm excited to present to you some of our research and some of our work on this important community project. A project I think has had significant results already, results that have impacted and will continue to impact significantly on the lives of children, their families and our communities. As we take a look now at the first slide, you will see that I am with the National Institute of Child Health and Human Development at the National Institutes of Health and that the National Institutes of Health is an agency within the federal government, particularly an agency within the Department of Health and Human Services as the health resources services administration shown on the graph above the NIH green box there.

The NIH is that agency within the Department of Health and Human Services whose mission is to conduct research and both behavioral and biomedical research as well as support research at academic institutions and colleges around the country. Our research is not only research that has impact around this country, but also around the world. And we also conduct a strong level of projects in the area of research training and infrastructure development. The primary purpose of our research is to improve the health of the nation of the United States and we say that this is done through research and research training. As we take a quick look at the four slides you'll see that the NIH carries out its mission through an organizational structure that is quite specific and quite directed. As you take a look at the various institutes and centers that make up the NIH you'll see there are 27 of them. Many of them will be very familiar to you such as the National Institute of allergy and infectious diseases. There are 27 acronyms. You have the National Cancer Institute which many of you are familiar with. The national heart lung and blood institutes. We like to say many of our institutes are organized around diseases and conditions while others are organized around systems such as the heart, lung institute and the national eye institute organized around an organ situation.

We have the NIMH you see in the middle line and the national Center for resources in the fourth line and the NCRR, as we call it, is the center that actually works to not only do research on many of the problems and conditions that are germane to the other institutes but the major entity within the NIH that helps us in infrastructure development. It has decided to make construction awards and renovation awards which is different from the other centers within our organization and of course on the first line at the end you'll see my

organization, the National Institute of Child Health and Human Development. Or NICHD. Now on slide five it will give you a brief overview of what our institute's mission in and when it was founded.

NICHD had its 40th anniversary a few years ago. Our institute was established by Congress for the purpose of conducting and supporting research and research training in areas related to maternal health, children's health and overall human development. You can see by our mission that while we put special emphasis on health problems of women and children, by virtue of our mandate we leave no human out because we're about human development. And human development is all inclusive. Now, as we take a look at the institute's mission you'll see that we have a four-prong mission. One is to help people have healthy babies, have healthy children when they want them. We want women to have no adverse effects from the reproductive process and we also want to help children reach their full potential to reach adulthood able to achieve whatever is possible.

And then fourth but not least we like to emphasize rehabilitation and an active participation and interest at specifically seeing there is minimal disability. If we can achieve at least some stage of rehabilitation, this rehabilitation would lead to a minimal amount of disability. While we carry out our missions through our research conducted in our intramural programs at the NIH, as with the other institutes at NIH the great majority of our research is conducted at institutions and colleges around the globe. We are an institute who has a very, very strong intramural program with lots of basic research that is conducted in the intramural program. We have a strong clinical program that translates

the basic research findings to practice and we have this large extramural community which is also very, very visible but most importantly carries out its responsibilities through four centers. The center for population research.

The national Center for medical rehabilitation research which really has the major responsibility for mission bullet four and then we have our newly established center, the Center for developmental biology and perinatal medicine. It is also through these centers that much of our collaboration with the other NIH institutes takes place as well as our collaborations through other HHS agencies and other government entities. We have been very much involved with HRSA and with the Maternal and Child Health Bureau for many years, not only in the area of SIDS but certainly in infant mortality and in strong programs to try to reduce infant mortality around the country. A member of the HRSA staff is also a member of our advisory council. We go back a long ways in terms of efforts to see that children not only have healthy starts but also healthy beginnings.

In slide seven you'll get a chance to see even though our mission is quite broad, there is one area that we are very, very strongly geared towards eliminating and reducing, and that is the large numbers of infants who die. Deaths of children before their first birthday is really an area we need to explore and we need to do something about this. While our mission is broad, I must restate that as a research organization, we put reducing infant mortality at the top of our list in terms of our priorities. Infant mortality as again I've mentioned the death of an infant before his or her first birthday is really critical in terms of our reduction. It is very much of a concern to me and to our community at large that the

U.S. has still one of the highest infant mortality rates as we begin to think about a developed country. As most of you well know who are logged into this webcast today, that our infant mortality rate is around 7 per 1,000 live births. To me that's a very, very unconscionable rate and we must do something to improve it. While we know infant mortality is high we can also recognize there are several conditions that contribute to infant mortality rate. When we begin thinking about the three major causes of infant mortality rate we'll have to recognize that congenital anomalies such as birth defects is still the leading cause of infant mortality.

The second leading cause of infant mortality is SIDS or -- the second leading cause used to be SIDS and that's where we want to go with this. The second leading cause is short gestation. And low birth weight. The third leading cause is Sudden Infant Death Syndrome, or SIDS. That's what I want to talk with you about today. Not only what is SIDS, I think most of you probably know. But how we've worked at the NICHD with our partners to look at reducing SIDS in one of our specified minority populations, the African-American community. Now, if you take a look at the infant mortality rate here you can see how the rate has dropped over the last ten, 15 years and you can see that whereas the general population in 2000 the rate was about 7.1 per 1,000 live births it dropped to 6.9 in 2001. But we did realize a slight increase when the final figures came out in 2002 to 7 per 1,000 live births. The general population. If you look at this curve which I can't see very well from where I'm sitting but I know the data pretty well. In the African-American communities the infant mortality rates is twice as high or greater when we look at various

regional and geographical areas particularly in our major urban communities. For African-Americans it's 13.7 and 13.9 per 1,000 live births. Keep in mind that's an average.

