

**Project IMPACT**  
**Sudden Unexpected Infant Death (SUID):**  
**National Developments, Initiatives, Studies and Opportunities**  
March 30, 2009

MARY ADKINS: Welcome to all of you from Project IMPACT, the sponsor and host of this live webcast. I'm Mary Adkins. I'll be your moderator for "Sudden Unexpected Infant Death (SUID) National Developments, Initiatives, Studies and Opportunities".

Before we begin the presentation, I would like to review some general information about the webcast. Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker's presentations. You do not need to do anything to advance the slides. 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 speakers questions at any time during the presentation. Simply type your question 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 on to the speakers periodically throughout this broadcast. If you don't -- 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.

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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 response will help us plan future broadcasts in this series and improve our technical support.

Next slide. I would like to acknowledge Paul Rusinko the federal project officer. Could we advance one more slide, please? Thank you. I would like to acknowledge Paul Rusinko the federal project officer and director of the four National SUID/Child Death and Pregnancy Loss Program. He's participating in this webcast and will respond by email to any questions directed to him during this presentation.

Next slide. This slide describes an overview of the webinar. We'll describe the National SUID/Child Death and Pregnancy Loss Program and the four program centers. Examine the transition in SIDS and SUID. We'll present the February 2009 pediatrics article "infant accidental suffocation and strangulation in bed" and we'll describe the CDC/SUID initiative and case registry pilot.

Next slide. At this time I would like to introduce Sandra Frank, the president of the association of SIDS and infant mortality program and the executive director of tomorrow's child Michigan SIDS. She'll discuss the pregnancy loss program and the four program centers. Sandra.

SANDRA FRANK: Thank you, Mary. Could I have the next slide, please? The National SUID/Child Death and Pregnancy Loss Program is funded by the federal Maternal and Child Health Bureau. The national SUID program is composed of four centers. These four centers are resources for programs and organizations that work with SUID, early child

death and pregnancy loss. The centers are your primary source for information, materials, technical support and communication needs related to SUID. I'm going to briefly give you an overview of the four centers as well as contact information. As you see on the slide, Project IMPACT is housed at the association of SIDS and infant mortality program. It is the communication hub for the centers and the program, the SUID program. We convene, connect and provide technical support to state and local efforts. Some of you may have participated in the regional meetings we conducted in California and in Florida in 2008. We will be conducting similar meetings in 2009. The Resource Center at Georgetown University is a second center. It is the Gateway to critical information on risk reduction, prevention and bereavement for pregnancy lost and sudden infant and child death. The Resource Center you'll probably recognize as the SIDS center from years past. The third center we would like to mention is the Program Support Center at First Candle. It provides education, training and bereavement services including a 24 hour bilingual bereavement counseling help line for families and the fourth center is the National Center for Cultural Competence at Georgetown University to help programs effectively address racial and ethnic disparities in perinatal, infant and child mortality loss.

Next slide, please. I just wanted to give you a snapshot of the home page for each of the websites of the four centers. This is the Project IMPACT home page. And you'll notice the first paragraph discusses today's SUID webcast.

Next slide, please. This is the home page for the Resource Center. The Resource Center housed at Georgetown University along with the MCH library, a fabulous resource for all of you. You can see across the top A to Z literally.

Next slide, please. This is the home page for the Program Support Center at First Candle.

Next slide. And the home page for The National Center for cultural competence at Georgetown University.

Next. This is the contact information for you on all four centers, as I indicated Project IMPACT is located in Lansing, Michigan.

Next slide. The Resource Center at Georgetown University.

Next. The Program Support Center at First Candle. Next and The National Center for cultural competence also at Georgetown University. It's my pleasure now to begin the presentation by introducing Dr. Carrie Schapiro Mendoza. Dr. Mendoza has been the lead on the CDD SUID initiative at the Center for Disease Control. She's an epidemiologist and team lead at the maternal and infant health branch Division of Reproductive Health, National Center for chronic disease at prevention. She's also the co-author of many of your -- of the February 2009 pediatrics article entitled U.S. infant mortality trends attributable to accident all suffocation and strangulation in bed from 1984 to 2004. Are rates increasing? That's the name of the article. Dr. Mendoza.

CARRIE SCHAPIRO MENDOZA: Good afternoon. I want to take the time to thank everyone that is participating in the webinar for your time and for your interest. And let's begin. I'll start off by talking about U.S. Trends in SIDS and SUID related mortality. The presentation outline will look like this. First I'll talk about and define SIDS, sudden infant death syndrome and SUID, the Sudden Unexpected Infant Death and I'll discuss trends over time and finally I'll give a small presentation of the pediatrics article published in

February 2009 regarding the increasing rates of accidental suffocation and strangulation in bed, which I refer to as ASSB mortality.

Next slide, please. The first for the definition. SUID stands for -- you can go to different audiences and everybody seems to have a different definition. When we hear at CDC talk about SUID we're talking about Sudden Unexpected Infant Death. These are infant deaths that occur suddenly and unexpectedly and have no immediately obvious manner or cause of death prior to a case investigation. And these exclude deaths which are obvious, have an obvious cause such as motor vehicle accidents.

Next slide, please. When I talk about SUID these are really a group of different causes of death or sudden types of death. You see I have this wheel with these spokes going out to the side. SUID is the middle but some of the different examples of SUID can include SIDS, it can include death caused by neglect or homicide. By hypothermia, by poisoning. Those called accidental suffocation, those that are undetermined or cause unknown.

Next slide, please. Hopefully after a case investigation, these SUIDs can be broken into two categories. Those that are explained and unexplained. Explained deaths would be deaths due to poisoning, helped injury or metabolic disorders. There are unexplained deaths referred to as SIDS or the ones undetermined or cause unknown or deaths that could be SIDS but we're not sure if it was a suffocation. And then next slide, please.