It does not speak to the 16 per 1,000 live births we may see in some of the inner cities and as high as 20 per 1,000 live births in other of our urban communities. We know the native American community also suffers from high levels -- high SIDS rate as well as high infant mortality rates. When we first began looking at SIDS. I think it's OK for us to take a hard look at what we think the causes of SIDS are. But we can realize that back in the 1970's and 1990's when we were first taking a look at SIDS and what caused SIDS, we saw a list that was a mile long in terms of the potential causes for SIDS. We saw things such as viral infections. We saw such things as bacterial infections. We saw such things as smoking. We saw such things as brain dysfunction. We saw cardiac arrhythmias. We're still perhaps where we were in the 1970's in terms of not knowing exactly what causes SIDS, but we know about what we can do to reduce its risk. So let's take a look at the next slide, if I may.

The next slide is what we are using as our official definition for what is SIDS. This is a definition that Dr. WELLINGER published in 1991. We say that SIDS is that sudden death of an infant. I must add healthy infant, under one year of age which remains unexplained after a thorough case investigation which would include performance of a complete autopsy and examination of the death scene and the review of the clinical history. While we know that's the definition for SIDS, we have also told you we don't know exactly what causes SIDS, although there is new research out that certainly suggests that

there could be various bio markers that we could use to give us an indication of what infants might be at risk for SIDS. We could also perhaps do some tests of the nucleus functions to see if there is a problem in the anatomy and pathology of that and we're already doing and have done for many, many years several epidemiology studies. It's from those studies that we've been able to identify the risk factors or some of the risk factors for SIDS.

I should adhere that SIDS is a syndrome which perhaps does include several components, which means that to look for one cause may not be the appropriate method of attack. But let's take a look at what some of the risk factors are today. First, we're still looking at the fact that race -- this is what we're going to talk about today -- seems to be a factor in the number of SIDS cases. Sex, it is still believed in many sectors of the biomedical research community that male babies seem to be more prone to SIDS than female children but we have to look at that much more carefully. We also know that low birth weight is -- seems to be a predictor in many cases. Pre-natal care, the lack there of when the mother isn't given prenatal care and there are seasonal effects. It's one of the reasons why we've taken October on as national SIDS awareness month because it gives us an opportunity to get the message out before the real cold season comes upon us. It appears that youngsters are much more likely to die of SIDS in the cold winter months. Of course, as we begin talking about this issue of bedding and this issue of covers and clothing and what we wrap our kids in from the standpoint of wrapping them much too warmly, that may also tie back into the winter months and the seasonal aspect.

We also know that women who smoke during pregnancy seem to have children who are at higher risk for SIDS and we also know that secondary smoke and people who smoke around kids put them at greater risk and also that babies who are in families or in a household with smoking has been prevalent that oftentimes these children succumb to SIDS. The age of the mother is a factor here, is a risk factor. Young mothers seem to have babies at greater risk of SIDS, specifically as we begin talking about teenage mothers and the problems that we're experiencing around the country as it relates to teen pregnancy and as I mentioned before, the birth weight is a predictor in many cases and this ties into the fact that many of these low birth weight babies are also pre-term. These are some of the epidemiology approaches that we've been investigating. The other thing that we really do know, there are some factors that we can look at that are practical and our communities can address as they begin to reduce the risk of SIDS in their own household. First we also say to the public that children should be put to sleep in safe cribs. Safety approved cribs that have slats that are tight together and not too widely positioned. Cribs that have nice, firm mattresses. Cribs that have no undo amount of bedding and that there are no stuffed, fluffy animals in the sleep environment. The children should not be dressed too warmly and as I mentioned earlier, there should definitely be no smoking around the child. In the next slide we will take a quick look at what some of the other countries have done in the area of SIDS.

Now, SIDS is not a U.S. disease or U.S. condition, let's say. It is no secret that other countries have experienced and are experiencing the problems of SIDS. Other countries have found just as we have that there are several risk factors for SIDS and these

countries are listed above and I'm sure there are others. These are some of the international segments in which the the NICHD has worked with over the years. They all have come down to one point and that is, a major risk factor for SIDS is -- seems to be prone sleeping or stomach sleeping, which means that in order to reduce the risk of Sudden Infant Death Syndrome it is imperative that we preach the importance of back sleeping to reduce the risk of SIDS. We wanted to go out and really find some scientific results that would not only support the fact that back sleeping was safe. I'll get to that in a moment. But most importantly to show that prone sleeping was associated with an increased risk of Sudden Infant Death Syndrome or SIDS. In the Journal of the American Medical Association our researchers reported that stomach sleeping was associated with an increased risk of Sudden Infant Death Syndrome.

This study was actually done in the inner city and it involved 394 mother/infant pairs. And of these 394 pairs it was seen that 157 of these infants were put to sleep on their stomachs. So 40% of these children were put to sleep on their stomachs. And this was also equated with an increase in SIDS among this population. Now, one begins to ask the question, where was this study done? And why -- what are some of the independent predictors of prone position sleeping? Why do youngsters -- why are youngsters put to sleep on their stomachs? If the community has heard and knows that back sleeping is best. One is social economic status or poverty. A second happens to be race. African-American parents and caregivers of children were more likely to put their kids to sleep on their stomach. The presence of the infant's grandparent in the household also seemed to have been a predictor of whether stomach sleeping or prone sleeping was the method of

choice. And, of course, when we asked some of the mothers who were associated with this study, they told us that they had intended to put their children on their stomachs to sleep before the child was actually delivered so that pre-disposition toward prone sleeping was already embedded in the mother's mind. So we need to think about this from the perspective of how can we convince the communities at large and, of course, this study was done in the inner city with an African-American population, that stomach sleeping is not the position of choice and that back sleeping would definitely reduce the risks of Sudden Infant Death Syndrome.

One of the things we had to do was to conduct research as well to confirm that back sleeping was safe and that it was effective. Now, many people have spoken over the years about the fact that particularly in the African-American community that individuals do not put children to sleep on their stomachs because -- on their backs because they're fearful that the children will choke, that they'll have reflux reaction and will choke and there are many myths that grandparents share with their daughters and their children that if the child is put to sleep on his or her back, their head will be deformed and will be flat on one side on the back or on the side if side sleeping is the method of choice, but in reality, all studies point to -- this is around the country, not just research that's been done in this country -- and the observations are clear and that is that a healthy child does not suffer any adverse effects of sleeping on his or her back. Now, that begs the question in terms of a healthy child. To assure that a child is healthy, dictates automatically that one needs to take a child in regularly for well child checkups into the pediatrician.

This is something that's also lacking in many of our communities. I want to reiterate and to stress that back sleeping does not promote choking and back sleeping is safe if the child is a healthy child. If the child sleeps on his or her back for any unusual period of time, particularly in the early months from, say, two to six months, there may be a little bit of flatness of the head on one side or the other but that usually fills out and, of course, when the child is just having play time we encourage the mother or the childcare provider to give the child a little tummy time while he or she is awake and while the adult is awake to watch the child. But in terms of the ordinary sleeping position, back sleeping is the method of choice. So it was decided that NICHD, along with some of its partners. I'll tell you who they are in a moment, would launch a campaign. The next slide will show you sort of the character associated with this campaign.

This was the back to sleep campaign which represented a public/private partnership to reduce the risks of Sudden Infant Death Syndrome. Now, who are the partners? The next slide gives you an idea of where we were when we started and who the partners were. Now, the campaign was actually formally launched in 1994, and that brings us to the excitement that we share today. That is the fact that we are celebrating our 10th anniversary in terms of the back to sleep campaign. I think you'll see in a moment that this has been a campaign that has been very well planned but most importantly has given us tremendous and terrific results. The campaign was formally launched by a press conference that was conducted by the surgeon general, at that time David Thatcher. It was great to have Dr. Thatcher to launch this campaign along with our back to sleep partners. I'm pleased to say the Maternal and Child Health Bureau of HRSA was one of

our partners. We launched the campaign with HRSA, with the American Academy of pediatrics who also had gone on record in 1992 to begin the promote back sleeping as the official sleep position of choice. They also proposed at that same time that if back sleeping was not one position that a parent could buy into or that a caregiver could buy into, side position was also appropriate.

You'll see from some of our most recent data we don't advocate for side sleeping. We feel that back sleeping should be the method of choice. In 1992 the American Academy of Pediatrics recommended back sleeping and in 1994 they joined us in this campaign. First candle, parts of the SIDS Alliance parents group was an active partner with us. The institution of infant mortality programs was a partner as was the National Institute of heart, lung and blood institute at the NIH and it does most of the sleep research at the National Institutes of Health. The partnership was alive and well and this year, to commemorate the 10 year anniversary I'm pleased to say that last week we held, with some of our new partners, a press conference with the mayor of Washington, D.C., mayor Williams, to commemorate the 10th year anniversary as well as to get the district of Columbia more involved in our back to sleep campaign. I'll show you what we did with them at the end of the presentation. In the next slides you'll see the results of this terrific campaign.

When we began the campaign back in 1992, you can see that the SIDS rate was about 1.2 per 1,000 live births. That means that for every 1,000 youngsters that were born, 1.2 died of SIDS. That was just at the time in which the American Academy of Pediatrics was making the recommendation. That was actually when the back to sleep campaign really

got underway. That was in 1994. And we were dealing with the SIDS rate then of a little over 1 per 1,000 live births. If you look at the SIDS rate today, you can see that we have cut the rate in half. We have reduced the risk of Sudden Infant Death Syndrome by 50%. And as back sleeping has increased, you'll see with the line there with the bar, the line going up towards the top, that as back sleeping has increased to about 87% of infants being put to sleep now on their backs, the SIDS rate is dropping. So obviously our goal is to get 100% of our infants to sleep on their backs.

Now, while this information and these results are very, very encouraging and actually very, very exciting, it tells us, of course, what one can do with a simple message. Not an awful lot of expense, not an awful lot of additional cost, a lot of staff time and a lot of planning, but it shows you what we can achieve by getting a message out and from switching to stomach sleeping to back sleeping. Now, we believe that if we could get not only more infants to be put to sleep on their backs and also to get less infants from being put to sleep on their stomachs and also to let infants being put to sleep on their sides we can reduce the risk of SIDS even much more efficiently because we still believe that switching from side to back is going to also improve the numbers. These simple changes will give us a real opportunity to reduce the SIDS rates much further and to have some promising reduction across our communities. Now, slide 16 gives you an idea of what the SIDS rates look like in the African-American community compared to the white community.

Now, you'll see there what we call sort of the average line, which again speaks to the SIDS reduction rate, the rate being 1.56 percent 1,000 live births. You take a look at the

pink line at the top and you'll see the SIDS rates from African-American -- for African-Americans is actually doubled. In fact, we say it's 2.2 times more likely to have an infant death from the African-American community when compared to a white baby. This tells you one thing. First, is that we haven't gotten our back to sleep message out and some of the risk reduction messages have not reached this community. It also tells us that where the infant mortality rate is going down, it's quite parallel. So the big health disparity and the big gap that we see in health status as it relates to SIDS persists. What do we want to do here? Well, we want to do two things. First we want to specify this population, the African-American population as a group that we want to target for SIDS risk reduction.