What happened, there was a yellow one on the left-hand corner and there is another category of death called accidental suffocation and strangulation in bed and that is the little bit of controversy as to whether it would be an explained cause of death or unexplained cause of death.

Next slide, please. So when I talk about sudden infant death syndrome the definition I'm going on is a sudden death of an infant under one year of age which remains unexplained after a thorough case investigation. What I mean by that is that there is the performance of a complete autopsy. A thorough examination of the death scene and a review of the clinical history. It came from the National Institute of child health and development in 1991.

Next slide, please. Now, having said that there is a 1991NICHD definition, the definition that they use for coding purposes and this is where we get our data on national trends to monitor SIDS surveillance. I won't go through the whole list. There are a lot of different items on it but basically when any of these terms are written on the death certificate by the medical examiner or the coroner, these in turn will be coded as SIDS in our national mortality files. So if it says SUID, Sudden Unexpected Infant Death, even if the medical examiner intended it to be something different from SIDS, it is coded as a SIDS death.

Next slide, please. Why do we need to be concerned about SUID? First of all attacks 4,600 infants a year. And the number of deaths attributable to SUID are comparable to birth defect mortality, one of the other leading causes of infant mortality in the U.S. About 2,500 of these SUID deaths are attributed to SIDS. Those are deaths to infant from one month of age up until the first year of life and it's the third leading cause of all infant mortality. And then accidental suffocation and strangulation in bed and you'll hear later about the study published in pediatrics but rates have more than tripled in the last decade from the 1990s. The early 1990s to the mid 2000 period and increased from 3.7 deaths per 100,000 live births to 12.5 deaths per 100,000 live births in 2005. The exciting thing about these deaths. Some of these deaths are potentially preventable.

Next slide, please. So CDC research has shown that the climb in SIDS have been offset by increasing rates to death by accidental suffocation and strangulation in bed and presented in the article of medical journal of epidemiology in 2006.

The next slide will show you what I'm talking about here. Just to orient you. What you're looking at is infant mortality rates due to SIDS, accidental suffocation and strangulation in bed combined with cause unknown deaths and you're also looking at a combination of these SIDS, suffocation deaths and cause unknown and looking at data from 1990 to 2005. You're looking at the dates from 1990 to 2005. On the Y axis you're looking at infant mortality rates attributed to each of these causes of death per 100,000 live births. The yellow line on the bottom are those deaths that were classified as accidental suffocation, strangulation in bed, as well as cause unknown. The line in the middle, I think it's blue, is the SIDS rates and trends over time. And finally, the top row, the light blue or the white is what is the combination of these SIDS and the accidental suffocation, as well as the cause unknown. And what you can see is that the SIDS rates, you look at that blue line in the middle, during the 1990s as a result likely of the back to sleep campaign and the American Academy of pediatric recommendations for back sleeping, that the rate of SIDS has declined. Nearly 50% from 1990 until about 1996. What you also see during that same time is the line on the top, that light blue or white line, it pretty much mirrors the SIDS line up until about 1996. And then finally on the bottom you see the combination of the suffocation deaths and the cause unknown and really there was not much fluctuation. No decline or increase up until about 1996. What you do see happening is that about 1996, 1997 the decline in SIDS can be explained by a somewhat increase in the deaths that are ASSB and cause unknown. So one is offsetting the other. And hence you see from about 1996, 1998, depending where you're looking at the top line on the top you see it stable. No decline or increase but it's telling me one is offsetting the other. In more

recent years when you look at 2001 on to 2005 you actually don't see a decline or increase in either the SIDS rates or the accidental suffocation and cause unknown rates.

Next slide, please. So what is going on here? Is this a change in practice? It appears that this change in classification might be explained by changes in practice. So maybe the way the death scene investigations are conducted have changed or maybe there is a cause of death -- a change in how cause of death diagnoses are made. Comprehensive death scene investigation is critical to accurately classify ASSB deaths. Autopsy alone cannot determine a SIDS or suffocation death. Now we've looked at that over time. Let me bring you to the pediatrics article published in February 2009. It was entitled the U.S. infant mortality trends attributable to accidental suffocation and strangulation in bed from 1984 through 2004, are rates increasing? Let me acknowledge my co-authors here Melissa Kimball, Kaye, Bob Anderson and Sarah Blanding.

Next slide, please. So why did we conduct this study first of all? What we knew from the American journal, the decline in SIDS was being offset by the decrease in cause unknown and suffocation and we wanted to get a better understanding what these accidental suffocation and strangulation in bed deaths were, the ASSB deaths. We also heard that many medical examiners and coroners were no longer reporting SIDS as a cause of death and that they were more likely -- perhaps even preferred using accidental suffocation in a sleep environment as a preferred diagnosis in place of SIDS.

Next slide, please. So what were the objectives of the study?

Next slide. The objectives of the study were four fold. First we wanted to explore trends in accidental suffocation from 1990 to 2004. I think in the actual article I had actually 1984-

2004. I had a 20 year period and what I'm presenting here from 1990 to 2004. A little less busy and I think it will be easier for you to follow. The second objective was to compare trends in other SUIDs such as SIDS as unknown cause with those of ASSB. The third objective we wanted to evaluate demographic characteristics of infants who had reportedly died of ASSB and finally, our fourth objective was to describe the primary mechanisms reported as leading to these ASSB deaths.