It also says if we're able to use a campaign of this nature to reduce the rates of SIDS in the general population, why not start looking at native Americans, let's start looking at African-Americans and in doing so not only will we reduce the SIDS rate across the communities, but we also will make a contribution, a significant contribution to the infant mortality rate. Now, when we began the back to sleep campaign back in 1994, we were losing about 5,000 -- a little over 5,000 babies a year to Sudden Infant Death Syndrome. Right now we're losing about 2400 as we looked at our statistics there for 2000 and 2001. But I've just learned from the person who runs our African-American outreach program the new statistics have come out. They came out on Friday, we got them. The final numbers from the national Center National Center for Health Statistics for SIDS and saw that actually the SIDS rate increased just a tad in the general population from .56 per 1,000 live births to .57. Interestingly, the increase is due totally to an increase in the white population. Let me show you this. Next slide, please.

Now, the SIDS rate as I just mentioned to you have been dropping. But they are still twice as high in the African-American community. I'm going to give you the good news before I take you to how we got there. The good news is that when you look at the final data for 2002 now, the data that Andrea just received on Friday, you'll see that the African-American SIDS rates have indeed dropped. They have gone from 794 deaths to 7 -- from 745 to 703. That's quite an interesting statistic. As we take a quick look -- I think I have them someplace here as they were just given to me, the statistics for the Caucasian population, let me show you what we have. In 2002 the number of deaths in the white population due to SIDS was 1494 deaths. That's compared to 1406 in 2001. So the number has gone up in the white population for SIDS. In 2002, the black population had a SIDS numbers. 703 deaths. It might be too soon for us to suggest that our targeted back to sleep campaign is having an impact this soon on the African-American community, but let's suggest that it has.

Let's go through what we have done in the African-American community to focus this back to sleep message. As I mentioned to you earlier, SIDS is 2.2 times more likely to occur in the African-American community as compared to the white population. We also know that black mothers and caregivers of youngsters are more likely to put their children on their stomach to sleep as opposed to putting them on their backs to sleep. We also know that the back to sleep campaign seems to work. This demonstrated focused campaign seems to be instrumental in reducing the risks of sudden infant death syndrome. Now, let's take

a look at the next slide to give you an idea of what we decided to do as we began to think about targeting the African-American community.

We've called this our African-American outreach initiative. It began in 1999 when we actually had a strategy planning meeting in Bethesda, Maryland, with the national institutes of health, NICHD, my organization, the SIDS Alliance and the national black child development institute. This was a not for profit organization within the Washington metropolitan area that focused on black children and their development. We had a focus group meeting that came out of this planning session and it was the focus meeting -- group meeting that suggested that we needed not only to put together a working group to look at these problems, but it needed to be a focus group to help us redesign our campaign materials to make them more sensitive to the African-American community and culture, as well as to get the African-American community involved early on in the design and information dissemination and the teaching and training of the back to sleep messages.

We were very, very pleased to see that these African-American partners were willing to come together and was also at that meetings that we invited several organizations that are sort of unorthodox when it comes to biomedical research. We invited sororities, fraternities and the various private organizations. We invited the women in the NAACP. The coalition of 100 black women and sororities and many more came. It was through working with these groups that they all said, we want to develop culturally appropriate material. We want to help you put together a resource kit that will be culturally sensitive

but also will have the material in it that our community can identify with and we want to launch some targeted summits around the country that will tell people that SIDS risk reduction is crucial and that we want to launch a program to save our children.

These three organizations held their three summits and the summits were held in three geographical locations. The first was held in Alabama. Very fitting for a project that will speak to the African-American community and the beginnings of saving our children. That summit was organized by the coalition of 100 black women. The second summit was held in Los Angeles, another community that has high infant mortality rates. And inner city, in particular. And that summit was hosted by women in the NAACP. Our third summit was the summit that was organized by Alpha KAPPA Alpha incorporated in Detroit, Michigan. The partners were very adamant about not only getting the message out, but they wanted it to be clear that SIDS was something that was real and that the message about reducing the risk of SIDS had to be a clear message.

There were some real concern that the back to sleep message and the little cartoon I showed you before was a cute logo, but it really did not give the message that the African-American community needed. They needed a clear message. And the message that they came up with was that babies sleep safest on their backs to reduce the risks of SIDS. Now keep in mind that this message was developed by the various participants of the focus groups as well as the various participants who participated in the summit. These participants came from all walks of life. They were the lay public, they were Congressional leaders, local leaders, church workers, other sorority and fraternity workers

as well as those individuals who had family members who had succumbed from SIDS or had known of someone who lived next door who had lost a child to SIDS. It was a very diverse population not only in terms of racial ethnic mix but with a focus on the African-American but very diverse in terms of disciplines and specific areas of interest. It was through these organizations and through these summits that our major project came about. And that was the project to train the trainers. It was clear that the government -- HRSA, NICHD, the national black child development institutes. Women in the NAACP, each of us could not do it alone.

It needed to be a partnership but most important it needed to be something that we also gave back to the community. So we have now had with our partners as they have expanded their efforts, more than 40 train the trainer sessions have been held around the country. These have involved close to 2,000 people who are training others about sleep positions, about the other risk factors for Sudden Infant Death Syndrome. These partners have also expanded their efforts to their regional groups, particularly the Alpha KAPPA Alpha sorority. Each of their regions have taken on SIDS. They've actually produced, with our assistance, a mother's day card that they hand out during mother's day to have the back to sleep message associated with it as well as the other risk reduction messages. They've done public service announcements and most recently we've been involved in working with them in various television shows and productions.

There is a particular television program that airs on weekends in Mississippi this is called "Women to Women" focusing on the importance of reducing SIDS on that show. It's

hosted by a doctor, who is the project director or the program director for Alpha KAPPA Alpha and the wife of the former governor of Mississippi. We've been working with our partners to expand our network and expand and deliver the message. Now, the networks are also expanding to incorporate other partners in their work. The women in NAACP have worked hard to try to get other professional organizations that cater to and relate to African-American women involved. They have taken it on as an important area for them and we just gave several keynote address at many of their links workshops. The most important being their annual health fair this past April. The national council of Negro women. We hope they'll become partners to expand our efforts. Now, community participation, if we can take a look at the next slide, community participation is critical.

And when you say you're going to have community participation, it really means that the community has to be recognized as full partners in your plan. It doesn't mean that you create the ideas, you create the messages, you do the research and then you tell the community to do it. The community has to be actively involved. We insist on having input from the people as we develop this campaign. And we've sort of built our campaign on a central theme. That theme is it takes someone to tell another one about the SIDS risk reduction method. In terms of doing this, we're expanding our network and we must do this all the time. We must continue to provide this message throughout the year, throughout the day, not just in October, not just doing SIDS awareness month. We need to harness the strengths of the community and we've already talked about what some of those strengths are, many times we fail to recognize that the community not only knows its community but it does have some good ideas about how the message can be translated.

We also know that the community workers can actually get to the community because the community trusts them and we've worked very, very hard to build up a level of trust and we've learned from this partnership that trust is critical. Not only do they have to trust that they are full participants in the initiative, but they have to be given the results of their efforts as soon as possible. I think one of the things that I appreciate so much about this back to sleep campaign is that we have worked with the community, we've worked with HRSA, we've worked with CDC to get the information about our statistics as soon as possible so we can give them back to our partners. They don't want to think they're out there working and day in and day out. Many of them really are through the regional efforts and through their local efforts. That they're working with their partners who many times are partners that you all know. Many of you sitting in front of your computer monitor right now and you know you're a partner particularly as it relates to healthy start and some of these things. We need to be cognizant of the fact that results are important. The progress of these studies need to be given to the public. They can understand it and they can appreciate it and they'll buy into what we're trying to do, I think, much more efficiently. The next slide tells you what we think about public trust.

Now, the NIH has launched a very, very significant project over the past year called the NIH roadmap initiative. Our director launched a roadmap initiative for several reasons. One was, he wanted to look at new pathways for discovery. What are some of the new pathways to making research discoveries? The second was to look at the research teams of the future. Who really should constitute the research teams of the future? Are they just

biomedical researchers, are they the general practitioners, the statisticians, are they the technicians and physical therapists? Yes, they're all of the above. We need to think about the partnerships. In thinking about these partnerships we cannot leave out the public. The third area of focus is reengineering clinical research. In order to really conduct clinical research and conduct it effectively and significantly, one needs to have patient recruitment. The only way to get patient -- get individuals willing to participate in clinical trials or even in a campaign such as this, there has to be that level of trust built into the activity. So probably reflects the fact that we want to paint a more accurate picture of the NIH and we want to be proactive as we direct and ask for participation in our community outreach projects.

We also feel that it's important to empower citizens to contribute to the success and I think that's what the back to sleep campaign has done. Particularly in the African-American community we have empowered our community to be a part of this. Not at a distance, but be an integral part of this message. And then last but not least I think we need to inform the American people about what we do. What research does, what it does not do, why we do the research we do, and what are some of the approaches we use to conduct biomedical research. As I told you early on, we still don't know what causes SIDS. I think it's critical that we tell the community that. We've got some very promising research that suggests the nucleus is involved and brain development. That's all we know right now. That result is not clear. It's not definitive but we need to let the public know that but we also need to be honest with them as they have been with us and they've said, they don't fully understand or appreciate the words back to sleep. What does it mean. Let's give the

real message. The real message is babies sleep safest on their backs to reduce the risk of SIDS. Back to sleep could mean go back to sleep baby. We have a good mattress here, get some sleep. They want a true message so the public is an intelligent public that we're dealing with.

Now, the next slide will give you an idea of some of the things that our partners told us that they thought would be critical and germane to this campaign and to the new literature. Obviously there were some things that we should have thought about ourselves and that was that the brochures and publications needed to be culturally sensitive and needed to have babies that looked like the community we were serving. The language had to be sharp and clear. And we needed to involve real people as opposed to cartoons in our campaign literature. It was also clear that for some of our communities of color, and not just Hispanic community here as we see some of our information or literature that's in Spanish, but there are many people of color, African-American heritage who also speak Spanish. We need to be sure our newest campaign literature not only was culturally competent and sensitive in appearance but the messages were as well and they were language specific in many ways. We also have provided for train the trainer sessions, these sessions we do around the country, many of them with our healthy start partners and with our women in the NAACP partners, with our Alpha partners and with our coalition of 100 black women partners. We do the train the trainer sections and the next slide will show you the kits we provide.

The kit has all sorts of wonderful pieces including a video, if you really like to have some motion and some live examples of how one puts a child to sleep on his or her back. We have guides to what is in the kit so that people will understand how to use the kit appropriately. Also, we have a brochure that gets to some of the things I suggested today, myths associated with back sleeping. Issues about head deformities which we just discussed that do not occur, as well as some just user friendly material such as magnets and a little TV guide, as well as print media. Print material. The other thing that we've added that is available to many of you out there are the little undershirts that we have produced with one of our co-sponsors and that's a little undershirt that says, put me on my back to sleep. The kit is very, very useful. We've heard from our partners who have done the train the trainer sessions that these are very public sensitive and that they've really aided them in their public awareness messages. Now, one of the things that we wanted to do. We recognized right away the trainer sessions were going to be very, very specific. Which meant that you're going to get a group of people in a certain location that were going to go out with the kits, meet with some of their community activist groups or parent/teacher association groups and so forth and these would be direct one-on-one head to head sessions. We also want to get the message out to the general public who was not likely to show up as a train the trainer, but who could benefit from hearing the message, as well as to benefit from additional material that we could provide them once they telephone us to let us know they were interested.