Next slide, please. So a little bit about our study methods. This was a population-based descriptive study and we used U.S. mortality data from the compressed mortality files from 1990 to 2004. This data can be located at a website at the CDC at the National Center for Health Statistics it's called CDC wonder. If you want to explore it, here is the website. This is death certificate data compiled at a national level from all infant deaths in the U.S. during a given year. There was also a secondary analysis so that we could attempt to look at the primary mechanisms attributable to ASSB deaths and we had data available for 2003 and 2004 where we actually had the written text that the medical examiner, the coroner or whoever certified the death certificate had written in the cause of death section of the death certificate. We could see if he or she had written sudden unexpected infant death there it was in front of us so we can make some judgment calls or perhaps they indicated some type of mechanism for the death. A parent overlay, an infant being placed on a pillow or blanket and suffocation.

Next slide, please. This is where it gets a little tricky. This is a little technical. If some body wants to repeat that analysis in their state, I used my definition for ASSB SIDS and unknown cause were the national classification of diseases. There was a version 9 and a version 10 and these are developed by the World Health Organization so that we can

compare deaths in a systematic way internationally. So here you can see the codes that were used.

Next slide, please. So just to be clear, I didn't make up this category called ASSB. It is an actual code on the death certificate, W75 if you look on the last slide and this really is a combination of deaths. This is no way the break them apart. It could be deaths that are attributed to suffocation by soft bedding or a pillow or suffocation on a waterbed mattress. It could be suffocation that occurs from overlaying. From someone, a caregiver, parent, sibling or someone else rolling on top of or against a baby while they're sleeping. This category also includes deaths that occur from wedging or entrapment between a mattress and a wall or the mattress and bed frame. And also this category of death includes asphyxiation or strangulation that occurs when an infant's head and neck are caught between crib bed railings or perhaps an infant neck is entangled around a Venetian blind cord hanging in the sleep environment. ASSB is not something I created but developed by WHO to capture all of these different mechanisms that can lead to accidental suffocation and strangulation in bed.

Next slide, please. So a little bit about the results of our study.

Next slide. So what this is, it's showing you on the Y axis again this is actually the same side you looked at earlier except you're looking at the accidental suffocation and strangulation in bed and you can see the increase from 1990 up until 2004. It went from 3.4 per 100,000 live births to 12.5 and you see that the biggest increase actually occurred around 1996. Again, just to put this into perspective for you, 1991 was when NICHD developed the new SIDS definition, in order to diagnose SIDS you needed to have a thorough examination of the death scene. 1992, 1994 was the back to sleep

recommendations. CDC released its sudden unexplained infant death investigation reporting form and guidelines in 1996. These were a standard for medical examiners and law enforcement to follow in order to conduct a thorough case investigation of a sudden unexpected infant death.

Next slide, please. Now what we're looking at here is again similar to the slide I showed you earlier as to, you know, SIDS being offset by an increase in unknown cause and accidental suffocation, but what I've done here is on the bottom line what you see is accidental suffocation and strangulation in bed and the category of death called unknown cause broken apart so you can see a little bit what was going on with those deaths. So the very bottom line is the ASSB deaths. You can see in comparison to SIDS, especially in the early years, the number of deaths was by far a lot less than the number of deaths that occurred due to SIDS. In fact, in about 1990 there were about 100 deaths that occurred per year where in 2004 there were around 400 deaths that occurred. So there are a lot fewer ASSB deaths and unknown cause but you can again see this pattern that from about 1996 on when you look at the combined rate on the top, that blue line, that has remained fairly stable. Any effort such as back to sleep campaigns don't seem to have had a big effect from 1997, 1998 on. It's still declining but seems to be offset by the increase in these other SUID.

Next slide, please. So here again is another way to look at this increase in suffocation deaths and cause unknown. What you see here is data from 1990 to 2004. And it is looking at 100% of the deaths that were classified either as ASSB cause unknown and SIDS. And the green line or the green color on the bottom represents the accidental suffocation death. The yellow is cause unknown and the red is SIDS. And if you follow, say, the green line from 1990 and you move across the slide from left to right, you see that

the proportion of deaths that were attributable to suffocation increased proportionately to all the SUID deaths. 1990 was a sliver. Very few deaths were called suffocation but in 2004 when you move across you see a bigger proportion of deaths that were called suffocation and also of deaths that were called unknown cause and a smaller percent that were called SIDS.

Next slide, please. So a little bit about the population and what these ASSB deaths look like. What we're seeing here is infant mortality due to ASSB by gender, male and female sex. Males have a slightly higher mortality rate due to ASSB compared to females.

Next slide, please. Here we see infant mortality due to ASSB by race and we see that Blacks are disproportionately affected 27.3 compared to 8.5.

Next slide, please. Here we look at the distribution of age death for accidental suffocation and strangulation in bed. These refer to 2002 to 2004 data and you can see that the deaths actually peaked at one to two months of age and that about 75% of these deaths occurred in the first four months of life. And this is pretty similar to what you see in the SIDS rate, although for that line that's marked zero that is all infants less than one month of age, there is usually a smaller proportion of deaths that are attributed to SIDS.

Next slide, please. So our secondary analysis, again, this is where we looked at data for 2003 and 2004 where we had the actual written text that the certifier wrote on the death certificate as far as cause of death. Let's look at this data.

Next slide. First we attempted to look at the mechanism attributed to suffocation in the U.S. and again, like I said it was -- this was a category of deaths, ASSB that combined

suffocation that was due to overlay, suffocation that was due to suffocation and a pillow, or deaths due to strangulation from a cord and we try to separate it out by using the words written in the text on the death certificate. Unfortunately 35% of the time there was no good information for us to be able to determine the mechanism of the deaths and that's why you see 35% of those we couldn't even determine. The data wasn't very good to support it. Of the data that we had the reported something it looked like that overlay occurred most of the time but again we don't know where those 35% of those unknowns would have been categorized and what the mechanism of death were. The message here is that we really didn't have very good data to determine the mechanism attributed to suffocation based on this death certificate data.