So the next slide shows you something else that our focus groups and partners told us would be important. That was to get the message out to the public transportation system.

Back about 2 1/2, 3 years ago we began by putting the baby sleeps best on its back.

There are many locations who also have done this. Not only on buses but wonderful billboards around the country also have this message. But one of the things that we heard was not just on the buses but let's try to get into the metro stations and have a ribbon cutting or launching in one of the metro stations in the Washington metropolitan area that has a high African-American population. We last week at the press conference with the mayor were pleased to announce that the Washington metropolitan transit authority had agreed not only to put the posters or the ads back on their buses beginning in November, but they're actually putting this very, very nice poster, a large poster, in metro stations in the areas of Washington, D.C. that have the highest African-American representation. So again, this was done through the help of our partners.

They went to the transit authority with us to ask for and to receive this wonderful opportunity to get the message out. Now, where does this lead us in terms of the future? Well, the first thing that we must say is that we really do believe that partnerships work and that they matter. It is through this partnership that the SIDS back to sleep message has taken on really a new life. Because it's from the African-American outreach project that we're now going to go into the Native American community to work on this dread condition. We also have worked with partners in various locations around the U.S. who have asked us to come into their communities to work. Many of you are perhaps familiar with the Mississippi delta project that was not only supported by NICHD and HRSA, but by our own Department of Health and human services and the Office of minority health within the Department of Health and human services has been a major participant in

helping us get the Mississippi delta project underway. One of the other studies that you probably have heard a great deal about over the last few years, I think I must tell you about. It is the national children's study, which is the study that was mandated in the Congressional language that was put in the NIH appropriations as part of the children's health act of 2000.

This act not only suggested that we do more in the way of children's health research, but it also targeted NICHD, the National Institute of Child Health and Human Development and the EPA and CDC as being other lead components in developing a National Children's Study. This study also calls for 100,000 youngsters from birth to 21 years of age to be studied. It would be the largest study of its type ever conducted. Not only in this country but conducted ever. And the idea here is that we would be looking at mothers -- suspected mothers or potential mothers before they give birth, with the understanding that there are environmental both uterine but also exogenous matters that contribute to child's health and well-being. We're hopeful it will be through the national children's study as we begin to look at infants pre-conception onward that we'll get a better handle on how chronic and acute conditions develop. It's interesting because I learned as I was preparing to provide this talk today, that it was through one of our early longitudinal studies, the perinatal study that gave us some indication of what some of the risk factors for SIDS might be. That was one of our earlier studies. So we're very hopeful the new national children's study will give us clearer indications as to how SIDS began and what some of the etiologies of SIDS really are.

We also plan to do a series of solicitations as well as RFP's from out of the national children's study and we also feel that working with HRSA and working with CDC and the Office of minority health we'll be able to buy in a great deal and put in on our support for the Mississippi delta project. Two doctors from the National Institute of Child Health and Human Development have been active in putting forth new RFA's to solicit grant applications in the area of infant mortality. And we have just launched a new initiative in still births. As you well know we aren't so clear as to what the connection is between still births and SIDS. So we're hopeful we'll get more information out of the still birth initiative that will shed some light on SIDS and its etiology. I mentioned earlier by research teams of the future and the fact that the NIH roadmap initiative will focus on that. We believe that the SIDS back to sleep campaign is just the best model. It's a best practice, if you will, of what research teams of the future should be about and like. The team should include not only multidisciplinary areas, it should include different agencies, different departments, different communities. And I believe that we can translate a lot of what we've learned from the back to sleep campaign to other campaigns that we need to launch, particularly the campaign on obesity and childhood obesity.

We're very excited about the fact in working with our partners we have an infrastructure already in place that involves the African-American community. What we really need to do is use the infrastructure to promote other health messages and other concerns. I would like to see us focus oh great deal on childhood obesity as we use this model that has already been described for you here today. Now, I want to remind you that even though we are focusing on the African-American outreach effort here today, we will begin to really

aggressively approach the Native American issue particularly as it relates to the high SIDS rates we see in that community and particularly across various tribes. But the whole problem and the real message here and the real theme is to focus on our children. The whole theme here really should be to save our babies. And we can save our babies in many ways. One way is certainly by reducing the risk of SIDS and reducing the number of SIDS deaths.

As we look at the very last slide, I believe it's close to the last slide, let's remember to practice the simple message, that it's our baby. We should own them in every way possible and remember that we can do better. As we look at the next slide, I encourage you as we begin to think about babies sleeping safest on their back and if there is new information that you don't have available to you that you think we might have I encourage you on the next slide to consider calling us at our hotline which for SIDS information is 1-800-505-crib or 1-800-505-2742. If you care to learn more about the NICHD programs, call us as well. But I do encourage you to go to our website, www.nichd.nih.gov. Again, I want to thank you for your attention. I want to thank HRSA Maternal and Child Health Bureau and the division for inviting us to address SIDS and the importance of partnerships, particularly as we think about reducing the risk of Sudden Infant Death Syndrome in the African-American community.

BENITA BAKER: Thank you, Dr. Maddox. Again, we encourage you to submit your questions by typing your questions in the white message window on the right of the interface. Select question from the dropdown menu and hit send. We do have a few

questions from the audience, Dr. Maddox. One of them is how is the data, the SIDS data, affected by the change in medical examiners' practices in diagnosing SIDS?

DR. YVONNE MADDOX: That's an excellent, excellent question. As I've gone around the country, actually giving the statistics and also working with our community partners in the SIDS risk reduction effort, it is very, very clear to me that the various state medical examiners are critical to not only diagnosing, but also very, very critical in delivering the statistics to national Center National Center for Health Statistics. One of the things that we really need to work on, that is to increase our partnerships with the state medical examiners. And really, I think, working with them to see that we're all on the same page. We believe that the definition that we have used since at least 1991 when Dr. WILLINGER worked with us and most medical examiners are trying to work with. Many of our presentations around the country, and we must have done a couple hundred, oftentimes the medical examiners are in the room and they are equally as concerned about the numbers and about the possibility for misdiagnosis, as well as the possibility in certain cases when it's a misdiagnosing it might mean underdiagnosing.

There has been some suggestion that they would actually meet with the American Academy of Pediatrics and we could look at some of this as a team. I do think it will require that. I do think the data is affected. There is some underreporting. I also think in certain locations there may be some overreporting. But I do think that as we look at the statistics, now, one would have to say if you look at the data prior to 1992, and you look at the statistics right around 1992/1994, the reporting -- in terms of the numbers seem to be

pretty, pretty much the same. In fact, the level was flat until we kicked in the back to sleep campaign. One would have to ask, are we sensitizing people that they're much more aware? I don't have a good answer for you but I know all the issues are critical and important and I can only say that I would encourage you, those of you in the various regions, to do all you can to help us come up with the definition not only that we as researchers and federal administrators can embrace but one which our medical examiners will embrace as well.

BENITA BAKER: Thank you. Another question is, does the data presented on SIDS rate include only SIDS or does it differentiate for other causes such as overlaying or other causes of suffocation?

DR. YVONNE MADDOX: Well, the thing about it is one of the things I should have mentioned, which was one of our most recent papers, gave some statistics. I do have someone in the room who could also work with me on this answer. But one of the issues that have also come to bear is the importance of bed sharing in this whole issue of SIDS. Again, it gets back to the issue of, you know, suffocation, because oftentimes the bed sharing does lead to adults lying or rolling on top of the infant and actually the infant suffocates. I do think when you look at the SIDS deaths as we do the death scene examination, I think all these questions are asked as one begins to look at the history. So I'm sure that those things are brought to bear as the state medical examiner does his or her death scene investigation but we're very aware there are other confounding factors within the household. I think we all relate to some of the issues I mentioned early on as

we began thinking what are some of the predictors of prone sleep position. It relates to socio-economic status and poverty. Many people don't have cribs to place their children in. We have several programs around the country, I'm sure some of you are involved in these programs that actually have standard crib donation programs. Many infants don't have a crib to go to sleep in every night. They do sleep in bed with adults. So bed sharing and other issues are certainly critical as we begin to think of the SIDS rate and the SIDS diagnosis.

BENITA BAKER: New York City Department of Health and Mental Hygiene conducted a study that showed reactions and responses to the back to sleep brochures that was consistent responding group. The groups felt as though the brochures were inappropriate to black audiences and felt that the message was stereo typical to Blacks. African-Americans. Have you gotten any feedback?

DR. YVONNE MADDIX: I guess I would have to ask the questioner, I don't know if she can answer this question for me, is whether the material that they were looking at was the old material or the new material. Because we certainly have heard that from the focus groups and from the partners as we began looking at the old material. I would hope that if the new material is creating that attitude or that concern, that I would like to know what it is and we certainly would like to address it. I don't know if it's the new material or the old material. I would really welcome hearing that and being able to address that.

BENITA BAKER: Another question. Do you feel that increase in the SIDS rates has anything to do with the medical community in inaccurately filling out death certificates?

DR. YVONNE MADDOX: Well, I don't know that it's inaccurately filling out the death certificate as much as I believe that it's related to the other previous questioner's concern. That is, misdiagnosis or maybe using another definition for diagnosing. I do think there is some confusion there and some differences of opinion. And I do think that oftentimes we do have a diagnosis that might not be acids diagnosis or we may have one that is missed. So yes, I do understand the questioner's concern but I don't think it's inaccurate from the standpoint of just the person misrepresenting what he or she sees. I think they are still struggling with the definition.

BENITA BAKER: Another question is what accounts for the increase in SIDS from 56 to 1,000 to 57. Is the data referring to 2001?

DR. YVONNE MADDOX: We really don't know. As I mentioned to you earlier, I just got the data today. In fact, you saw me fishing around trying to find my paper. I understand from our staff that they received the information I guess on Friday. We don't know that yet but we certainly are going to look into it. It's very interesting because, as I mentioned earlier, that slight increase that we've seen is reflective of the majority of the community, the white community is not reflected of the African-American community because we're delighted to see the SIDS rate has actually dropped. So as we look at the SIDS rates in African-American, I gave you the numbers. I told you that the number of SIDS deaths in

2002 were 703, down from 745. But the rate has actually dropped, of course, because the numbers of have dropped. The SIDS rates now are 1.18 per 1,000, in 2002 it was 1.2 in the African-American community. And the white rate has gone up from .44 to . 47. We don't know the answer to that but we'll do our best to try to tease it out.

BENITA BAKER: Why do more babies die of SIDS in the winter months?

DR. YVONNE MADDOX: It's sort of funny because you've asked several questions. Your listeners have asked several questions about diagnosis. I certainly don't want to think that something is happening in the diagnosis is just seems to be something that one feels compelled to make in the winter months. We really believe that it has something to do with the fact that the children are either put in the crib which maybe there is too much bedding, they're dressed too warmly, the environment is too hot. Many people think that you need, because babies are so soft and cuddly, you need to wrap them up in so many layers. Well, you know, they are just like we are, whatever comfortable temperature that is in a room for adults should be the temperature you maintain in the nursery and the temperature that a child is just fine for a child.