Next slide, please. Again, in the secondary analysis we wanted to look at sleep surface or place where the infant death occurred. And again, you look at that first column it says unknown because about 50% of the deaths, a little more, we really had no good data as to the sleep surface or the place where the infant death occurred. And you can see that actually infant deaths occurred on all sleep surfaces on beds, on sofas, on cribs and again the message here is we really didn't have very good data to examine this issue.

Next slide, please. Then again we wanted to look I wonder how many of these deaths occurred because of bed sharing or co-sleeping. So we attempted to look at that and again look what we find on that left-hand side. We see this big box called unknown, about 42% or 43% of the deaths we could not determine whether or not bed sharing or co-sleeping were -- could be somehow associated with the infant death. The other thing is a lot of the times on the death certificate probably more often than bed sharing we saw the word co-sleeping. Having the word co-sleeping on a death certificate to me is not very informative. There is no way that we could determine whether this was a bed sharing on

the same sleep surface on a bed, if it was bed sharing or sharing the same sleep surface that was a couch. We couldn't determine if it was co-sleeping that referred to a baby sleeping in the same room as the mom or perhaps one of those co-sleepers, the little attachment you can hook onto the bed that essentially is a separate sleep surface. There is no way we could really determine that. The message here was again really poor information from the death certificate as to be able to tell us whether or not bed sharing or co-sleeping was somehow associated with the infant death.

Next slide, please. So just to summarize, next slide. Infant mortality rates attributable have quadrupled. The reasons for the increase are unknown. Male and black infants seem to be disproportionately affected by ASSB. The other message was that infants die in all sleep environments on adult beds, cribs and other sleep surfaces. I guess there is another little bullet from the secondary analysis where we looked at the infant deaths the information wasn't sufficient to be able to look at the mechanisms or the sleep surfaces involved in these infant deaths and that these deaths are potentially preventable.

Next slide, please. So why did increase in ASSB? Again, the cause of this is unknown. It appears that the way medical examiners and coroners, the people responsible for certifying the infant deaths seems to be a change in the way they're diagnosing the deaths. They are moving away from SIDS as a diagnosis and reporting more suffocation deaths. It is possibly related to better or more thorough death scene investigations. Maybe the release of the CDC reporting form, it could be stricter adherence to the 1991 SIDS definition which called for thorough examination of the death scene, complete performance of an autopsy and review of medical records and due to an increase in local and state level child death reviews.

Next slide, please. So what do we need? You saw from that secondary analysis that we really need improved data to increase our knowledge about the events and circumstances associated with SIDS and other SUID. If we want to understand the mechanisms that are associated with these accidental suffocation deaths and determine the degree of evidence they could determine or differentiate a SIDS death or an accidental suffocation, whether it was overlay or suffocation in a pillow, we need improved data. One of the ways we think we can get improved data we need supplemental data. It's super for us to monitor trends in SIDS and other SUID deaths over time but if we want to understand more of the events and circumstances we need something like a SUID case registry. We hope by building upon child death review teams that are currently going on at several local and state levels this would be the best way to actually capture this information and use it and be able to look at data at a population level.

Next slide, please. So Lena will talk to you a little more about what we've been doing here at CDA as far as our SUID initiative case registry and activities. I want to acknowledge the other CDC SUID initiative team. Lena Camperlengo, another epidemiologist on our SUID team and others. Next slide, please. I want to thank you all for your attention and I look forward to answering about five minutes of questions right now.

LENA CAMPERLENGO: Thank you, very much, Carrie, for that very interesting and informative presentation. And we have been receiving some excellent questions and we're going to share a few of those with you right now. First question. The National Center for health statistics defines SUID as unexplained. It appears that CDC defines SUID as unexpected. Could you clarify?

>> So I think what you were saying you said that NCHS The National Center for health statistics defines SUID differently than the way we define it?

>> That's the question. The question has to do with the words unexplained and unexpected.

>> Okay. I'm not so certain that NCHS actually has a code called SUID. When I showed you the slide of how NCHS actually codes some of the SIDS death, if a medical examiner or coroner wrote Sudden Unexpected Infant Death there is no different in the terminology and it would be coded as SIDS. For me it goes back to the initial slides. I like to consider all deaths that occur suddenly and unexpected deaths as Sudden Unexpected Infant Death after a thorough investigation, those unexpected infant deaths can be further categorized into those that are unplanned and unexplained. I hope that cleared up the questions and answered it maybe a little.

>> We have a couple questions related to the category ASSB. The first one is, does ASSB include deaths on couches and other unsafe sleep environments.

>> I'm fairly certain that what will happen if on the death certificate the medical examiner or coroner, the death certifier writes asphyxiation or suffocation and mentions any type of sleep surface, be it a bed, crib or sofa, those would likely be classified as ASSB deaths.

>> Okay.

>> So it includes all sleep surfaces, crib, mattress, bed, sofa or car set.

>> Okay. Thank you. Well, what about the geographic distribution of ASSB? Is there an increased incident in certain areas geographically? Caller: In my paper I don't recall. I think we may have looked at certain states and they were -- somebody wanted to email me that question, there are three or four states that didn't use the term ASSB at all in some of the years. As far as if one state was using more than another, again we're only talking about 400 deaths and if we start to break that down by the 50 states, the rates that I would come up with would become very unstable and unreliable so I guess in a nutshell we weren't really able to look at that at a state level to see if there was more ASSB in one state or another. Some states didn't use that category of death at all.

>> How old is the ASSB code? Our questioner is saying that she hasn't heard of it or use medical examiners use this category.

>> That's a really good question. And I was hoping she might know how old the code is. I don't know how old it is. It's not anything new. It used to be referred to mechanical suffocation in earlier versions of ICD9 and we switched to ICD 10 in 1999. A medical examiner wouldn't write accidental suffocation or strangulation in bed. They would write asphyxiation and mention a sleep surface, a bed, couch, sofa, couch, floor and that terminology and those terms would be put into a computer algorithm to generate the code called ASSB. Probably the specific term accidental suffocation and strangulation in bed was introduced in 1999 with the ICD10 coding system. Prior to that time it was called mechanical suffocation.

>> Okay. Thank you, Carrie. Stick around because we're going to have more questions after Lena is finished presenting. We have been receiving many, many excellent questions but now we're going to introduce our next speaker, Lena Camperlengo, a colleague of

Carrie's. She's the program coordinator for the Sudden Unexpected Infant Death initiative also at CDC. Lena.

>> Thank you, Mary, good afternoon, everybody. I would like to thank Mary, Sandra and Paul for hosting this event today and this afternoon I'll talk to you about our SUID initiative. By SUID I'm talking about Sudden Unexpected Infant Death and the case registry we're just developing here at the CDC.

Next slide, please. Today's presentation will follow this outline. We'll talk briefly about our background. Carrie was kind enough to provide you with a lot of definitions and statistics and we'll talk about what the CDC has been doing. There is a lot of buzz about the last bullet, the case registry. That's the tip of an iceberg. There has been a lot of work going on for years at the CDC. The initiative was the sudden infant death reporter form, it's revision, guidelines, curriculum, training academies, visibility studies as well for a SUID case registry. We'll talk about all those this afternoon.

Next slide, please. Let's start off with a background.

Next slide. Some of these are a repeat of Carrie but I felt like they were important enough to restate. Why should we be concerned with SUID? They -- the rates are comparable to the rate of mortality due to birth defects. One of the top three causes of infant mortality in the United States today. More than half of these 4,600 SUID deaths are attributed to SIDS. Within that category of SIDS, a sub category of SUID, SIDS is a leading cause of death for post neonatal mortality. One month to one year of age. Babies between that age range. It happens to be the third leading cause of death to all infant mortality. Carrie presented her paper on accidental suffocation and strangulation in bed and you

understand rates have tripled or quadrupled since the 1990s. Just to frame it all, I really like to think of this as potentially preventable infant mortality. If there is a way or a message that we can do with health education like the back to sleep campaign successfully had done in the early 1990s to reduce these infant deaths due to unsafe sleep environments or whatever causes, these are potentially preventable infant deaths.

Next slide, please. You saw this slide before. Let me orient you to it very quickly. The red line in the middle is the decline in SIDS since the early 1990s that we talked about. The yellow line on the bottom is a combination of deaths due to ASSB and cause unknown. And you can see starting in the later 1990s one is offsetting the other causing almost a flat line in the top line, which is a combination of all those causes of death.

Next slide, please. So why should we be concerned about these changes in reporting practices? Are they shifting from SIDS to ASSB and cause unknown or are those preferences of the medical examiner and coroner these days? We're concerned about this because not many sudden unexpected infant deaths are investigated. When they are investigated a lot of the cause of death information is not collected or reported consistently. So that really hinders us in our ability to be able to monitor the national trends and you saw when Carrie presented that the information just wasn't on the death certificate. Where was this baby located and where was the baby found. What sleep surface, with whom, all of that information was missing. So if we want to reduce these infant deaths we need valid and reliable data to support our research and prevention efforts and monitor our success and evaluation.

Next slide, please. So the crux of all of this, then, is on the case investigation. And the importance of case investigation it helps to determine accurate cause and manner of

death. It helps to distinguish between all the different causes of SUID that Carrie talked about earlier. If you recall the spokes on the wheel, there are many different types of Sudden Unexpected Infant Death and hopefully after a case investigation they're broken down into explained versus unexplained. But the case investigation also helps us improve the validity and reliability of our data. We can monitor trends. What characteristics are associated with these types of deaths. Risk factors, design interventions to prevent SUID and evaluate those programs.

Next slide, please. So what are the components of a good death scene investigation? A comprehensive death scene investigation includes things like scene shots, photographs of the scene that are recreated hopefully with a doll. Those were dolls used for scene reenactments. Infant death scene investigators often bring with them a doll to recreate the scene and photograph where was the baby placed to sleep. Where was the baby found. Where was the baby last known alive? The completion of the Sudden Unexpected Infant Death reporting form is another piece of the investigation. Unless this information is collected at the scene it's just not available to review teams such as child death review. A complete autopsy is the second part of a case investigation and that includes tests like toxicology, histology, radiology, etc. The third component is a review of the maternal and infant medical record to identify possible biological risk factors or possibly even external risk factors like a maternal injury during pregnancy. The important thing is that all of this information should be available to the medical examiner or coroner before they determine the cause and manner of death. That way these professionals have in front of them the most accurate and complete information in order to make the most accurate diagnosis of death.

Next slide, please. So at the CDC we developed a SUID initiative. A couple years back in the mid 1990s and today I'm going to talk about some of the initiatives that they have had.

Next slide, please. The goals of the CDC's SUID initiative included standardized data collected at the death scene to promote consistent diagnosis of cause of death. Hopefully with all that information collected at the death scene by promoting consistent diagnosis at cause of death we can improve our national reporting of SUID and we can potentially prevent some of these SUID by using these improved data to identify those populations at risk and develop prevention strategies.