If we believe that some of the cause of SIDS is related to the nucleus, the area of brain that signals gas exchange, it may very well be that when these youngsters get bedding caught in their faces or get so deeply embedded in them and a mattress that is too soft, that they actually suffocate. And they don't have the reflex, because the brain has not developed in such a way that they can turn their heads and that's why we believe that

SIDS is so frequent in infants from three to six month period or certainly during the first year of life because that's the critical period. I believe that if they -- if children can overcome that one year period, and if the nucleus and brain development issue is something critical in this entity, then after one year of age we think the brain then catches up and development sort of occurs. It could very well be that the issue of heat and warmth and suffocation are connected to the pathophysiology that we see with the research we're doing in the laboratory.

BENITA BAKER: Are there any gender differences in the number of babies that die from SIDS, do more male babies die from SIDS than females?

DR. YVONNE MADDOX: Yeah. Now, we have been saying this, I think I mentioned this early on in my presentation, that sex was a risk factor for SIDS and it was very, very clear to us early on that male babies seem to be more at risk of SIDS than female babies. I don't know the answer to that. But I can tell you based on my other research, because before I became involved in children's health research, my research was in cardiovascular physiology and we know the male species, male infants, are more prone to deaths in many cases and we believe it may happen to be related to either the white chromosome and the fact it conveys a level of development that really requires a lot more research. We also believe that in the early stages pre-imprinting is occurring that testosterone may actually not convey a strength but may actually cause a weakness in the species and only whether the estrogen levels have reached a certain rate or certain level that we convey protection to youngsters in general. So all of this happens in utero so I can't say this is the

true cause of why more males appear to die. More males appear to die in almost every disease or condition unless it's a disease or condition that is manifested genetically by the X chromosome.

BENITA BAKER: You had mentioned about side sleeping being a factor in SIDS. Could you talk about that a little more?

DR. YVONNE MADDOX: Sure. When the American Academy of Pediatrics made its recommendation in 1992, they actually recommended back or side sleeping. Now, one of the reasons being is that you have to ask the question, why do people put their infants to sleep on their stomachs when they've already heard -- I think many people know the back to sleep message, they hear it but still put their youngsters on their stomachs to sleep. The reason people say they do it is because the child sleeps better on their stomach. They're more relaxed, more comfortable, they sleep better, they sleep longer, they seem to be much more rested. And I think what the American academy of pediatrics was doing at the time was really give parents and childcare providers some options. They understood it would be a long haul, perhaps, to move kids from sleeping totally on their stomachs to on their backs, so side sleeping was a happy medium here and there are those who still say that the kid sleeps better on his or her side than they sleep on their stomach.

But the reason we're not advocating side sleeping and actually would like for parents to hear us and caregivers to hear strongly, back sleeping is the way we want to encourage

our children to be put to sleep that first year of life. That's because if they're put on their side to sleep, they're very much likely to roll over on their stomach. More likely to roll on their stomach if they're on their side than on their back. Oftentimes a child will be put in his or her crib on the side propped up along the side of the crib. The way to roll over is on your stomach, not your back because you have the side there protecting you. So we want to promote back sleeping, not side sleeping for that reason.

BENITA BAKER: I have a comment. One audience member states that SIDS programs aren't involved in the -- SIDS programs that are not involved in the SIDS Alliance have not been included as partners in this effort. And they encourage you to reach out to this particular group, ASIP would be a good conduit for such an effort.

DR. YVONNE MADDOX: We're happy to hear that. In fact, for those of you who know NICHD as a federal agency, you know we build our research and our information dissemination whether it's SIDS, autism researcher or reading research, we build on partnerships because we've long recognized that the way to get biomedical research conducted and accepted and also to get the public involved in clinical research requires the public's role in relationships with us early on. We'll take on as many partners who step forward and want to participate. We've actually gone out to seek partners and that is certainly an organization that we very excited about potential partnership. We'd be happy to do that. Thank you very much for the comment.

BENITA BAKER: I think this will be the last question we'll take on the air. We'll answer your questions through email. But one member asks that while putting babies on their backs, that that's the message of choice for African-Americans, those particular families who did share have multiple health risks that can contribute to the death of infants. Are there any recommended messages to those families?

DR. YVONNE MADDOX: In regards to bed sharing or in regards to--

BENITA BAKER: The member doesn't say.

DR. YVONNE MADDOX: Well, I think one of the things that we need to say is that I think that a child, and particularly an infant, really deserves and really needs his or her own place to sleep. It's unfortunate that our society and the circumstances don't predict and don't allow every child to have that. I think one of the things that we need to think about, this is a big problem, this whole business of infant mortality and health disparities in infant mortality, and the role that the community can play. I think there are all sorts of communities here. When we talk about the public trust in sharing it's not just the federal government or NICHD or -- we can go on and on. It's the community effort. A real partnership. One of the things I would like to see is I would like to see us launch a project in which every family, in particular every new mother who goes home with a child, is asked the question, do you have a crib? Do you have a place to put your child?

And somehow there could be a program that would promise and give every child a crib. And, of course, that doesn't answer your questions about some of the other confounding diseases and other conditions, but we could certainly say that that child had a place to sleep that was his or her own, at least for that period of time. There are many community groups that are providing cribs. There are many crib donation programs around the country. Unfortunately there is not enough money to see that the numbers of cribs are the numbers that we need to have in place for the birth rate that we have in this country. But that's something that the federal government needs to think about and maybe working with HRSA and some of our other sister organizations that are much more involved in services research than we are. I failed to say this project is very unusual for a National Institute of health organization to do this sort of community outreach and service oriented project. We're mainly clinical research, translational research in nature but again I think it speaks to our commitment to reducing infant mortality, which does require a lot of additional research.

BENITA BAKER: Well, thank you, Dr. Maddox and I would like to again thank Dr. Maddox for being here with us today and presenting this valuable information. And thank you in the audience for joining in.

DR. YVONNE MADDOX: Thank you very much. My pleasure.