Next slide, please. To date we have completed that big chunk of the iceberg that's underwater that not everybody has been familiar with along the years and the SUID initiative has already completed these activities. We have revised the 1996 infant death scene investigation reporting form sometimes called the SUDER. It was revised and after the revision there was a development of the SUIDI training curriculum as well as the training materials and guidelines. We conducted five SUIDI training academies and trained people how to complete the investigation reporting form. How to do doll reenactment and scene photographs and all the other things that entail a comprehensive death scene investigation. We disseminated the form and the materials that go along with it. They're all available now on our website free for download. The website is on your slide.

Next slide, please. Since completing these activities, we've had some impact that we've been able to measure. We've obtained some professional endorsement from national as well as state organizations including the national sheriff's association and the National Association of medical examiners. Those 250 plus medical/legal professionals that we train in the training academies have gone on to train more than 15,000 other professionals

on how to complete a comprehensive infant death scene investigation. We've integrated our training materials into academic curricula including not just academic curricula but institutional curricula so different jurisdictions include our curriculum on how to conduct a complete infant death scene investigation. We've educated our partners who have then gone on to facilitate state and even local legislation in the State of Washington they've mandated the use of the SUIDI reporting form.

Next slide, please. One of our other completed activities includes the SUID case registry feasibility study. This was conducted with about seven states who were already using or integrated into the national violent death reporting system. So we used those teams at the state level NVDRS teams at the state level to conduct this feasibility studies. We asked the states to go back and collect data from all the SUID deaths they had in their state from the years 2004 and 2005. They had to abstract data from a large variety of sources in order to complete the case registry that we developed. What we did then is we assessed how available was this information, how complete would a case registry be if we had created one and where were they finding this information and where were they finding difficulty getting this information? This helped to provide information for us to help move forward with the development of a multi-state and ultimately national SUID case registry.

Next slide, please. So after the feasibility study the states that participated told us in their report that they felt that the child death review system would be a good system to build upon because they had access, often legislated access to a lot of the information they needed to collect. They asked us to please minimize the number of variables collected because it's difficult to collect a large number of variables on the flip side they asked us to expand the case definition because they felt that some of the sudden unexplained or unexpected infant deaths out there were not being captured because the codes were not

as broad as they would like. They also asked us to please developed a web-based data collection system. It was easier to collect information that way and enter it realtime and also to improve the distribution and training of the infant death scene investigators. What they found is that the information wasn't collected at the scene. The information wasn't available to review.

Next slide, please. This is a quote from one of the evaluation reports from the feasibility study. It says a major increase in the capture of SUIDI information will depend on changes in the death scene investigation protocol and/or their implementation. Much of the requested SUIDI information was not available in existing documentation. This really highlights the point that unless the information is collected at the death scene, that is not available to review, it won't be available to a case registry so once again we're going back to that comprehensive case investigation.

Next slide, please. The current activities we have going on at the SUID initiative include evaluating the success and impact of the SUID training academies. While we had more than 250 people trained in these academies in the more than 15,000 trained out in the field what we really want to understand is did this eventually impact jurisdictional or state policies? Did anything change in the way people practice their infant death scene investigation? We've also been working on developing a national SUID case registry. We've had a couple of information gathering sessions in the year 2008. We've identified what variables we would include and just released a funding announcement on grants.gov.

Next slide, please. So let me talk a little bit more about the national SUID case registry and the development of that case registry.

Next slide. Let me start off with some real basics here, though. What is a case registry? In essence it's a surveillance tool and it entails the routine collection and analysis, interpretation of dissemination of the data about SUID in this case. So our eventual objective is to reduce the morbidity and mortality and we collect the information, interpret it and get it into the community.

Next slide, please. That is evident here where you see the cycle. The public health surveillance cycle starts with identifying cases, collecting the information, acting on the findings and evaluating, refining and continuing and continuing. It is not really gathering data for data's sake. It is gathering data so we can do something about that. The act on finding bullet in your circle here is a very important one that we take seriously.

Next slide, please. Right now in order to conduct SUID surveillance what we have are the U.S. mortality files and as we've heard, death certificates oftentimes don't have a lot of the extra information and really there is not often a lot of space to put that information on the death certificate. So we don't get the characteristics, the demographics, we get the demographics but not the characteristics. Where was the baby sleeping, what was it wearing, where was it found, what did the bedding look like? None of that information can be captured on the actual death certificate so it lacks a lot of this information that we're really interested in.

Next slide, please. Why do we need a case Registry? The case registry will help us accurately monitor the incidence of and the characteristics of these deaths attributed to SUID in the United States. It will supplement the data we have from the death certificates because death certificates do provide valuable information. We can use the information to

inform prevention activities and potentially save infant lives and it will provide a potential source in the future if we want to do a case-control study.

Next slide, please. The objectives of our case registry are to collect consistent information about the data of SUID cases and we want to improve the quality and completeness of the data collection system so all of that, the death scene investigation, the review of the medical records, autopsy are all systems that impact the completeness and the quality of the SUID. And we want to try and improve those systems. We want to be able to use the sub classifications of SUID to better understand where the gaps are in this system so we can then turn around and be able to support them. We want to improve the knowledge about the trends and characteristics then associated with SUID.

Next slide. Some of the activities that we've done so far in getting this case registry developed, we created program models, logic models and concept models on how data would flow from the infant death to a review team to a case registry and all of this is really being built, then, on The National Center for child death reviews program and the child death review case reporting system. We've also defined a minimum set of variables and we anticipated what the research questions were with our partners and how we would build in program activities -- program evaluation questions into the case registry and the variables chosen to go in that case registry. We've developed some sub categories of SUID so we can better understand and improve SUID and the other systems that impact SUID like the medical/legal system. We planned a pilot project. Collection activity on the SUID case registry for four to seven stays in our first initial pilot.

Next slide, please. This brings me to the funding announcement. We have a funding announcement out now for the SUID case registry pilot. The funding announcement was

released on March 11 at [WWW.grants.gov](http://WWW.grants.gov) as shown below. At this point Allstate health departments or their bona fide agents are eligible to apply. We encourage proposals. They must be electronically submitted by May 11, 2009. The funding announcement code, CDC-RFA all that good stuff right there is on your screen and you can easily find it on [www.grants.gov](http://www.grants.gov) by searching for key word SUID. We're accepting proposals. I cannot tell you very much more about the SUID case Registry pilot project at this point in time.

Next slide, please. I can tell you what we expect to happen. Our expected impacts for the SUID case registry short term we'll increase our knowledge about the events, characteristics, surrounding the SUID deaths. At the national, state and local level you'll be able to determine that. The medium term impact would be that we could identify at-risk groups. Develop and evaluate prevention and education programs. Promote policy and practice changes for investigating SUID, and our long term impact is to reduce our potentially prevent infant deaths.

Next slide, please. This is just a sort of overview of the systems involved in the SUID case registry. Starting on the left with the scene, the scene is where the SUIDI reporting form or jurisdictional equivalent collects the good information at the scene so we understand it better. That might include EMS run reports, law enforcement. All these other agencies that impact and come together at the scene and that information then is given to the pathologist where the autopsy and toxicology report are generated. The coroner and medical system would have this information available before they certify this death and the death review team, whether it is a child death review team or another infant mortality review team would have all this information available to be able to identify areas for intervention.

Next slide, please. Now, this didn't all happen in isolation at the CDC. We have numerous partners that have helped along the way from revising the SUIDI reporting form to implementing the training academies to coming to organizational and information gathering sessions on how to develop the SUID case registry. This list just includes some of our federal partners.

Next slide, please. We also had non-federal partners who helped us all along the way including professional medical associations, SIDS and SIDS prevention organizations and advocacy groups as well as law enforcement agencies. If you recall the national sheriff's association endorsed us at the national level. So this is not even fully inclusive. There were many, many organizations that came in, might have participated in one or more of our completed activities and we continue to count on our partners both federal and non-federal partners as we move toward the development of the national SUID case registry.

Next slide, please. And I'll end on the same slide Carrie did. Carrie, myself, and others.

>> Thank you, Lena. Well, the questions have been rolling in and we're going to start with a few that I think would be directed to you, Lena.

>> Okay.

>> Here is the first one and then we have numbers that we'll defer to the two of you to sort out who might best answer. So this one is for Lena. I am from a very rural state. Will preference for the pilot project be given to states with a larger population and therefore a higher number of SUID deaths?

>> Thank you for that question. That's a really important question. We actually have fielded a number of those questions from a number of states. The question basically is ask will I be at a disadvantage if I'm a smaller state and we don't have as many SUID deaths as a larger state might? There are a number of criteria spelled out in the funding announcement on which we'll evaluate and score your proposal. We definitely encourage every state to apply if you're interested and in reality you're doing these activities anyway. So if we can help support you with the funding for the case registry, then it's a win/win situation. We do not give preference to one state versus another. Now, we do say in the funding announcement that we reserve the right to take a state out of rank if you have less than 75. 75 SUID deaths a year in your state is not considered a minimum. Let me give you the scenario. I have two proposals. You both scored a 98 but one is a Texas and one is a Rhode Island. We might go with Texas, we might not go with Texas. We might decide the systems in place in the smaller state are more adequate to us in the pilot phase. It's a complicated question. We encourage you to apply and that's just one of many, many components that we look at when scoring your proposal. I hope that answered your question and that you will submit your proposal.

>> Another one about the proposal. Does the submitting agency have to be a state agency? What about a non-profit?

>> The eligibility criteria says you have to be the state health office or the state health department, whatever you call it in your state so we have a single point of entry. We also say or their bona fide agent. So if you're working in a state with your state health office and you submit something together, then that is acceptable. If a proposal comes from something outside of the state health department or its bona fide agent it will be

considered ineligible. I encourage you to work with your state health office on your proposal.

>> One more question about the proposal. Questions about eligibility and the application process, is it clear who those questions should be submitted to?

>> Our program officer's name is Carrie Louis Gilman. Her information and contact information are outlined in the funding announcement.

>> Very good. Well, we're going to go on to some other types of questions. This goes back to the issue of ASSB and the question is, I think we've already answered that one about the -- you did talk about death on couches and unsafe sleep environments. But here is one about do you have information about how many of the overlay deaths were due to the mother overlaying versus anyone else?

>> You're asking whether I have any information about the death -- on the death certificate in 2003 and 2004 data that said something about the infant being overlayed whether it was a mother or someone else and I have no information and that's why we need a better data system.

>> Okay. Thank you. What about the difference in gender with the male/female death? Is it significant, statistically significant and if it is what is your theory about why there is a gender difference?

>> I would say that there is a statistically significant difference. It was three-fold. 27 versus I don't remember, it was a lot larger the rate for black infants compared to white infants. A

reason for that I really don't know. The same thing happens with SIDS deaths, you see that same pattern.

>> With gender are you talking gender or race?

>> Talking about race. It was slightly higher in males compared to females and the same thing again happens both for ASSB deaths as well as SIDS deaths.

>> Okay. How about -- here is a good question that we debate a lot. When an infant is placed prone and there is a death, is this considered in their crib would you call this an unsafe sleep environment and is it then coded as such? Just the simple fact of the prone position.

>> I think being placed to sleep in a prone position is a risk factor for SIDS as well as suffocation death. How that will be coded, that really depends on the person who is certifying the death, how the medical examiner and coroner, what their diagnostic preference is or their level of knowledge about SIDS.

>> Sort of in the same vein, numbers of concerns and questions about the issue of telling SIDS and SUIDs as one code. Can you talk about that a bit more?

>> I think the reason I tallied the SIDS and the suffocation and the cause unknown together as one code was to make a point. These deaths are often difficult to differentiate from one another especially where there is not good death scene investigation data. The death certificate cannot tell us anything about the quality of the death scene investigation or the quality of the autopsy. Autopsy alone cannot differentiate between these types of

debts. Because it seems that there is -- there has been a change in the way medical examiners and coroners are classifying these deaths moving away from SIDS and calling them suffocation it seemed like an appropriate thing to combine the deaths to look over time. If you looked over time at the combination of the deaths and saw it flatten or saw no increase or decrease, when you could see when you looked at the SIDS rates or the unknown rates and the accidental suffocation you could see though SIDS was declining for those years when overall the combined SUID was flat it was explained by the increase in accidental suffocation and unknown cause deaths.

>> Currently what percent of medical examiners or coroners are using the CDC SUID reporting form nationally.

>> We hope we can evaluate that in the future. We don't have a good idea of that.  
Excellent question.

>> What is actually known scientifically about the mechanism of overlying?

>> That I really can't answer that question. I don't have information to answer it. It seems like you would have to go to the medical examiner or forensic pathologist maybe. Pediatric pathologists who study those suffocation deaths that might be able to answer it. What was the question again?

>> We'll move on to another one. Do you have any knowledge of other countries and how they deal with SUID deaths? How are they classified?

>> I don't have any information about how other countries classify their SUID deaths. I know that Fern Hawk this year or late last year in 2008 maybe in pediatrics published a study looking at international rates and comparisons of SIDS and I will say if I recall correctly it is not an easy task to go and have real clear definitions or the same definitions applied equally in different countries. The things available in other countries to do autopsy is difficult and really varies.

>> Along the same lines we're aware the United Kingdom, specifically England, have courses now on conducting death scene investigations for infants and children. They were part of the 250 people who attended our training academy. They learned about investigating infant deaths here and brought it to the United Kingdom. New Zealand started a SUID case registry a number of years ago and they found they didn't have the information to put in the case registry so they built it but there was nothing to put in it because they forgot to first train their death scene investigators on how to conduct a death scene investigation. Now they're using the CDC materials and curriculum to train people in New Zealand how to conduct infant death scene information. All this information you're asking about, was it a safe sleep environment, the mother rolled over, that information can be gathered at the scene.

>> Thank you. Another question. In jurisdictions where SIDS is not used as a diagnosis, what is the leading cause of post neonatal mortality?

>> Good question. Hum. I haven't actually looked at that but it would be whatever the fourth leading cause -- or the second leading cause of infant mortality is. I'm not 100% certain what that is without looking at the data. That's an interesting question. But to help

to answer that, you would not find -- if they weren't using SIDS, you might find accidental suffocation or it might be called unintentional injury. You wouldn't find as a leading cause undetermined cause for leading causes of infant mortality.

>> Okay. Here is a question about alcohol and drug use. Are there statistics that control for alcohol and/or drug use when we're talking about the overlaying situation?

>> I have to tell you that I'm not aware of any studies that have looked at accidental suffocation that was an analytical, cast case controlled study that looked at accidental overlay deaths and drug or alcohol use.

>> Once again, if we collected that information at the death scene and then had that available to review teams, then it would be in the new SUID case registry.

>> Some of the studies out of England, trying to remember the name of the studies. They might have actually looked at alcohol and drug use in some of the other sudden unexpected infant death they looked at. The ones that were explained.

>> Here is one we often debate. That has to do with can a bed be made safe for bed sharing and should there be prevention messages that describe the parents how to do that?

>> If you're looking for answers for the safest sleep environment and whether they should share a sleep surface I encourage you to talk to their private pediatric provider or family care doctor.

>> Do either of you want to comment about prosecuting parents if you have feelings about that or just comments to make on that issue?

>> I have no comment. We have no comment.

>> Okay.

>> We're not involved with prosecution of cases or even certifying these infant deaths.

>> Okay. Well, do either one of you have some summary remarks that you would like to make before we wrap up?

>> I guess a summary remark that I would like to remark, maybe in follow up to the other question. I encourage parents to talk to their doctors. We really go along with the AAP recommendations and the back to sleep campaign and certainly the safest place for an infant to sleep is on a close sleep surface that is separate from the sleep surface of a parent. It should be free of blankets. The baby should be placed on its back to sleep. There shouldn't be any pillows or stuffed animals or anything like that in the environment.

>> I would like to end also, Mary, if I could by saying a lot of the questions you had out there today are fantastic questions, that's the kind of questions you hear when you review these deaths. And so much of it depends on that comprehensive scene investigation that if you are just itching to know the answers to these questions and you have a team that wants to review and put into action some local plans, then go to your death scene investigators, support them. Have them trained and support comprehensive infant death scene investigations so we can have this information about what happened and what were

the circumstances about this infant's death so we can pinpoint those areas in which we can intercede with an intervention and prevent some of these infant deaths potentially.

>> Thank you. Before we wrap, do either one of you have any comments about twin deaths?

>> We have no comments on twin deaths. I haven't studied them.

>> Okay. Well, thank you very much to both of you for your presentations, for your willingness to answer questions. And thank you to all of you who did submit questions. Please take time to fill out your online evaluations. We really value your comments and suggestions. You will find this webcast archived at [www.mchcom.com](http://www.mchcom.com) so you can review it at a future time. Thank you again to our speakers and all of you who participated and have a good afternoon.

>> Thank you.